KAROLINSKA INSTITUTET
Institution for women and children's health
Unit for reproductive health
VT18 Master thesis in sexual, reproductive and perinatal health

Experiences and knowledge on Dysphoric Milk Ejection Reflex (D-MER)

-A study by means of a mixed method design approach

Erfarenheter och kunskap om Dysforisk mjölkutdrivningsreflex (D-MER)

-En studie med hjälp av Mixad metod

Master thesis in sexual, reproductive and perinatal health, 15 hp
(Advanced level), 2018

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Sammanfattning

Bakgrund: Ur ett globalt perspektiv är amning viktigt för barn- och mödrars hälsa både på kort och lång sikt. Förmågan att amma innefattar både endokrina och autokrina funktioner via fysisk stimulering och frisläppta hormoner. Dysforisk mjölkutdrivningsreflex (D-MER) är ett tillstånd som kännetecknas av dysfori, ett plötsligt känslomässigt fall, hos vissa kvinnor i samband med mjölkutdrivningsreflexen. Barnmorskekompetens kräver förmåga att både identifiera och stödja amningsproblem så som D-MER. Det finns brist på vetenskaplig och klinisk kunskap om D-MER.
Syfte: Att öka medvetenheten om D-MER genom att beskriva kvinnors erfarenheter av tillståndet samt undersöka barnmorskors kunskap och erfarenhet av D-MER.
Metod: Mixad metod av både kvalitativ och kvantitativ design användes. De två grupperna av deltagare rekryterades via Facebook med hjälp av snöbollsurval. Semistrukturerade intervjuer genomfördes med 14 internationella kvinnor med erfarenhet från D-MER medan kvantitativa undersökningar var tillgängliga online för att fyllas i av legitimerade svenska barnmorskor. Data som samlades in och analyserades av intervjuerna användes som grundmaterial för att skapa en kvantitativ undersökning för internationella kvinnor. Kvalitativa data analyserades med hjälp av innehållsanalys medan kvantitativa analyserades med hjälp av beskrivande statistik.
Resultat/Slutsats: Kunskap om D-MER bland barnmorskor är otillräcklig. Ovanliga upplevelser av amning samt brist på kunskap och stöd när man söker hjälp från hälso- och sjukvårdspersonal, drabbar både mödrar och barn negativt genom förkortad amningsperiod och anknytningssvårigheter. Forskning kring D-MER är sparsam. Samtidigt har brist på kunskap och forskning om D-MER negativt påverkat kunskapen bland barnmorskor, vilket kan antas leda till sämre amningsstöd.

Nyckelord: Dysforisk mjölkutdrivningsreflex, Amning, D-MER, Kvalitativ, Kvantitativ, Barnmorskor

Abstract

Background: Worldwide, breastfeeding is important for infant's and mother's health in short- and long-term life. The ability to breastfeed involves both endocrine and autocrine functions via physical stimulation and the released hormones. Dysphoric Milk Ejection Reflex (D-MER) is a condition characterized by dysphoria, a sudden emotional drop in some women just prior, or in connection to the milk ejection reflex. Midwives competence requires an ability to both identify and support breastfeeding problems as D-MER. There is a lack of scientific and clinical knowledge regarding D-MER.
Purpose: To describe women's experiences of D-MER, and to examine midwife's knowledge and experience of D-MER.
Method: A mixed method design of both qualitative and quantitative approach was conducted. Targeted participants were women with D-MER and midwives, recruited via Facebook using snowball sampling. Semi-structured interviews were performed with 14 women with experience of D-MER while quantitative surveys were available online to be filled in by licensed Swedish midwives. Data collected from the interviewed women were analyzed and used to create a quantitative survey that approached women worldwide. Qualitative data were analyzed using content analysis while quantitative were analyzed by means of descriptive statistics.
Results/Conclusion: Almost two third of midwives were not familiar with D-MER and only one third of them were aware of D-MER symptoms. Negative experiences of breastfeeding, as well as lack of knowledge and support when seeking help from health professionals, can affect both mother and child negatively by shorten period of breastfeeding and bonding difficulties. Research on D-MER is very scarce. At the same time, lack of knowledge and research on D-MER has adversely affected the knowledge of midwives, which will expect low level of breastfeeding services.

Keywords: Dysphoric milk ejection reflex, Breastfeeding, D-MER, Qualitative, Quantitative, Midwives

Acknowledgements

We would like to pay our respect to Lactation Consultant Alia Macrina Heise, the founder of D-MER website and Facebook support-group from which we recruited participants. Thank you for all that you have done for the women suffering from D-MER. We wish to thank the women who has participated, your courage to share your experiences impressed us and we are deeply moved by your stories. To our Supervisor Amani, your knowledge and willingness to pursue this extensive thesis with us, enabled us to complete our work and we can´t thank you enough. To our families, thank you for your patience and support enabling us to proceed and complete this important thesis for women, children and families affected by D-MER worldwide. Finally, we wish to thank fellow midwife-students as well as examiner who came with valuable inputs enabling us to present this thesis in the very best way possible. Without the support group, participating women, our supervisor, our families, fellow midwife-students and examiner, this thesis would never have been possible.

Forever grateful, Thank you!

Andréa and Jaqueline

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Introduction

When becoming mothers, we both experienced that breastfeeding did not meet our expectations as a nice bonding experience. For one of us, letdowns were correlated with feelings of homesickness and dread at the beginning of breastfeeding or pumping sessions. When seeking help from health professionals, no help was offered, as these symptoms were neither understood nor recognized. Months later, a research on the internet described Dysphoric milk ejection reflex (D-MER). It was a relief just knowing about what it was. The fact that research on D-MER is scarce and us being midwifery-students, led to an interest in researching experiences and knowledge on D-MER. Since knowledge of breastfeeding, and ability to provide support when nursing problems occur it is part of a midwife's responsibility, therefore we decided to dedicate our master's thesis for this issue.

Background

Breastfeeding

Definition

Socialstyrelsen (2016) described breastfeeding based on the definition: "Exclusive Breastfeeding means children who have received breast milk only, as well as vitamins or medicines (e.g. vitamin D). Partial breastfeeding refers to children who have had breast milk supplement, vellum or other diet, in addition to breast milk" (Socialstyrelsen, 2016a, p. 2). World health organization [WHO] has since 2002 recommended exclusive breastfeeding during the first six months of life. This followed by complementary food with continued breastfeeding for up to two years (WHO, 2002). In 2017, WHO and United Nations International Children Emergency Fund [UNICEF] described that the global goal of exclusive breastfeeding the first 6 months of life for a long time been to reach 50% by the year of 2025, increasing to 60% by 2030. There are 129 countries with breastfeeding statistics from which only 23 achieves at least 60% excklusive breastfeeding the first 6 months post partum (WHO & UNICEF, 2017).

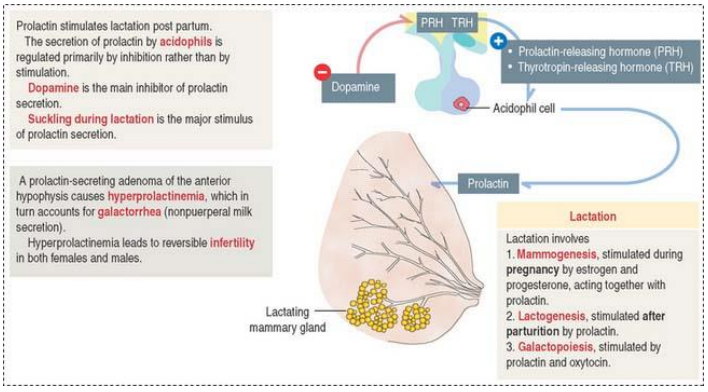
Breastfeeding health effects

Socialstyrelsen (2016a) explained the health effects of breastfeeding as multi-faceted for both mother and child. American Academy of Pediatrics [AAP] (2012) showed that breastfeeding improves infant and maternal health in low-, middle- and high-income countries. Both Socialstyrelsen (2016a) and AAP (2012) described that for the child there is a reduced risk for example respiratory- and gastrointestinal infections, Sudden infant death syndrome and infant mortality, allergic disease, inflammatory bowel disease and obesity. AAP (2012) also described that women's health benefits of breastfeeding are both short- and long

term. It varies from for example less postpartum bleeding, lactation amenorrhea thus spacing child birth to reduced risk of postpartum depression, breast- and ovarian cancer and cardiovascular disease (AAP, 2012).

Physiology of lactation

Buhimschi (2004), as well as Jonas and Woodside (2016), described that the ability to breastfeed involves different stages and changes from endocrine function during pregnancy, to autocrine after delivery of child and placenta, through sensory stimulation as suckling from the child and from hormonal effects. Buhimschi (2004) described lactation function as divided into different phases; **first phase:** mammogenesis, meaning development of mammary glands initiated in utero during the embryonical stage, continuing through puberty and finally through changes during pregnancy under influence of prolactin, which is the main regulator of milk synthesis, as well as estrogen and progesterone. The last stage of mammogenesis is involution where the mammary gland undergoes remodeling as a result of weaning (cessation of breastfeeding, when infant changes from independence on breastmilk to complete independence from it, Greiner, 1996), with the ability to repeat the mammogenesis cycle during next pregnancy. **Second phase:** lactogenesis 1, when breast starts to produce colostrum through stimulation of endocrinal system in middle of pregnancy and continues until around two days postpartum (Neville, 2013). This is followed by lactogenesis 2, milk production increases due to a decrease of both estrogen and progesterone, and the rapid increase of prolactin after birth. Lactogenesis 2 is dependent on a transformation of endocrine to autocrine function, initiated 3-8 days postpartum, and is also referred to as milk coming in (Neville, 2013). Buhimschi (2004) explained Galactokinesis as milk ejection reflex, and its dependence on nipple stimulation that sends signals to the posterior lobe in the pituitary gland, resulting in the release of oxytocin. This causes the myoepithelial cells to contract then milk production occurs and released out of the alveoli during child suckling. The milk ejection reflex takes approximately 30-60 seconds.



(Clinicalgate, 2015)

Oxytocin increases few minutes before suckling begins and enhances as a response to suckling stimuli and is followed by an abrupt decrease approximately 20 minutes after nipple stimulation began (Buhimschi, 2004). Buhimschi (2004) clarified further that mechanical stimulation like suckling, with help of oxytocin, empties the breasts and increases prolactin, whereas it is well known that dopamine has an inhibitory effect on prolactin and consequently affect milk production. Galactopoesis, also known as lactogenesis 3 according to Sriraman (2017), is maintenance of lactation driven by milk extraction of which the secretion mechanism of prolactin works both inhibitory and stimulatory through Hypothalamus. Buhimschi (2004) discussed the role of these factors on influencing the inhibitory mechanism (dopamine, GABA-system) and the releasing

mechanism (thyrotropin, peptides, angiotensin). There is also an autocrine/paracrine function that helps to control prolactin secretion, these factors are dependent on oxytocin, serotonin, opioids, histamine, and substance P. Estrogen and progesterone also has the ability to modulate the prolactin release. Sriraman (2017) further described that Prolactin Inhibiting Factor (PIF)is inhibited when the breast is emptied through nursing or pumping, initiating milk production, whereas if the breast is full it inhibits production through the feedback inhibitory mechanism of lactation and milk production reduces. Adequate Galactopoesis is therefore dependent on frequent suckling and/or emptying breasts to maintain elevated prolactin levels after completing breastfeeding following lactogenesis 2 (Buhimschi, 2004: Sriraman, 2017). According to Grattan (2015) the prolactin system is the most complex and versatile of all the hypothalamo-pituitary axes and the combined functions of prolactin control maternal adaptation from pregnancy to lactation.

Knowledge & Support

Midwifery knowledge provides an ability to identify individuals with special needs for care and support and includes breastfeeding and breastfeeding complications (Socialstyrelsen, 2006). In an open letter signed by i.e. health visitors, midwives, pediatricians, general practitioners, lactation consultants, breastfeeding counselors and university researchers following a series on breastfeeding in The Lancet, Professor Nigel Rollins, one of the series authors, stated:

> The success or failure of breastfeeding should not be seen solely as the responsibility of the woman. Her ability to breastfeed is very much shaped by the support and the environment in which she lives. There is a broader responsibility of governments and society to support women through policies and programmes (*sic)* in the community" (Rollins, 2016, 2nd para.).

Bergmann et al (2014) described that already in 1991, UNICEF together with the WHO presented "Ten Steps to Successful Breastfeeding" (see table 1). The purpose was, and is, to ensure support for breastfeeding mothers. Socialstyrelsen (2006) clarified, that this includes identifying and assessing breastfeeding complications in both normal and complicated care and early parenting. According to Meleis (2010) health care professionals are often a primary contact and have a part in the parents' transitioning. McFadden, et al. (2017) described support for the mothers as education to the staff which can include improvement, reassurance, information, praise, opportunity to

Table 1, Ten steps to successful breastfeeding (WHO/UNISEF,1989)

1	Have a written breastfeeding policy that is routinely communicated to all health care staff.
2	Train all health care staff in skills necessary to implement this policy.
3	Inform all pregnant women about the benefits and management of breastfeeding.
4	Help mothers initiate breastfeeding within half an hour of birth.
5	Show mothers how to breastfeed, and how to maintain lactation even if they should be separated from their infants.
6	Give newborn infants no food or drink other than breast milk, unless medically indicated.
7	Practise rooming-in - that is, allow mothers and infants to remain together - 24 hours a day.
8	Encourage breastfeeding on demand.
9	Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.
10	Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.

discuss and regular ongoing contact both one-on-one, on the phone, in group and in- and outside of the hospital. It was also clear that all forms of extra support decrease the cessation of both partial and exclusive breastfeeding during first six months postpartum. Ekström and Thorstensson (2015) showed that increased knowledge and breastfeeding support had a positive impact on mother's feelings towards their child, an earlier initiation, higher frequency and longer duration of breastfeeding than mothers with standard support after delivery. Broberg, Almqvist, Risholm Mothander and Tjus (2015) described attachment like a psychological relationship between the child and its nearest caregiver and emphasized that attachment theory is about humans being social creatures who needs each other to live and survive. Meleis (2010) further described that skills are vital to identify, inhibitory and promotion aspects that affect the process of parenthood, meaning that factors affecting transition in either a positive or negative direction, include: environmental support, relevant information from healthcare professionals, advice from safe sources and getting answers to possible questions. Accordingly, healthcare personnel must identify possible vulnerability and assess measures that promote a positive transition process (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000; Meleis A., 2010).

Breastfeeding and motherhood

According to Dietrich Leurer and Misskey (2015), breastfeeding is described by mothers as a positive experience characterized by love, feeling great, awesome and amazing, as well as proud to have pursued although problems occurred, and that breastfeeding is highlighted as a unique mother and child bonding experience. However, Thomson, Ebisch-Burton and Flacking (2015) suggested different aspects which affect motherhood. They explained that when feeding method were not experienced as expected by herself or others, to breastfeed or not, often leads to feelings of isolation. This due to potential pressure which is counterproductive "breast is best", inadequacy, inferiority, humiliation and failure, especially during contact with health professionals with fear of reprisals. It is also common to describe feeling out of control, dependent on others, getting insufficient information and lack of feeding support (Thomson et al, 2015; Hvatum & Glavin, 2017). Watkinson, Murray and Simpson (2016) stated that women have knowledge about the health benefits from breastfeeding but also emphasized that even without physical problems, breastfeeding is a potential trigger for negative emotions and sensations. This was described nearly 20 years ago by Schmied and Barclay (1999) who concluded that experiences of breastfeeding could vary a great deal. They discovered some women were experiencing breastfeeding as pleasurable, sensual and intimate. These women felt that the relationship with their child was very powerful, having an embodied connection, a sense of personal ownership or possession over their child whereas breastfeeding for other women felt difficult, unpleasant, disappointing and overwhelming. These women instead felt like the reward did not exceed their effort (Schmied & Barclay, 1999).

Previous research has focused on physical breastfeeding difficulties (Bergmann et al, 2014). Approximately 80% of mothers' experience breastfeeding problems and it is well known that it reduces the breastfeeding rate drastically (Bergmann et al, 2014). Previous research has also established that degree of self-efficacy in breastfeeding mothers has a great impact on the ability to overcome difficulties that may occur (Jager, Skouteris, Broadbent, Amir & Mellor, 2013). This means breastfeeding difficulties that appear in the early postpartum period have a negative impact on the mother's needed confidence to be able to overcome future breastfeeding difficulties. It is also emphasized that self-efficacy can be developed and/or increased by for example: encouragement from friends, family or health professionals, but also from physiological states like happiness and bonding (Jager et al, 2013). Since mothers can view breastfeeding as a source of maternal identity and self-worth, negative experiences of breastfeeding may have a negative impact on the mother-child relationship (Watkinson et al, 2016). Kroll, Kamboj, Curran and Grossmann (2014) described similar findings when showed breastfeeding and its influence on biological and psychological processes, impacts not only maternal behavior in general, but more so on emotional functioning during motherhood.

Dysphoric milk ejection reflex [D-MER]

D-MER is not yet recognized as a medical condition, meaning that still there is no diagnoses in relation to symptoms. This term was described in 2007 by Lactation Consultant Alia Macrina Heise who experienced the condition while breastfeeding her third child. Alia is now an international speaker and published writer on D-MER (2017) and creator of both website www.d-mer.org (2008) and Facebook support-group "Dysphoric Milk Ejection Reflex (D-MER): Support group from D-MER.org" which started in 2008 and has 45 countries represented by its 1200 members. The first published research on D-MER was a case-study of one woman's experience (Cox, 2010) followed by a case-report in 2011 by Heise and Wiessinger. Heise (2018) described D-MER as characterized by dysphoria, which imparts *dissatisfaction, unrest and impatience* (Nationalencyklopedin, 2017). Dysphoria thus contradicts the euphoric foundation of excitement, relaxation and general well-being (Nationalencyklopedin, 2018). Heise and Wiessinger (2011) explained D-MER in one of few published materials as a sudden emotional drop in some women just prior/in connection to the milk ejection reflex. Symptoms are described in words of wistfulness and self-loathing with various severity and seems to be caused by a physiological process. Kroll et al (2014) emphasized that breastfeeding is a complex and dynamic biological and psychological process which influences many emotions. Heise and Wiessinger (2011) hypothesized that a transient decrease on dopamine level may be responsible for the D-MER effect experienced by mothers. Ayano (2016) described that dopamine is a neurotransmitter and plays a central role in the brain, for example inhibition prolactin, pleasurable reward behavior, mood and emotions as well as controlling nausea and pain processing.

Volkow, Wang, Tomasi and Baler (2013) showed that abnormal dopamine levels can cause emotional disturbances like dysphoria, negativity, low mood and lack of enjoyment.

Research problem

Knowledge and research on D-MER is scarce, which can lead to lack of knowledge among midwives and therefore the service that they will provide for women with D-MER will be poor. Bad experience of breastfeeding may lead to long and short-term consequences regarding child's and mother's health.

Aims

To *describe* experiences of D-MER from a patient perspective and to *examine* midwives' knowledge and experience of D-MER.

Objectives

1. What experiences do women with previous or ongoing D-MER describe?
2. Are midwives aware of D-MER?
3. How does D-MER affect women´s breastfeeding, bonding and parenthood?

Method

Design

We conducted an exploratory mixed method design, where both qualitative and quantitative methods were applied. A mixed method is suitable to use when the topic is neglected or under researched and also if participants are difficult to be identified or accessed, as mentioned by Creswell and Plano Clark (2011).

Participants:

1) Women who are suffering or have had experience of D-MER.

Both groups of women were targeted via Facebook regardless of their location, one support group for women with experiences of D-MER that consists of over 1000 members worldwide. Another, Swedish breastfeeding support group that has over 23 000 members, consisting of members asking and giving each other support on various breast-, bottle- and/or formula feeding issues.

2) Licensed midwives in Sweden.

The Midwife Facebook group consists of over 4000 members living in Sweden.

Study phases

Phase 1.1: Interviews with women on their experiences of D-MER.

Phase 1.2: Based on the data from women's interviews (e.g. their answers) an online anonymous survey was created by common topics that appeared. The survey was then distributed in the Facebook-group for women with D-MER (See attachment 3 for "D-MER survey" for questions).

Phase 2: Anonymous online survey with close and open-ended questions was created for Midwives to examine their knowledge on D-MER.

Data selection

The participants consist of two separate groups, as shown in table 2 below:

Table 2, Inclusion and exclusion criteria

Phase 1.1 and 1.2 Women who had a previous or ongoing experience of D-MER was approached.	***Inclusion Criteria:*** Knowing of D-MER as a condition and becoming aware of it being the reason for the experience within first year postpartum. Regardless of sociodemographic (country, age, number of children).
	Exclusion Criteria: more than 1 year postpartum before becoming aware of D-MER
Phase 2 Midwife in a Swedish midwife forum was approached	***Inclusion Criteria:*** Midwife, regardless of knowledge and/or experience and current employment.
	Exclusion Criteria: Other professions.

Sampling

Sample size for qualitative data is adequate when saturation is reached, according to Polit & Beck (2012). In fact, they further recommend continuing with two more interviews afterwards to establish saturation. Keeping saturation in mind, and the fact that the studies carried on D-MER are very few, the estimated number of women with experience of D-MER needed for individual semi-structured interviews were between 10-20. The number of women who reported interest via e-mail to-participate in interviews was 24. All of them received information letter about the study and a consent form. Of the original 24 women, 22 answered via e-mail and still wanted to participate. Six women did not respond to e-mails when trying to book an appointment for an interview within the allotted timeframe and one woman responded she did not want to be audio recorded, finally resulting in 15 booked interviews. Lastly, one woman was not available when it was her time to be interviewed, resulting in qualitative data collection from 14 women. For quantitative data from women as well as midwives´, sample size is vital according to Polit and Beck (2012). Polit and Beck (2012) reported that the statistical power is the ability to show true relationships between variables; the probability of rejecting false null hypothesis. Because there is a lack of research on D-MER

(only two case studies), we could not calculate power and then calculate sample size, therefore our strategy was to include as many as possible in order to reach sample representation.

Data collection and instruments

Recruitment

Participants were recruited via Facebook using snowball sampling. Snowball sampling is a cost-effective, practical, easy and fast technique and suitable for population which is hard to determine or reach (Polit & Beck, 2012). We published a flyer in two Facebook support groups: one targeted women worldwide with D-MER "Dysphoric Milk Ejection Reflex (D-MER): Support group from D-MER.org", another targeted women in a Swedish breastfeeding support group (“Amningshjälpens slutna grupp”) that focuses on a wider spread of nursing/pumping issues, to participate in interviews. The D-MER support group, were allowed to share the survey with other groups targeting breastfeeding issues. The publishing was followed by three reminders and the survey was active between February 20th and March 5$^{th, 2018}$. The midwives were recruited from a community group for midwives on Facebook, “Barnmorska- aktuellt och intressant”; and they were asked to answer an online survey that contained close and open-ended questions regarding knowledge and/or experience of D-MER (see attachment 2). The original post was followed by two reminders and the survey was available between January 6th and February 5th, 2018 but was prolonged to February 15th due to low response rate. By prolonging the survey and give information about current number of participants, the number increased from 66 to 115 participants after the last reminder.

Data collection

The interviews were conducted by both authors of this thesis via Facebook Messenger (video) at a time and date of the participant’s convenience during January 2018. The interviews took in average 35 minutes (11-55 minutes) and followed a semi-structured approach with 17 questions of both qualitative and demographical character and were designed by us authors and approved by our supervisor (see attachment 1). Semi-structured interviews, meaning that the same questions for all women was asked, with supplementary questions depending on given answers, were conducted for flexibility of addressing D-MER. The interviews were recorded and then transcribed by both authors separately. Both authors then listened to the recorded interviews again while comparing to each other’s transcripts to make sure that the transcriptions was correct. The data collected from the interviews was analyzed then used to create a **s**urvey that was published on the same Facebook support group for women who had had or were currently experiencing D-MER, as well as in the Swedish breastfeeding group (see table 3).

Table 3, An example on process from content analysis to survey questions

Code	Subcategory	Category	Survey question
It definitely affected the bonding to the baby, she could not be around baby for more than five minutes by herself (A30)	Negative impacts on bonding	Consequences of having D-MER	45. Do you feel like D-MER has affected you bonding experience to your child(ren)?
D-MER hasn´t affected the bonding (F17)			46. If yes, please describe in what way:

A web-based program provided by Karolinska Institute, "KI Survey", was used for designing both the quantitative surveys. The interview questions and surveys were designed by the authors and approved by supervisor Amani Eltayb, Postdoc.

Data analysis

Because the investigated subject is unexplored, inductive content analysis was chosen to analyze women's experiences of D-MER and midwives' knowledge, as well as experience, of D-MER (Polit & Beck (2012). To achieve good understanding of the collected data, we read it several times. The interviews were transcribed verbatim and compiled, meaning that the content was encoded, and meaning-bearing units were identified and created on the basis of similarities, as well as differences, which then was condensed into smaller units. These were gathered in subcategories and categories. An example of this process is shown in table 4. The qualitative data from the survey for women was analyzed by grouping quotes based on common denominators such as similar experiences and /or statements. Quantitative data was analyzed using the statistical Program: Statistical Package for the Social Sciences (SPSS) version 24. Statistical analysis provides data description within a certain sample of population, (Ejlertsson, 2012). Data were cleaned then coded for example if the answer "Yes" or "No", then "Yes" will be coded 1 and "No" 2. Quantitative data were then presented in tables.

Table 4, Example of Content analysis

Meaning bearing unit	Condensed meaning unit	Code	Subcategory	Category
B8# I kept trying to tell people, and people kept telling me it that it was postpartum depression, and I said No, that these things are different, said this, the symptoms don't match up	People kept saying it was postpartum depression even though she felt the symptoms did not match up	People kept saying it was postpartum depression even though she felt the symptoms did not match up.	Lack of knowledge and poor services by health personal regardless of their health profession	Seeking help from health professionals regarding D-MER

Ethics

The Medical Research Council (MRC, 2017) recommends following different ethical principles when research is carried out. Therefore, we applied the principle of autonomy regarding participants and the justice principle by doing good and causing no harm (MRC, 2017). This was assured by providing the

participants detailed verbal and written information about the study. Participants consented verbally during interviews. In case of surveys, a letter of information appeared first, then the consent was achieved after respondents clicked the answer "Yes" to the question "Would you like to participate". The letter explained about the study's purpose and all aspects of consenting to as voluntary participation, confidentiality, and that they could cancel at any time without any further explanation. Collected material was confidentially handled through its anonymity and safe storage as described by MRC (2017) and Polit and Beck (2012), meaning audio recordings and transcriptions were kept on USB at Karolinska Institute in Stockholm.

Results

Results will be presented as follow:

Study 1.1, Women interviews (qualitative data) were analyzed by means of content analysis. Second, the findings from study 1.2, Women survey that covers their experiences of D-MER, were analyzed using descriptive statistics while qualitative data from open ended questions were analyzed by content analysis. Third the finding from study 2, Midwives survey, the close ended questions were described via applying descriptive statistics and content analysis was applied to analyze open ended questions.

Study 1.1: Interviews

Interview participants

Fourteen women from five different countries were interviewed. The majority of women were from the USA (n = 8), followed by the UK (n=2), Sweden (n=2), and then Iceland (n=1) and Australia (n=1). The median age of participants was 36 years old. Nine women were first-time-mothers, four had two children and one had three children. Out of the fourteen women, nine were still breastfeeding. The five women who were not breastfeeding during the time of the interviews had breastfed in average for about six months (range 3 weeks to 21 months), however the median breastfeeding duration was 6 weeks. None of the women were smokers. Six women stated having a history of anxiety or depression while another six women were without a history of anxiety or depression and the rest (two) had not been clinically diagnosed. Out of the 14 women, three had experience of postpartum depression or anxiety. Demographics of the interviewed women are displayed in

Table 5, Interview demographics

Number of participants	14	
Median age	36 (range 30-41)	
Country		USA=57% (*n=8*)
		UK= 14% (*n=2*)
		Sweden= 14% (*n=2*)
		Iceland= 7% (*n=1*)
		Australia= 7% (*n=1*)
Smoker	None	
Number of children	1-3	1 (*n=9*)
		2 (*n=4*)
		3 (*n=1*)
Breastfeeding period	3 weeks-21 months	
History of anxiety or depression prior pregnancy		Yes= 42,9% (*n=6*)
		No= 42,9% (*n=6*)
		Maybe (undiagnosed)= 14,2% (*n=2*)
History of postpartum depression or postnatal anxiety		Yes= 21% (*n=3*)
		No= 79% (*n=11*)

table 5. Their experiences of D-MER are described in five main categories and ten subcategories as shown in table 6.

Table 6, Categories and subcategories

Categories	Subcategories
Experiences of D-MER	Negative emotions and physical symptoms
	Symptoms intensity shown fluctuations over time
Consequences of having D-MER	Weaning
	Not weaning but women continue breastfeeding under stress
	Negative impacts on bonding
	Women's self-stigma and feelings of guilt
Seeking help from health professionals regarding D-MER	Lack of knowledge and poor services by health personal
	Treatment suggested by different health professionals
Coping strategies	Knowing more about D-MER created mental preparation and acceptance
	Strategies
Retrospective insights by participants	

Experiences of D-MER

Negative emotions and physical symptoms

The majority of women interviewed described symptoms of anxiety, nervousness, worry and emotional unsettling like dread, void and/or shame. D-MER was by some described as a wave of depression or sadness, and that all the joy had been drained, one woman stating that it was particularly hard to go through repeatedly and frequently during the day. Some women felt irritable, annoyed, agitated, frustrated and spoke of a loss of control over their bodies, actions and/or thoughts resulting in for example, a less strong hold of the baby, saying things one did not mean to spouse or having suicidal thoughts. The symptoms were for the most parts experienced as sudden and transient:

> *It was amazing to me, how I could be totally happy and then all of a sudden, it's like somebody flipped a light switch and I could feel incredibly anxious and a little bit of depression mixed in, but mostly anxiety, very just nauseous and general feeling of just feeling really bad. And it would last for like a minute or two and then go away, disappear* (D)

> *When I started breastfeeding, I just had feelings of rage and suicidal thoughts and severe waves of depression and the severe waves of depression would only last for about a minute* (A)

Some of the women interviewed described that when D-MER appeared they did not understand what was happening, three of them said that it started within the first week postpartum while another woman described that it took a while before D-MER occurred. Five of the women described that they felt it as a clear connection to milk letdown. The symptoms were described to start at the beginning of a breastfeeding or

pumping session and last for 30 seconds to one minute, for some up to two minutes, for one woman as long as five minutes, or even for the duration of the whole feeding. Three women in the interviews described that they forgot about D-MER in between the feedings, until it happened again. One of the interviewed women described having symptoms like D-MER prior to pregnancy and another during the third trimester of pregnancy.

Symptoms intensity and shown fluctuations over time

The women interviewed gave fluctuated statements considering D-MER appearance. The majority experienced the symptoms every, or for the most times when nursing or pumping. A couple of women described occurrence changing to become less frequent or more sporadic over time. In terms of intensity, several women spoke of it being variable, for some with no apparent reason whilst others felt a correlation as, decreasing when laying down or when being able to think about it ahead, increasing when baby latched on again, or if the mother was stressed. It was common to mention unmet physical needs as a factor influencing D-MER intensity, like sleep deprivation, hunger or thirst. Several the of interviewed women also stated that it seemed to ease with time, some specifying it being at its worse during the first six months postpartum.

> *The severity of it really varies, the feelings are probably similar but because they're more or less severe, they feel different. Different like, levels of sadness … more recently it's been less intense, thank goodness, so now I would say it's even like, as light as like, melancholy*
> (K)

Two women interviewed, however, stated the opposite, feeling that the intensity increased with time, one of the two also experiencing a difference in intensity and frequency between her two children. Three women spoke of night feedings influencing the intensity, two felt it was less at night and one felt the opposite and suggested it has to do with more time passing between feedings. The frequency of feeding or pumping having an impact on intensity was mentioned by other women as well. Two said that waiting too long between the feedings in the beginning could result in more intense D-MER. Three of the interviewed women felt that nothing improved or worsened the symptoms. In terms of pumping, women gave various descriptions in their interviews, some felt that D-MER was worse when pumping, others less, and three women did not feel a difference between the two.

Consequences of having D-MER

Weaning

Several women described that they weaned because of D-MER. One woman felt she could not handle both D-MER and postpartum depression and weaned because of it:

My mental health, the connection I was having with my children, with my family, it wasn't just compromised… I was miserable… My health, my life was in jeopardy, it wasn't worth it, it was too much for me (B)

Another described that she could not handle the feeling of dread or the intensity of D-MER. The decisions to wean was described as hard and could lead to feelings of guilt, one woman stated she felt brokenhearted to have weaned early and that she blames D-MER for it. However, three of them also stated that stopping breastfeeding in turn, stopped D-MER. Two women stated that they are planning to, or already give formula or other supplements, sometimes to not have to feed as frequently, and by that avoiding D-MER. That implied transitioning from exclusive to partial breastfeeding earlier than recommended, or as one of them confessed:

Actually, to be honest, it has happened, when I know she wants to be on the breast all the time during the evenings, I can pretend that's she's not hungry, so I play with her, so I might not have to do it (I, translated)

Not weaning but women continue breastfeeding under stress

The majority of interviewed women described that D-MER did not affect their breastfeeding regarding duration or frequency. However, it was expressed that it was hard to pull through, and that thoughts about weaning all together, or to some extent, to get a break from the symptoms, had occurred. Two interviewed women wondered if a reason for D-MER not having affected their breastfeeding, could be that symptoms and intensity maybe varies between individuals. Other reasons for pursuing breastfeeding even though they experienced D-MER were that some could not bear to end it themselves, before their child was ready or that they felt that breastfeeding was the best for their child. Some women also stated that they continued to breastfeed because they would have felt guilty if they had stopped because of D-MER. Half of the women interviewed described feelings of discouragement, feeling down, anxious, sad and not looking forward to breastfeeding when knowing D-MER would appear. Breastfeeding their child became more of a shore, an obligation. It was also mentioned by a few women that the frequent and repetitive mood swings caused by the condition, had a negative effect on their quality of life. Women described feeling guilty over their negative feelings towards breastfeeding and felt that they wanted the feeding to be over and done with. Grief over not enjoying breastfeeding like others appeared to do, was commonly mentioned, and that it caused feelings of conflict at every feed.

I wanted to keep on breastfeeding, but I think all the time that I didn't want to, but I will because the will to do it is stronger than D-MER, but it is a, a fight inside me every time (I, translated)

Negative impacts on bonding

In terms of bonding experience, a few interviewed women did not feel that it was affected by D-MER, stating for example that it was not a "yes or a no"- thing, or was not sure if D-MER alone affected the

bonding due to other breastfeeding difficulties or other factors in the beginning. Most women described that D-MER affected the bonding. Four women felt that it did initially, when not yet realizing what was happening, or due to the frequent feedings, or having more intense D-MER symptoms, but that the effect it had lessened over time.

> *I felt I was worried it would affect me bonding with him initially as well because I hated doing it and it made me feel horrible to do it so, that wasn't a nice feeling I think that probably affected my bonding but I think that's improved over time since he's got older and he's more reactive and smiling and things like that it means that we can interact in other…* (L)

Some women felt the bonding was affected because of the idea that breastfeeding was supposed to be a bonding moment or something pleasant, but that the women just did not enjoy. Another woman spoke vividly of the feeling of missing a key piece when it comes to bonding, she was struggling to feel that happiness since she still associates holding the baby with anxiety and pain. Others spoke of missing out, not experience that closeness, one even spoke of fear of resenting her child in terms of bonding due to D-MER. A couple of women stated that D-MER hindered them from enjoying their children and two spoke of bottle-feeding as something where bonding had to be worked on or learned, to happen. One of the two spoke of compensating feelings towards the child when giving bottle. She felt adamant that the baby still was going to be fed in someone's arms and being snuggled. Some women described that it was impossible for D-MER not to have affected the bonding. Two women in the interviews stood out with their experiences, where one woman felt that D-MER made her struggle to keep calm with her oldest child while nursing and thus affecting that child more than the one being breastfed. The other felt that the bonding in fact maybe became stronger because she pursued although she experienced D-MER.

Women's self-stigma and feelings of guilt

Women gave descriptions on if and how D-MER affected their motherhood, many felt that it did, and failure seemed to be the prominent emotion. Women described that they felt like a failure to both themselves and to their child because of not being able to breastfeed as long as they had liked, or for letting their negative emotions get in the way of breastfeeding and/or feeling they did not try hard enough.

> *Absolutely, it absolutely affected me, and my relationship and my confidence (*I, translated)

Feeling pressured to breastfeed from family members, society and themselves was mentioned, and it became clear that feelings of guilt occurred due to the expectation that nursing was supposed to be experienced as something positive. Several women felt guilty because they did not want to breastfeed, and others spoke of feeling inadequate, or that D-MER made them feel as they had failed in terms of breastfeeding. This could cause feelings of wanting to give up breastfeeding all together. Other emotions experienced, regarding feelings about themselves caused by D-MER, was shame, unloving, worthless, sexualized and suicidal.

Isolation was also mentioned, because of experiencing that others judged them for not breastfeeding. One woman spoke of this causing her to build up a general anxiety in regard to, and prior breastfeeding, she did not want others to see her go through a D-MER episode. It was also mentioned to have a fear of being treated poorly by others. One woman explained that she avoided talking about D-MER because she did not want to have to explain and/or have people dismiss it as postpartum depression, she emphasized that she adjusted herself depending on who she was talking to and how she was treated:

> *Friends would ask, well it wasn't just friends, people that, you know people just asked, they see me giving my child the bottle and they ask me why I wasn't breastfeeding. And depending on how people asked me, the answer was generally the same, I kept it synced, but I either answered with a stern "that just didn't work for us" or was just "it didn't work for us" (sad voice)* (B)

Women expressed how D-MER affected their social life and network. This included being able to relate to others and/or others to relate to them as well impact on the relationship with partner. It was described that people did not understand how bad breastfeeding made them feel and that people thought they just "gave up" when deciding to stop breastfeeding. Several women described that not being able to relate to others had a significant impact on motherhood. This due to that other mothers talked about how great they felt while breastfeeding whereas these women felt like crawling out of their own skin and scream which causes feelings of envy. One woman also described that when thinking she was alone with the experience, caused the biggest impact on her motherhood, another woman emphasized not being able to articulate her feelings to anyone and that she isolated because of shame:

> *It isolated me, and I would say that I isolated myself, but I did it because of all these factors of like, trying to handle this thing, with all these things going on at the same time, I didn't want to be around other people that didn't get it (...)Even with the mommy groups that I have, I said I was not having the same experience that everybody else was and when my friends were talking about how great they felt and that... It made me feel like a bad mom, so I just didn't talk about it* (B)

Seeking help from health professionals regarding D-MER

Lack of knowledge and poor services by health personal

The interviewed women sought help from various professionals, including; Obstetricians/Gynecologists, Endocrinologist, Nurses, Midwives, Child Health Care Services, Physicians/General Practitioners, Pediatricians, Health Visitors, and Lactation Consultants. Three women had not sought help from any health professional, two of them because they had not realized that they had D-MER, at the time they met their doctor. The interviewed women also stated not being helped when reaching out to a health professional. They felt in some cases dismissed, being told that the symptoms were normal and that it would pass. Some

met professionals who, despite women bringing information about D-MER, continued dismissing it as for example caused by too tight peck muscles, a mental health issue or as postpartum depression:

> *I was able to tell my physicians what was happening, said, I feel this awful sensation, I feel my let down reflex, milk comes in, its connected, it has to be connected. And I kept trying to tell people, and people kept telling me it that it was postpartum depression* (B)

Being ignored or not helped or not taken seriously made some women regret even telling a professional about their experience and several of the women expressed that there was no point in telling anyone about D-MER. One woman even described that when she told her midwife during postnatal period she felt that it was more important that the baby was fed and gaining weight and less about the breastfeeding experience. One woman described in her interview that after delivery of her third child; felt she had to breastfeed even though her previous breastfeeding experience was written in her charts with recommendation not to do it, due to the staff not preparing food for the baby:

> *And it was it my charts when I delivered my third, that the plan was that I was not going to breastfeed. And when I delivered her, there was no milk ready for her, and I was treated as a mom who just didn't want to breastfeed. When she was born, and she was crying, I knew I had to help her, and they didn't have any milk ready, so I did what I had to do (*B)

Only a few women met a professional that had heard about D-MER: one midwife that had heard about the symptoms but not knowing what it was, a lactation consultant and one obstetrician-gynecologist who gave the name for it, another obstetrician/gynecologist who took the symptoms seriously and had an interest in learning about it, and a therapist who wanted to look into it. The help the women received was referral to psychological care, one open-minded endocrinologist who read about it, a lactation consultant who explained the symptoms as a reflex response and not psychological, and a pediatrician:

> *A pediatrician didn't know about it either, but she managed to listen to me and I told her, and she asked me to wait in the waiting room, she Googled, and she brought, I think there's maybe just one article on D-MER online, so she printed it and gave it to me, so it's, it's the oxytocin that flows. So yes, she asked me a couple of times if I needed to see a psychologist* (I, translated)

Treatment suggested by different health professionals

A few of the interviewed women gave examples on treatment or medications recommended for D-MER. One got help from a lactation consultant that provided her with coping techniques and recommended that she gave formula for a couple of feedings a day because of the impact D-MER had on her wellbeing. She also took a gene test recommended by a therapist to try and figure out how she would react to certain medications. Some women tried antidepressants and one was a dietician and tried to think nutritionally. Oxytocin was mentioned by one woman, explaining she was prescribed oxytocin nasal spray to help with her problems with letdown reflex, but that it made her D-MER more extreme:

> *I could always feel my breast fill with milk but the letdown did not come but anxiety and everything came, but my kid didn't get the milk and she always would get really angry at*

the breast so when she was three months old I talked to my doctor and asked him if he could help me and then he said "why don't you just quit?" and I was not ready to quit so he gave me a medication, which is actually oxytocin spray, nasal spray, and it helped but it made my D-MER symptoms more extreme (E)

Coping strategies

Knowing more about D-MER created mental preparation and acceptance

Many of the women in the interviews spoke of the impact of knowledge about D-MER had. In many ways it helped them mitigate by knowing about what the symptoms were and that they were transient enabled them to endure. In some cases, learning about D-MER was the reason for them to be able to pursue with breastfeeding.

As soon as I found out about it I could sort of just relax a bit more and I felt like I didn't know if I really liked my baby or something but actually I realized that maybe it's a hormonal thing and then I became a lot more relaxed about it so I suppose I just wished uhm, I'd known about it earlier so I didn't feel so strange (G)

The use of the social network was also commonly expressed by the women. They described that the support group on Facebook had been helpful because they did not feel alone and could get support from others with D-MER. One interviewed woman felt that being able to contribute by telling her story made her feel better.

Strategies

Some women developed coping strategies that they put into place in order to pursue breastfeeding. It was common to prepare and accept that D-MER would appear, and trying to think that it would pass, think of something positive, breathe and power through. Keeping occupied with TV, Facebook, Instagram or Pinterest was also mentioned together with having partner or family talk to them or help them breath trough the episode. Others used ice-water or food, tried to plan around the feeding so the distractions could be set into place. One woman specified further in her interview, that she tries to think that D-MER is connected to milk letdown, and by that a good thing since it enables her to breastfeed. Women also shared their experiences on what they had tried or had thoughts about. One woman tried placental encapsulation, which did not work, another magnesium supplements recommended online, which she could not tell if it helped, or if it was time passing that lessened D-MER. Another spoke of laying down when nursing, to help with the anxiety, or scratching her arms as a distraction. One woman did not experience D-MER at first with her second child, but when she stopped taking the pain medicine prescribed following her cesarean, the symptoms emerged.

Retrospective insights by participants

Some women emphasized the importance of knowledge in professionals, to be able to get adequate help. Six of the women described that they would have advocated for themselves more, maybe Googled it sooner, or

would have been more confident and sought proper help, like getting psychological support for the mental or other issues that D-MER caused or made worse. One woman wishes she had not accepted being dismissed in the beginning, and another woman even stated she would have bottle fed from the beginning instead of breastfeeding, and others gave examples on what they would have done differently to mitigate with the situation:

> *I would have gone into a calmer environment and talked more to my husband about it because I always thought I was crazy because the people around me didn't quite understand what was happening… (E)*

Overall there was disappointment that there was not enough research on D-MER, and they are hoping that more research brings a bigger general awareness. Women expressed that awareness of the condition might prevent women from prematurely weaning and initiate support earlier. The majority of the women described that whoever helps women postpartum, should be aware of D-MER and emphasized that it is important to differentiate D-MER from postpartum depression.

Study 1.2: Survey for women with D-MER

A total of 146 women answered the survey "Experiences of D-MER", however two women were excluded since they did not match the inclusion criteria. Missing data were ranged between 0%-3% in all most all questions, however the highest missing answer was 10% on an open question (what the women did instead of seeking professional help to overcome D-MER). The median age of the women was 32 years (range between 22 and 48), and most of them lived in the USA (47%) and UK (35%), while the rest were from Canada (6%), Australia (4%), Sweden (4%), the Netherlands, Norway, Denmark, France, Indonesia and Ireland had 1% participants each. Most women had one (33%) or two children (46%), few had three (16%) or four (5%) children. Almost 85% of the women with more than one child answered the question whether they experienced D-MER with all children or not, the majority (53%) did experience D-MER with every child. Almost 66% of participants had a previous history of anxiety and/or depression, furthermore,

Table 7

Do you have a history of anxiety, depression or other disturbances?

		Frequency	Valid Percent
Valid	Yes, both anxiety and depression	63	43,8
	No	42	29,2
	Yes, anxiety	20	13,9
	Yes, depression	11	7,6
	If other, please specify	8	5,6
	Total	144	100,0

Table 8

Did/do you have postpartum depression or postnatal anxiety?

		Frequency	Valid Percent
Valid	No	69	47,9
	Yes, both postpartum depression and postnatal anxiety	31	21,5
	Yes, postnatal anxiety	25	17,4
	Yes, postpartum depression	19	13,2
	Total	144	100,0

13% had experience of postpartum depression (tables 7 and 8). Only five (3%) women were smokers, three of them smoked during pregnancy and breastfeeding.

The symptoms described by the interviewed women were in many ways consistent with the findings in the quantitative survey. When asked to list the three most prevalent symptoms of D-MER, the following three symptoms emerged from the survey; “anxious, restless and nervous” (43%) followed by, “dread” (34%), “sad” (31%). The most frequently chosen symptom alternative in the survey were “anxious, restless, nervous”, “emotional disturbance (dysphoria)”, “dread” and “sad”. Melancholy, depressed, homesick, nausea, anger, thirst and suicidal thoughts were also mentioned amongst others (see table 9). The women in the survey had the opportunity to specify other symptoms than the ones listed in the question, resulting in descriptions of irritation, panic or panic attacks, guilt and grief, feeling lonely or overwhelmed, exhausted, disgusted, disassociated, helpless, fear, hatred, dislike, itching, giddy, impending doom and hot flushes. Others described feeling like suddenly being surrounded by a black cloud. It was also mentioned by several, feelings like they were about to, or did cry during breastfeeding, as one woman in survey described:

It was very powerful, it would be like hitting a wall. I could feel okay when I sat down to breastfeed and then get hit with such powerful sadness and melancholy and emotions, I'd cry and want to die right there

Table 9

Symptom Frequency

		Responses		
		N	Percent	Percent of Cases
Symptom experience	Anxious, restless, nervous	99	12,7%	69,7%
	Emotional disturbance (dysphoria)	88	11,3%	62,0%
	Dread	80	10,2%	56,3%
	Sad	77	9,9%	54,2%
	Melancholy	62	7,9%	43,7%
	Depressed	58	7,4%	40,8%
	Homesick	55	7,0%	38,7%
	Nausea	53	6,8%	37,3%
	Angry, rage	45	5,8%	31,7%
	Shameful	37	4,7%	26,1%
	Thirsty	44	5,6%	31,0%
	Loss of appetite	27	3,5%	19,0%
	Physical pain	23	2,9%	16,2%
	Suicidal	11	1,4%	7,7%
	If other, please specify	22	2,8%	15,5%
Total		781	100,0%	550,0%

a. Dichotomy group tabulated at value 1.

Most (83%) of respondents stated that symptoms of D-MER were intermittent, followed by 17% saying they were continuous. More than half of the women (57%) described that they had forget about having D-MER in between feeding sessions. Considering symptom debut while nursing or pumping, it was most commonly answered to experience D-MER within one minute after latching, one to two minutes prior letdown, or at letdown (see table 10) whereas 17% did not specify time to a reference point such as "from latching" which led to inability to further analyze their answers. Most of the women (58%) experienced symptom duration while feeding/pumping as less than three minutes. Over one third (35%) stated a duration of less than one minute, however duration for up to an hour (1%) or for the entire feeding session (11 %) was also mentioned. More than one fourth (27%) of the participants stated that they had experienced symptoms like D-MER prior pregnancy, and one fifth (20%) had experienced it during pregnancy.

Table 10

Symptom start D-MER while feeding/pumping

		Frequency	Valid Percent
Valid	Within 1 min after latching	36	26,1
	Within 1-2 minutes before letdown	28	20,3
	At letdown	24	17,4
	Within 1-2 minutes after latching	13	9,4
	3- 5 minutes after latching	4	2,9
	Immediately	4	2,9
	Other	5	3,6
	Did not specify	24	17,4
	Total	138	100,0

Of the women participating in the survey, 41% felt that D-MER symptoms could worsen and all of them chose to specify further in an open question. on what could affect the symptoms. The most frequently stated factor influencing D-MER was unmet physical needs (lack of sleep, dehydration, hunger). Other things mentioned was if one already felt emotional, like having a bad day or being in a bad mood, or if it went to long between the feedings. Some women also mentioned clutter/messy environment, stress and night feedings as other aspects that worsened D-MER symptoms. It was also described by a few, that ovulation or the premenstrual period in the cycle had influence on D-MER, being around others, like extended family, or that physical contact made it worse. The majority of participants (87%) answered that they at some time extracted milk by pumping. Of those, 24 women (19%) felt the that D-MER was worse when pumping compared to when breastfeeding, 44 (35%) felt D-MER less when pumping, 45 (36%) felt that it was not any difference between the two, and 12 (10%) did not know whether or not they experienced any difference.

Almost three quarters (74%) of survey participants felt that their breastfeeding was affected by D-MER. When specifying in a multiple-choice question, how their breastfeeding was affected by D-MER, 63 (44%) women answered they did not enjoy breastfeeding their child, as shown in table 11 below. More than one fifth (*n=33*) stated they weaned prematurely, 23 women gave formula instead of breastfeeding their child, and five women decided not to breastfeed siblings because of having an experience of D-MER.

I feel sad that I gave up breastfeeding my daughter. I successfully breastfed my previous children for much longer with no D-MER symptoms

I prayed a lot. I night weaned much earlier than I had intended on doing so. I had to take many breaks from my child to calm myself

Table 11

Effect on breastfeeding Frequency

		Responses		Total percent of participants
		N	Percent	
Effect on breastfeeding[a]	I did not enjoy breastfeeding my child	63	34,6%	43,8%
	I weaned prematurely because of D-MER	33	18,1%	22,9%
	I bottle-fed with formula because of D-MER	23	12,6%	16,0%
	I did not breastfeed as frequently as I wished	17	9,3%	11,8%
	I chose not to breastfeed siblings due to D-MER	5	2,7%	3,5%
	Don't know	2	1,1%	1,4%
	If other, please specify	39	21,4%	27,0%
Total		182	100,0%	126,4%

a. Dichotomy group tabulated at value 1.

It was expressed in the surveys open questions, feelings of that experiencing D-MER as transient and of having the opinion that nursing is good for the baby, made them determined to pursue breastfeeding. The same women, however, emphasized that pursuing breastfeeding while having D-MER caused negative impact on their feelings towards breastfeeding. It was also mentioned by some in the survey, that they felt emotionally drained because of the emotional rollercoaster D-MER was experienced as, and that breastfeeding did not give the expected reward.

It made me reluctant to breastfeed my first. It prevented me breastfeeding my second. With my third I knew what it was and I was able to cope/ breathe through it

I feel like I did not have a joyful experience nursing my infant like I did with her older sibling. I began regretting the decision I had made to nurse her. I felt like the feelings I was having might not be worth the benefit

It makes me very aware that it is a personal sacrifice to breastfeed. It makes me conflicted about breastfeeding almost every time I feed my baby

Several women (n = 22) expressed that own research on the internet, for example: Google, Facebook and support groups, getting "pep talks", was the main thing that they did to cope, to find an explanation and learn coping mechanisms, however, one woman stopped breastfeeding after learning about D-MER on the internet. Another woman described she read as much as she could, then educated her partner too about D-MER. Knowing what it was, was the most frequently chosen factor when women in the survey were asked to answer what made D-MER easier to manage (see table 12). That was answered by 22% of the women and some of them amplified this in an open question; that gaining knowledge on D-MER sometimes was enough for them to relax about it, manage by themselves and not seek any or further support.

Table 12

If Yes, what made it easier? Frequencies

		Responses		Percent of
		N	Percent	Cases
What made it easier[a]	Knowing what it was	29	22,3%	70,7%
	Keeping yourself occupied with cellphone, TV, friends and family etc.	18	13,8%	43,9%
	Breathing through it	18	13,8%	43,9%
	Positive thinking	10	7,7%	24,4%
	Eating or drinking while breastfeeding	10	7,7%	24,4%
	Having slept well	12	9,2%	29,3%
	Ice water	4	3,1%	9,8%
	Physical stimulation as scratching or foot massage	6	4,6%	14,6%
	Support from health care professional	1	0,8%	2,4%
	If other, please specify	22	16,9%	53,7%
Total		130	100,0%	317,1%

a. Dichotomy group tabulated at value 1.

Didn't need help, information from the D-MER website was enough. I knew the cause and that it wasn't something wrong with my mental health

The result from the survey was in several ways congruent with that of the interviewed women. Some of the women (14%) that answered if anything made D-MER easier felt that distractions with cellphone, TV, friends or family was useful. Several women (14%) also felt it was helpful to breathe through it, some also answered that food/drinking, ice-water, not being tired and physical stimulations could be used. It was also mentioned to have support around from spouse and family that could distract the woman with massage, talking her through it and being around.

Breathed through it. Had I had the option to stop feeding, I would have done. However, my daughter was very ill with GERD and breastfeeding was the only thing that eased her (almost continuous) pain. We tried to get her to take a bottle/cup but she wouldn't so I had to persist with feeding (and did indeed carry on until she was 2 years 7 months, D-MER stopped when I day weaned around 20 months)

Some women in the survey described that the braced themselves in advance of D-MER. Others tried to relax, used willpower, staying positive, controlling diet, mindfulness or, as two women from the survey specified, biting teeth together in anger or determination. It was mentioned by some, that they ignored D-

MER symptoms in order to see it through. One woman expressed focusing on her end goal, prolonging breastfeeding as a strategy. Others reminded themselves of the condition only appearing for a transient episode and one reassured herself during feeding, that it's the hormones that causes this.

I continued to breastfeed as normal and just waited for each episode to pass. I made sure I was in a safe place to breastfeed and did lots of positive thinking

Remind myself while I feed that everything is ok and it's just hormones and I will feel fine when the feed is over

Some women chose to answer an open question about what could improve D-MER where they gave comments like; improved after return of menstruation, anxiety/depression or iron medications, changing position, different nursing techniques, essential oils, privacy, positive environment, counting for the duration of D-MER etc. One woman's statement stood out from the majority by expressing:

Just accepted it, actually find it quite interesting

Table 13

Do you feel like D-MER has affected you bonding experience to your child/children?

		Frequency	Valid Percent
Valid	No	91	64,54
	Yes	36	25,53
	Don't know	14	9,93
	Total	141	100,0

The majority of participants in the survey (63%) did not feel the bonding to their child was affected by D-MER, but 25% felt it was. They were given the opportunity to describe in what way, resulting in descriptions of feeling that the bonding was delayed because of D-MER. This could be due to the experience of breastfeeding as emotionally and physically difficult, or that it was hard to feel a loving bond when having a regularly sudden dysphoria happen. It was by some described that they did not bond with the child until they stopped breastfeeding, regardless of how long they breastfed, while others developed a strong bond in midst of D-MER, or even felt it became stronger because of it.

I didn't have a bond until I stopped. I knew I had to protect him and care for him, but I didn't like him until I stopped. And then I was extremely guilty for feeling that way

I have an amazing bond but it does make me feel resentful at times

It makes me feel a special connection with my baby because I some ways, she helps me as I snuggle her when the wave hits. So, I think it helps our bond. Although it was not this way with my first child. I felt helpless with him

Other emotions associated to the bonding experience and/or the child was guilt, annoyance, disgust and anger. Women in the survey described being rude, angry or impatient with or to their children when the D-MER appeared, a couple women described how D-MER affected their temper, and one spoke of having severe physical reaction to D-MER:

Makes me rude to my child and hit him, makes him cry and maybe hates me

I was short tempered, angry, and impatient with my child. I yelled and snapped at her for the pain and negative/anxious way I felt during much of our nursing sessions

The anxiety and anger and disgust were feelings that shouldn't have had that much space in the beginnings of bonding

Table 14

Has D-MER affected your relationship with your partner?

		Frequency	Valid Percent
Valid	No	77	54,6
	Yes	51	36,1
	Don't know	10	7,1
	I don't have a partner	3	2,1
	Total	141	100,0

When asking if the women felt that their relationship to their partner was affected by D-MER, the majority (55%) said no. However, approximately one third of participants felt that the relationship was affected. The women had the opportunity to describe in what way in an open question, resulting in qualitative data that varied from not being able to have any physical contact at all, not wanting to be touched during breastfeeding or not wanting partner near, even after feeding ended. Common expressions were intolerance and anger. For the majority of women these feelings were a response to what D-MER triggered, whereas it for others was the feeling of being touched that triggered D-MER itself. Quite a few mentioned the impact D-MER had on their intimate relationship, both under the breastfeeding period but also years after weaning. The impact was described as: changed intimate habits, to not trigger D-MER symptoms, feeling that sex was less enjoyable or less comfortable, feelings of emptiness post orgasm and a general loss of libido. In those cases where D-MER was trigged by physical stimulation, it was commonly described as happening because of nipple- or breast stimulation, either when being sexually intimate but also in general for some women:

I don’t want him touching my breasts in any way. Whereas when I was pregnant and before, it was very enjoyable

It was commonly expressed from women in survey that both the women and their partner felt it was hard to understand what was going on. Women expressed that their partner could understand neither D-MER itself nor how it made them feel which led to not feeling and/or receiving support. This caused feeling disappointed, frustrated, resentful, less patient and could lead to negativity in the relationship:

I get frustrated that he doesn't understand my struggles or appreciate how hard it is to continue nursing and I get snappy with him when I am going through my D-MER symptoms while nursing. He doesn't offer any emotional support or encouragement

My partner has been very supportive, but I often snap at him when breastfeeding or am very upset. While we try to isolate it as “just the D-MER speaking” it’s hard on both of us because it changes the atmosphere if we’ve bickered. I think it also makes him feel very guilty/helpless, because he can’t improve the situation

He does not understand what breastfeeding meant to us. I felt it a threat to my sanity that anyone could ask us to stop. Things are normal again since weaning, but a little mistrust always persists now where before there was only harmony and support

D-MER caused some partners to pressure the woman to stop breastfeeding. For example, one woman from survey described that D-MER made her partner less willing to accept breastfeeding with the second child. To encourage formula/stop breastfeeding and not get support to be able to continue despite of D-MER caused trust issues and made them upset, angry and unsupported. There were also partners from survey who in contrast wanted the woman to keep breastfeed when she did not, causing an impact on the relationship:

He really keeps asking me to pump so we don't have to use formula. It's a little bit of tension when I have to keep explaining that the way it makes me feel is not worth the benefits to me. I think my child will benefit MORE from me being my best most comfortable self. He forgets that I experience D-MER and I have to keep reminding him it's not as simple as me being lazy or forgetting to pump...

It was mentioned that bonding with partner was harder because of D-MER, that feelings of resentment or envy occurred, of what one had to endure when the partner did not. However, a few women stated that the bonding with their partner was positively influenced because they could be supported in their experience of D-MER. One woman emphasized that being able to discuss and learn about D-MER together made them understand each other better. For some women it became easier with time to receive support and one woman spoke of the help she received in keeping the environment pleasant and how that impacted the partner bonding in a positive way:

Not negatively. He is very understanding and willing to help make my environment as pleasing as possible to help support me throughout D-MER episodes throughout the day

Table 15

Do you feel like D-MER has affected how you view yourself as a mother?

		Frequency	Valid Percent
Valid	No	75	53,2
	Yes	52	36,9
	Don't know	14	9,9
	Total	141	100,0

The women were asked if they felt that D-MER affected how they viewed themselves as mothers. The majority of the women in the survey (53%) answered that they did not feel it did, however 37% felt it was affected. Those who felt their view on themselves as mothers was affected, could specify how in an open question. The women described that they questioned their ability to be mothers, especially in the beginning when not knowing about D-MER. In the survey it was commonly described as feeling as less of a mother, a bad mother, like something was done wrong, not being good enough and less confident. Several felt like less dedicated mothers because they felt they should enjoy and look forward to breastfeeding. One woman even expressed a "hate of being a mother". Another woman described breastfeeding caused feelings of disappointment towards herself. D-MER was described as very

much affecting how they looked at themselves as mothers, feeling like a failure and inadequate in several ways.

The stress of feeling fight or flight multiple times a day had a significant effect on my resilience, which made me less patient with my husband and children. I feel shame about not being as good a mother as I want to be

Feel inadequate and shameful, feel like more of my identity is being stripped away

I felt trapped and just wanted to die. It's not nice to feel like that when one's baby is close to you; so, connected to you and it can sense how it's mother feels every time

I feel inadequate as I will unlikely breastfeed my next child which breaks my heart. I also hate that my memories of breastfeeding are tainted when it is something I should be proud of as a mother

Four women in the survey however, described that they did not feel like D-MER had an overall negative impact on their motherhood. Stating for example, that while D-MER was an unpleasant experience, being able to thing logical about it, that it would pass, lessened the effect of impact on motherhood. Some women expressed that the experience required mourning, and others felt conflicted between taking breastfeeding too far or being strengthened by experience. Further, a few described that the experience has strengthened themselves, making them feel proud as a mother to have pushed through it.

I know how strong and fierce I can be, I so wanted to breastfeed my child, I wanted that connection and I'm disappointed and grieving but I did everything I could AND more to give my child my milk, I took it too far because it was hurting me tremendously. I won't do it again and I have some regrets but I grew and learned of my strength during that experience

Most of the women in the survey (54%) did not seek help from any health professional, but 44% did. However, the rate of being satisfied was low, 48 women (76%) was not happy with the help received by their health professional. When asking why the women did not seek help, most of them stated that they perceived the professional's knowledge and ability to help as lacking, either about D-MER or with breastfeeding and related issues in general. Others felt that the treatments or actions recommended and read about, like antidepressants or weaning, did not apply to their wishes and there for did not seek any help. Four women further described having other contact with professionals that in some ways was experienced as hard and caused them to not bring up D-MER.

Table 16

Did you seek help from any medical professional for ex. doctor, midwife, lactation consultant

		Frequency	Valid Percent
Valid	No	78	54,2
	Yes	63	43,8
	Total	144	100,0

My children were tongue tied. It was hard enough getting that fixed. I couldn't face another battle

*There isn't a lot of information or research. The IBCLC (*International Board-Certified Lactation Consultant*) that I did speak to told me that I had a nipple infection while refusing to see me in person*

It was commonly described that the women did not feel D-MER was bad enough to seek help for. Fourteen women gave examples of this, stating for instance; that because the feeling being "fleeting" it did not cause any concerns, that it was not severe enough or mild, quick and passing. Ten of the women said that their own lack of knowledge was a factor causing them not to seek help, like not realizing they had D-MER or understanding what was happening, that it was a condition or something one could seek support with. Eight women in the survey stated that their own feelings about D-MER made them avoid seeking help. Four women spoke of feeling ashamed of what they were experiencing, one woman felt silly and another worried that she was not going to be taken seriously. Two women thought it was a part of their postpartum depression and anxiety, another woman believed it was all in her head since she never heard of someone else describing it. It was also described by one woman, that she still has not accepted that her body is reacting in this way, causing her to not seek help for it. Two women also described that they in some ways did not care about how they felt, that breastfeeding was to important and by that did not sought any support. Two women spoke of fear of being judged by the professionals and either be deemed unfit or having the child taken away from her if she told about her feelings of wanting to hurl away the baby when nursing:

I felt like a monster for having the feelings I did. I thought my child would be taken away from me if I told a professional that I was terrified that I wanted to hurl my baby away from me when feeding. I didn't even tell my husband. It was the most isolating experience of my life

Of the 63 women in the survey that sought support, only 9 were satisfied with the help received. They generally spoke of being satisfied because they felt validated or taken seriously, having an open-minded health professional, were given information on D-MER or referral to therapists who could help with the feelings of guilt, or coping strategies.

Table 17

If yes, were you satisfied with the help you received?

		Frequency	Valid Percent
Valid	No	48	76,2
	Yes	9	14,3
	Don't know	6	9,5
	Total	63	100,0

LC (Lactation Consultant) *figured out what it was but I had already weaned my first at 7 months. Knowing what it is now has helped me tremendously and I nursed my 2nd for 1 year and still nursing my 13-month-old*

Study 2: Survey for midwives

Participants

A total of 115 midwives answered the survey about D-MER. The midwives median age was 37 (range from 24 to 73 years). The biggest age group of midwives was found within the range of 31-40 years (45%) followed by "51 and above", "41-50" and lastly "24-30. The median years of working experience was six years (range from 0 to 50 years) with the majority of midwives in the spectra of 0-5 years (49%) (see table 18). The midwives worked in a variation of workplaces and in many cases, combining different employments as for example, rotating between delivery ward and postnatal/maternity ward. It was most common to work at delivery ward (33%), postnatal/maternity ward (30%), maternity clinic (15%), or at a breastfeeding clinic (7%).

Table 18

Years of working experience			
		Frequency	Valid Percent
Valid	0-5	56	48,7
	6-10	24	20,9
	11-15	10	8,7
	16-20	6	5,2
	21 and above	18	15,7
	Not specified	1	,9
	Total	115	100,0

Existing knowledge on D-MER among midwives

Of the 115 midwives who answered the survey, 40% (*n*=46) replied that they were familiar with the term D-MER, 60% (*n*=69) were not. Less than one third, 31% (*n*=36) of the midwives replied that they had knowledge of the symptomology of D-MER whilst 69% (*n*=79) did not. It was more common to know about D-MER in the group of midwives that worked at the postnatal/maternity ward, delivery ward, maternity clinic or breastfeeding clinic (see table 19 below).

Table 19

		Do you know the term D-MER?					
		Yes		No		Total	
		Count	Row Count % (Base: Responses)	Count	Row Count % (Base: Responses)	Count	Row Count % (Base: Responses)
Place of work	Delivery ward	18	30,0%	42	70,0%	60	100,0%
	Maternity/postnatal ward	24	43,6%	31	56,4%	55	100,0%
	Maternity clinic	10	37,0%	17	63,0%	27	100,0%
	Breastfeeding clinic	8	66,7%	4	33,3%	12	100,0%
	Other	4	50,0%	4	50,0%	8	100,0%
	Youth clinic	3	60,0%	2	40,0%	5	100,0%
	Gynecological ward/clinic	2	25,0%	6	75,0%	8	100,0%
	Antenatal ward	1	33,3%	2	66,7%	3	100,0%
	Education/research	1	25,0%	3	75,0%	4	100,0%

The midwives most commonly attained knowledge on D-MER through education/publication (12%), secondly through “Social or other Media” (10%). It was equally common to either have personal or family or friends with experience of D-MER as learning about it from a patient (5%). About 4% stated that they got the information from a colleague and 2% did not know where they attained knowledge (see table 20). Some midwives gave examples on learning about D-MER through for example, book about oxytocin, searching on the internet and reading articles after having met women who was experiencing unrest and anxiety while breastfeeding, from celebrity, through friend, magazines and via podcast. Three midwives stated that they had own experience from D-MER and three had family or friends who did. Four midwives came across D-MER on the Swedish Facebook-page “Amningshjälpens slutna grupp". Some midwives emphasized that D-MER is not spoken of neither during the professional education, with the expectant mothers at the maternity clinics nor at the maternity/delivery ward. One midwife expresses a wish for this to change:

Table 20

How did you find out about D-MER?

		Frequency	Valid Percent
Valid	Education/publication	14	12,2
	Social and other Media	11	9,6
	Personal or family/friends experience	6	5,2
	Patient	6	5,2
	Colleague	5	4,3
	Other	2	1,7
	Don't know	2	1,7
	Don't know about D-MER	69	60,0
	Total	115	100,0

…This is unimaginably not something that is even touched at the midwifery education. Too bad, I think, as this needs to be highlighted more

Majority of midwives described that there is a lack of knowledge about D-MER, that it is a condition few seems to know about, neither healthcare professionals nor breastfeeding women. The idea of it being a hormonal condition was mentioned by four midwives and that it can affect the women both during and between breastfeeding sessions, spoke of the theory that dopamine plays a part in D-MER:

…There is very little research on the condition. There are theories of deviating dopamine function, but nothing is proven yet…

When midwives were asked about D-MER, they described it as a condition that is sudden and transient in connection to breastfeeding and/or the milk letdown. The symptomology of D-MER was described as characterized by a vicious circle of negative thoughts, emotions like discomfort, mental stress, panic, unhappiness, hopelessness, meaninglessness, concern, pain and nausea, but it is prominent that anxiety and/or depression is at the top of the listed symptoms. One midwife also recognized the duration of the symptoms and described it as quickly transient and lasting for seconds or minutes whereas another midwife expressed that D-MER could last for both a minute as well as a whole breastfeeding session, emphasizing

that D-MER can cause discomfort both physically and psychologically. A few midwives also pointed out that darker feeling can occur. One midwife explained that she had met a woman who felt her hormones was "out of play" because she wanted to "throw the child out the window" in the beginning of every breastfeeding session but that she could control herself until it disappeared. Wanting to hurt themselves and/or their child was something several midwives described, emphasizing just how sever the symptoms can get and feel for the women. One midwife also points out that this could be more severe the more frequent the women experiences D-MER. One midwife described that in worst case, the darker thoughts and feelings can become reality:

> *Two mothers have been convicted of SBS* (Shaken Baby Syndrome). *Both have described that it happened in connection to breastfeeding. One of them I followed up with the second child and I advised her not to breastfeed and she described herself that it was a completely different experience. No bad thoughts, just well-being. Have met a number of other mothers who describe an immense discomfort while breastfeeding and who's gotten better when they've stopped*

Experience

The majority, 96% (*n*=111) of the midwives, answered the question whether they have met anyone with D-MER or not. Two-thirds of midwives had never met a patient with D-MER. Of those who had, most had seen a patient once a year or less with D-MER, more seldom, 8% (*n*=9) answered once every six months or more frequently. One midwife stated that the women raised the problem at the postpartum check-up. Several midwives stated that these women need many visits, supportive talks and to be confirmed emphasizing that through good support and information the woman could continue to breastfeed with understanding of why she felt like she did. It was clear that knowing about D-MER was a relief:

> *A patient who described the symptoms associated with the traumatic breastfeeding experience. Much anxiety due to feeling unwell when breastfeeding. Another patient who experienced grief associated with letdown. Everyone was relieved when I could refer to D-MER. Believe that we need to inform that there are women with experience of it*

Several midwives stated that it can be difficult to recognize D-MER. One midwife´s opinion on D-MER stood out from the majority, stating:

> *The diagnosis is based on an assumption. Differential diagnosis ...*

Most midwives however, explained that the difficulties with identifying these women were due to it happening simultaneous as other common experiences post-partum, for example "baby blues", or that they seek help/are identified at the Child Health Care Centers when coming for checkups with their baby. Some midwives also point out that it is probable that they have met women prior to having knowledge on D-MER, as one of them said:

The woman did not show what she felt so strongly. I understood that much later. Those who choose to have a bottle feed may feel like it, but if we as women and workers may not be aware of symptoms or can interpret them

Treatment

When asking if the midwives knew of any treatment 98% (*n*=113) answered in total and 6% (*n*=7) of them said they knew of some treatment while 92% (*n*=106) denied knowing any treatment. One midwife specified never had heard or read about any evidence-based treatment or method for D-MER. A couple of midwives expressed that not breastfeeding at all was the solution. However, the most prominent ideas of what would help the women seemed to be support through conversations, confirmation of the condition, a name for what is happening, being believed in and positive associations to alleviate the negative feelings of breastfeeding. One midwife with experience of meeting women with D-MER said:

… it helps to know that it is a reaction to the oxytocin surge - and that the symptoms often become gradually less noticeable… Some can pump to better control boost and expulsion and not have to manage the child at the same time ... (emotionally unpleasant connection) There are suggestions for herbs that increase dopamine inflow, and possibly medicine, but I have never experienced medical treatment. On the other hand, it can be good for the mother to systematically try and see if something improves or worsens the symptoms, for example, if she does something that can increase stress, such as drinking coffee or not drinking enough ... Exercise can reduce the symptoms ...

Potenial consequences of D-MER

Breastfeeding

In the survey, midwives were asked if they, according to their experience, thought D-MER has any effect on breastfeeding in any way. The majority of midwives (63%) thought it could while approximately one fifth (22%) did not think it did. Several midwives further mentioned in an open question, that D-MER can cause the women to not breastfeed. One midwife had a personal experience from a mother of four children who suffered of D-MER with all of them. Her symptoms were anxiety and painful letdown which caused her to only breastfeed for a week, but never in front of anyone, and ultimately switched to formula. A second midwife described that her sister had D-MER with her second child and that she managed exclusively breastfeeding for 5 months. It was explained that she thought the severity had eased up a bit the last month before weaning but that the overall consequence for her having D-MER, was that she wishes more children, but never wants to breastfeed again. A third midwife expresses that she recognizes meeting several women who´ve stopped breastfeeding because of negative associations:

Hard to really know how many breastfeeding women with D-MER I've met, but several women who've stopped breastfeeding because of the distinct feeling that breastfeeding

triggers negative associations, which in turns triggers feelings of guilt because of not being able to breastfeed…

Midwives also described that knowing about D-MER can help women to continue breastfeeding, that knowing it wasn´t "her fault" could make the experience okay. Others expressed that knowing what it was opened for understanding and by that, an opportunity to find ways to manage to be able to continue breastfeeding:

I have met several women with D-MER. A woman understood after several years when I told her about D-MER that that was what she had when she nursed. No one had previously understood that she had Dysphoric milk ejection. It was a great relief for her. That she received validation on what she had experienced. She thought she was crazy and chose not to expose herself to breastfeeding when she got her second child. Now that she understood what she was, she could imagine getting pregnant and breastfeeding again

It was emphasized that D-MER complicated breastfeeding through problems with the letdown reflex which might not be as effective as it should. Pointing out that instead of it being something cozy, breastfeeding turns into a nightmare. It was also stated that there was a belief that D-MER could create a mother who became afraid and at a risk of developing postpartum depression, that the women can feel ashamed and feeling that the negative emotions are taboo to speak of. The majority of midwives describes that not knowing about D-MER and/or not getting support, can lead to weaning. It was also clear that the midwives felt like women with experience from this, to a lesser extent wish to breastfeed, that the women might chose to feed her child in other ways because of the tough experience. A couple of midwives added that the negative association between anxiety and breastfeeding greatly increases the risk of weaning prematurely or not breastfeed at all. It was also pointed out that the condition occurring several times a day has a big impact:

I can guess that it is experience as psychologically difficult with having these feelings several times a day, maybe so tough that one stop breastfeeding earlier than desired. Can also imagine that it may give (unwarranted) feelings of guilt towards the child that you feel like that when you feed and are close to your child

Parenthood

A little over one third of midwives did not think the transition to parenthood could be affected by D-MER and one fifth did not know. However, many thought it did. Midwives expressed that the women's transition to parenthood could be affected (44%) if the mother is feeling bad for a long time, risking development of depression which would make it more difficult to "be a parent". They also emphasized that not being able to feed their child the way they choose, failing to breastfeed and/or experiencing recurring discomfort over breastfeeding could develop a general feeling of not being able to be a parent who loves the child. It is stressed that breastfeeding is such a big part of the first time in parenthood that with D-MER on top of that makes it difficult to distinguish parenthood as a positive experience. Several midwives fill in that not only

can it take longer and be more difficult to transition into parenthood because of D-MER, the women can feel uncertainty, insufficiency and guilty conscience towards the child. Without knowledge, the midwives state that the women probably can doubt her ability as a mother, especially since it is expected that the woman will breastfeed. They also emphasize that many women feel that their role as a mother is compromised if breastfeeding does not work, that they feel like insufficient, failed and "bad mothers" because of the lack to enjoy feeding their child. There is also an affect by expectations of breastfeeding and its experience:

> *A depressed, anxiety sufferer has difficulty associating. Maybe even develops aversion against her child if she is filled with such bad, negative emotions during lactation and begins to associate everything that has with the child to do as something negative*

Bonding

According to their experience, 45% (n = 52) of the midwives think that D-MER can affect the bonding between mother and child. Some answered "Yes" without specifying in what way, which gave a total of 62% (n = 71). Some answered that they didn´t know (13%, n = 15) while 25% (n = 29) replied "No" as shown in. The midwives agreed on that negative emotions in connection to breastfeeding can lead to bonding difficulties. Describing that the negative feelings can get associated to the child. A couple of midwives described that women can feel insufficient and have a guilty conscience towards the child. Others expressed that the woman may choose not to hold the child and even not wanting to be "skin to skin" as recommended. Someone felt that it did not affect in the long run whereas another midwife stated:

> *One is breastfeeding the baby so often and then if you feel negative feelings at every breastfeeding session, I think that it may affect the connection in a bad way*

Several midwives expressed concern for bigger impacts, meaning that the bonding could be disturbed due to stress every time the child latches on and worries about if the child could sense that. It is also emphasized that the common knowledge on breastfeeding being "nice and loving", "a cozy moment" and that it "promotes bonding" is the direct opposite of what these women are experiencing which midwives feel describe is guilty, reluctant feelings towards breastfeeding. Another midwife stressed that the guilty feelings is caused by fear of the symptoms, not be able to breastfeed and fear of failing as a mother. They also point out that difficulties getting help, explanation or even understanding for the situation can lead to women not daring to tell about their feelings, with the possible consequence of doubting their feelings towards their child:

> *Because the woman is feeling bad and it, indirectly is the child that is the reason for it because it needs to be breastfed then maybe the mother blames her bad mood on the child*

The midwife with experience from women with D-MER and SBS (Shaken Baby Syndrome) expressed concern over that the risk of violence could be because of the mother doubting her feelings for her child and/or bonding difficulties between them.

Discussion

Result discussion

The purpose of this mixed method study was to raise awareness on the neglected condition namely D-MER. The study aimed to describe women's experiences of D-MER, in addition to also describe the existing knowledge and experiences of midwives on D-MER. According to women who suffered from D-MER, feelings of anxiety, restlessness, nervousness, dysphoria, dread, sadness and depression were the most prominent symptoms. However, they varied in intensity, duration and frequency. While the majority of midwives did not know about D-MER, those who did know of it, described similar symptoms. Most women felt affected by D-MER to some extent in relation to their breastfeeding experience, bonding and motherhood, but also in regard to their relationships with partner. The effect on bonding, motherhood and breastfeeding were also stated as a possible consequence of D-MER, by the midwives. The women gave examples on coping strategies and what was helpful in mitigating the D-MER experience. Gaining knowledge on the condition was most important, followed by keeping oneself occupied or breathing through it. Both groups stressed the need for more awareness on breastfeeding problems in general, but also specifically on rare and neglected conditions like D-MER. The majority of participants with D-MER reported ending up with no proper help when contacting health professionals. Instead, they have been classified as normal or had other diagnose than D-MER and they did not feel they were taken seriously. The discussion focused on describing the main results in relation to the studies aim, research questions with addition of aspects of value since D-MER is an unknown condition. Presentation is under headlines according to the results categorization.

Experiences of D-MER

The results showed that the symptoms of D-MER vary between individuals, as well as when breastfeeding. It is connected to the milk letdown, comes suddenly, transient with a duration usually lasting seconds to minutes. This is consistent with symptoms described in Heise and Wiessinger (2011). There are other conditions or diseases described with similar symptoms: one is *Breastfeeding Aversion and Agitation* (BAA) which by Yate (2017) is described as overall, negative emotions in breastfeeding women. It appears that women with BAA also experience symptoms with various duration and frequency that differ in every feeding session, like with D-MER. For both of them it can start from the beginning, but for some it can take months for symptoms to appear. In D-MER women got symptoms in connection to letdown regardless of

external factors whereas in BAA women reported the biggest trigger for symptoms being their child's physical behavior as irritating when for example nipple tweaking and wandering hands during breastfeeding (Yate, 2017). In contrast, with D-MER, the symptoms can be both physical and psychological characterized with feeling anxiety, restless, nervous as the most prominent ones experienced, followed by emotional disturbance (dysphoria), dread and sadness. Whereas, in BAA, anger is the most prominent symptom (Yate, 2017). Some of the symptoms however, differ somewhat between D-MER and BAA. For example, women with D-MER described feelings of homesickness, whereas women with BAA according to Yate (2017) reported wanting to run away. Another condition associated with negative emotions associated with breastfeeding and with similar symptomology is described by Watkinson et al (2016) and it is called *embodied emotional sensations*, meaning sudden emergence of distressing emotional and visceral experiences and they exemplify sadness, anger and anxiety as common symptoms. These three descriptions of negative emotions in connection to breastfeeding has several similarities (symptoms) which makes one wonder, could it be beneficial to use one common name for *negative emotions associated with breastfeeding* and differentiate between them via symptoms duration and/or frequency? For example, our results showed that women with D-MER described symptom duration not always being connected to the milk let down, which on the other hand, stated as D-MER symptoms in one of previous study. Dopamine has been suggested to play a role in causing D-MER condition (Heise, 2018). There is however another neurotransmitter, serotonin, that affects our cognition, attention, pain, arousal, sleep, appetite, mood and emotions, according to Brummelte, Glanaghy, Bonnin and Oberlander (2017) who describes that serotonin also plays a role in breastfeeding. Until today, the exact mechanism and neurotransmitters or hormones that cause D-MER condition remains unknown.

Our results are in line with previous literature that reported different degrees of symptoms intensity with D-MER. It could range from mild, described as melancholy, to more severe as violent thoughts and actions aimed towards themselves, as well as to their child. Both Yate (2017) and Watkinson et al (2016) describe encounters women with desire of hurting their child, specifically, these women mentioned thoughts of throwing their baby away while breastfeeding. One woman described her violent behavior towards her child as she been hitting him/her due to D-MER. This is interesting since, even though there were few midwives who had met women with violent symptoms, in this study one midwife reported meeting two mothers guilty of *Shaken Baby Syndrome* (SBS) in connection to D-MER. Vinchon (2017) described that even though child abuse has an overwhelming majority of male perpetrators; *Shaken Baby Syndrome*, in general, can happen in any social group and that the difference between child abuse (like beating) and shaking, is clarified as beating being intentional, whereas *Shaken Baby Syndrome* is universally triggered (e.g. not one specific trigger). Neither our findings nor Yate (2017) found any pattern as to who's at risk for developing BAA or D-MER since the participants represented different ethnicities, ages, marital and educational statuses which

Forster and McLachlan (2010) stressed as good since when it comes to women's decisions about baby-feeding, it is important to take personal- and sociocultural factors into consideration. Women with D-MER described mood swings and constantly experiencing "a fight inside me every time" before breastfeeding. This is in consistent with Yate (2017) finding when he described knowing breastfeeding were the best alternative and at the same time experience negative emotions in connection to it, caused women with BAA to often feel an "internal conflict", being angry before and/or during breastfeeding. Women with D-MER reported having symptoms with different degrees in other situations than breastfeeding, like for example during pregnancy and in connection to the menstrual cycle (ovulation, PMS, Premenstrual syndrome, premenstrual phase). This was also found in women with BAA, for example with return of and/or during menstruation as well as correlated with their ovulation (Yate, 2017). Our findings are in agreement with other studies showing that women acknowledged aversion towards breastfeeding which led to feelings of guilt and shame. In line with our results, women felt lucky to manage D-MER and breastfed, but it was very stressful for them since they felt bad while doing it (Yate, 2017; Watkinson et al, 2016).

Consequences

It was surprising that majority of interviewed women breastfed accordingly, or close to WHO´s recommendation despite of D-MER, even though some women weaned earlier than they had planned due to the symptoms. The reasons for continuing breastfeeding despite of D-MER, ranged from feeling it was not bad enough or feeling it was just a light melancholy, to have feelings of inadequacy and guilt if they would have weaned because of D-MER, but also having knowledge on the health benefits of breastfeeding and breastmilk for the child. Midwives believed D-MER could affect women's everyday life regarding everything from motherhood and bonding to consequences for breastfeeding. Coats et al (2014) did not want to use the term of transitioning to motherhood in their study since they felt it was difficult to separate it from normal challenges of adjusting to changes in life. However, in this study most women stressed the importance of how D-MER impacted their everyday life. The majority of women felt, to some extent, that D-MER had a negative effect on their motherhood, as well as the bonding to the child. In contrast, some women described that D-MER affected neither their breastfeeding, bonding nor motherhood. They described forgetting about D-MER between feedings and were surprised when the feelings occurred again. Several women described feeling strengthened in her motherhood due to D-MER since despite of it all; they managed through it for her child. To feel strengthened by overcoming obstacles has been described when it comes to breastfeeding before (Jager et al, 2013) and is reinforced by WHO and UNICEF (2017) who also emphasizes, "Support can help women to sustain appropriate breastfeeding practices, overcome difficulties that arise, and prevent new problems from occurring" (WHO & UNICEF, 2017, p 7).

The women felt pressure to breastfeed from family, society and themselves, which is reinforced by Spencer, Greatrex-White and Fraser (2015) who described that women know about the health benefits of

breastfeeding and not rarely it is the motive for both initiating as well as continuing breastfeeding. There is a common perception of "the breast is best". Martin, Ling and Blackburn (2016) also showed the benefits of breastfeeding but also points out that infant formula is intended as an effective substitute with every effort to mimic the nutrition profile of breast milk to promote normal growth and development. The women idealized others and compared themselves both in real life and towards media images. This obligation to breastfeed made room for error, meaning that if a woman started breastfeeding and then failed and switched to formula, that is better than not have tried at all (Spencer et al, 2015). Some women with D-MER reported hiding and lying behaviors towards their social network and partner, which is in line with Spencer et al (2016) who found women with common breastfeeding problems are often able to maintain a public pretense by keeping a brave face presenting themselves as calm, in control and coping in their new role, even though their real feeling is completely the opposite. Instead of feeling breastfeeding was effortless and enjoyable; they felt it was characterized of negative emotions. They explained them hiding the difficulties and struggles had to do with societies normative of "a good mother" meaning doing "the right thing" through the moral obligation of breastfeeding because breastfeeding commonly is perceived as "breast is best". One woman even said she initiated breastfeeding to "keep everyone quiet" according to Spencer et al (2016) who also described that it was of great importance to not be seen as a failure. This is also confirmed by Bergström et al (2017) when he found that concealing behaviors can be used by people not wanting to make bad impressions in their social relationships or be a burden. They also emphasized that people do not want to be overwhelmed with different advices which is a common issue when it comes to breastfeeding problems and advice from both healthcare professionals as well as the overall society (Lagan, Symon, Dalzell & Whitford, 2014). Not seeking help was described by the women as a result of thinking that the symptoms and feelings were something normal that a new mother goes through. Spencer et al (2015) further described that women lacked support when wanting to quit breastfeeding regardless of having justified reasons for it. They felt "naughty" when not obeying healthcare professional's advice regarding mixed feeding, nipple shields or weaning. It was also pointed out that the decision to stop breastfeeding needed to not only be a personal choice but be sanctioned by both healthcare professionals and by partner as well. This could be a problem since some women described feeling undermined about their breastfeeding ability from family and/or friends (Spencer et al, 2015). Martin et al (2016) emphasizes that the decision to breastfeed is personal and influenced by many factors, and also points out that there are situations where breastfeeding is not suitable and/or possible. Lack of support from peer, family and/or from health professionals led the women to the perception of exclusive breastfeeding being an unrealistic ideal (Spencer et al, 2015) which is consistent with that even non-breastfeeding women experiences feelings of maternal guilt due to health care professional's promotion of breastfeeding (Benoit, Goldberg & Campbell-Yeo, 2015; Forster & McLachlan, 2010). Coats et al (2014) and Bergström et al (2017) concluded that women wanted emotional and practical support from partners and close family. It was also mentioned that even though partners often were an additional support, the women

still felt that the partners simply could not fully understand what the woman was experiencing. Watkinson et al (2016) noted that the negative breastfeeding experience put a strain on the partner relationship. The need for support outside the relationship with partner is something that women in this study also stressed, like for example from colleagues and healthcare professionals (Coats et al, 2014).

Women with D-MER felt guilty when the breastfeeding did not work as they had expected and did not have the confidence that it would. Instead of being a positive experience, one woman described living in a nightmare. At the same time women also clarified they would have felt guilty if they had stopped breastfeeding so instead, the majority of women continued. This is consistent with some midwives stating that they believed D-MER could cause the woman to stop breastfeeding while others described that women they have met could continue just by have the condition recognized by professionals. Women in our study described isolation due to feelings of shame, being viewed as a subpar mother and fear of being treated poorly. Spencer et al (2015) showed the same findings where high expectations on themselves, as well as by others to exclusively breastfeed made some women avoid attending their local postnatal group because of not wanting to feel like a failure or be judged. Coats et al (2014) also found that women could feel like "the black sheep" in a postnatal group when experiencing horrible feelings, like being a "black cloud" to everybody when you're not able to relate to one another. In their study the women described that groups do not have to be run by healthcare professionals but just be included for people with the same problems, so they can feel like it is not their fault that they're not bad mothers which could help. Bergström et al (2017) described that some people do not want to participate in activities due to their symptoms and that it can make them feel sad, lonely and disappointed. This is in consistent with our findings that some women isolated themselves due to D-MER. Bergström et al (2017) pointed out that one main concern could be not being taken seriously with regards to the symptoms which also is consistent with the women in our study who felt that people could not understand what they were going through, especially since the symptoms for the most part is physically invisible.

Coping

Coats et al (2014) stated that admitting to a problem was perceived negatively on their independence, as well as ability to cope. Our results however, showed that coping mechanisms was helpful to not feel crazy or alone and made it possible for pursuing breastfeeding. The women described “just knowing about it” was crucial to be able to mitigate the experience. The women described “just knowing about it” was crucial to be able to alleviate the experience. Sixty-six women who participated on the survey have mentioned seeking help to overcome symptoms of D-MER, only 9 of them were satisfied with the support they had received which reflects on the lack of knowledge and skills on breastfeeding issues among health professionals. Further the women emphasized effective ways to cope where the support group being most important followed by distractions like acceptance and breathing through it. This is consistent with Yate (2017) who

added mentally talking to themselves to get through it and manage. Our results showed keeping distracted like preparations of food or beverage, watching TV and/or social media, physical support like massage or soothing verbal support from spouse and/or family members. Karlsson et al (2016) also described that distractions are well researched on, and helpful, when working with children in healthcare. They emphasized that given support needs to be wanted, understood, perceived as safe and voluntary to work distracting from negative thoughts. However, one of our participants did not want to be distracted but instead felt the need to focus on the breastfeeding to able to cope through, even though the symptoms then felt worse. Another woman, watching TV and/or eating made the symptoms worse because she felt she could not control her thoughts when D-MER occurred. This was also found by Karlsson et al (2016) who stated that there are those who rather observe procedures which would make a forced distraction to cause loss of control instead of somewhat relief from negative thoughts and feelings as intended. A couple of women in our study stated that physical contact, like massage, could help. Karlsson et al (2016) found the same in children as it offered a feeling of closeness, comforting and when distractions are appreciated it makes the situation easier to handle. For people with chronic pain conditions, Bergström et al (2017) described that strategies and distractions, both physical and psychological, even if they do not make the pain go away entirely, can help to ease the pain. The women in this study stated that distractions did not make D-MER go away, but it could help to cope with it while it lasted and therefore it felt better.

Similar to our findings, Coats et al (2014) stated that majority of women felt unsupported by healthcare professionals at some point during their postnatal period both by inaccessibility, felt mistreated, ignored or got the wrong type of support. For example, to little practical guidance and often referral to somebody else as if they did not want to help. This also implies when at home, since the health visitors who came appeared to be in a rush and therefore did not have time to talk about the mother's emotions or breastfeeding issues (Coates et al, 2014). For example, one participant described feeling like the health professional was more interested in the baby gaining weight than how the breastfeeding experience felt. Further, our results showed that women appreciated support from others with similar experiences, which is reinforced by Coats et al (2014) who also found that social support was appreciated. Not because it necessarily made them feel better, but to have people to talk about it with. The majority of women had their symptoms perceived by health professionals as something normal and/or postpartum depression (PPD) and recommendation to seek psychological support for it (Coats et al, 2014). Watkinson et al (2016) also found that professionals may misdiagnose breastfeeding struggles as PPD. Our participants stated that being unhelped and/or not taken seriously made some women regret even telling a professional about their experience and several of the women felt like there was no point in telling anyone about D-MER. According to Coates et al (2014) one woman described her experience like having both terrifying thoughts of PPD and feeling normal. This of course stresses the difficulties of what symptoms that derives from where. Spencer et al (2015) also

concluded that women fear criticism from healthcare professionals which can make them not only hide and lie about breastfeeding difficulties, but it inhibits them seeking help needed. Coats et al (2014) further describes that some women acknowledge the negative emotions whereas some instead avoid them, but at the same time, some women determined to breastfeed makes them ready to put up a fight for it to succeed. In our result the number of children was between 1-3 and several of the women had experienced D-MER with every child. This correlates with Coates et al (2014) who found that breastfeeding issues was notable in half of the women with more than one baby included in their study, thus not only for first-time parents.

When it comes to treatment, women described having tried somewhat different approaches. It varied from vitamin supplements to trying to think nutritionally to affect hormones. One woman who also had PPD got antidepressants as treatment which helped with those symptoms, but not the symptoms of D-MER. The midwives had very few thoughts about treatment. It ranged from a majority who had not heard about it at all, to one midwife thinking D-MER is a differential diagnosis based on assumptions. Another midwife stated support through conversations as helpful while another explained that connecting negative feelings of breastfeeding to positive associations instead, could ease the symptoms. Several midwives speculated about the cause for the D-MER condition being hormonal. One midwife discussed that Dopamine is a strong factor connected to the milk ejection which is in consistence with the well-known finding of Dopamine affects our mood and emotions Ayano (2016). Heise and Wiessinger (2011) emphasized that Dopamine increase cause inhibition of prolactin, but they also stress that the exact timing and interactions of Dopamine, Oxytocin and Prolactin releases in humans still are unclear which indicates there is not yet full knowledge of all aspects regarding lactogenesis. Neville and Morton (2001) described that the milk composition varies to suit the infant’s needs, and this is partially regulated through hormones. This means the nutritional need for a mother increases while lactating meaning if a mother is having trouble catering for nutritional and sleeping needs, from a physiological point of view it could affect the breast milk. Grey, Davis, Sandman & Glynn (2013) describes that cortisol has been shown to affect babies' temperament and Glynn, Davis, Schetter, Chicz-Demet, Hobel & Sandman (2007) adds that this especially in mothers with elevated levels in their breast milk. For this reason, Yate (2017) discuss whether mothers with BAA could have higher levels of cortisol whilst breastfeeding than those without BAA which in turn could cause the symptoms. Fallon, Groves, Grovenor Halford, Bennett and Harrold (2016) also found that breast milk composition can be affected negatively by postpartum issues like anxiety or depression. Interestingly, Stuebe, Grewen and Meltzer-Brody (2013) could associate difference in oxytocin response during breastfeeding in women with symptoms of depression and anxiety.

Existing Knowledge on D-MER among midwives

The majority of midwives had no knowledge on D-MER while few knew about it and described symptoms that were similar to women’s descriptions of D-MER symptomatology. The midwives speculated that D-

MER could have a negative effect on mother-child bonding if the negative emotions of breastfeeding, unintentionally, was directed towards the child, as well as affecting the duration and/or frequency of breastfeeding. The majority had no idea regarding treatment but emphasized the importance of women's support through conversations to alleviate the negative feelings associated with breastfeeding. Low knowledge of midwives will lead women to doubt their ability to provide support and this was confirmed by majority of women stated that health professional who help women during postpartum period should be aware of D-MER, emphasizing that it is also important to differentiate D-MER from PPD. Pope and Mazmanian (2016) stresses that negative breastfeeding experiences may be a risk factor for developing PPD even though breastfeeding itself, at the same time, could offer protective benefits against it. This is reinforced by Hahn-Holbrook, Cornwell Hinrichs and Anaya (2018) who conclude that maternal mental health problems are a major public health challenge across the globe. Negative breastfeeding experiences is a risk factor for developing PPD (Pope & Mazmanian, 2016). PPD, in turn, increases the risk of developing in to depression according to Dennis and Dowswell (2013) who conclude that the lifetime rate for women to develop depression is 10-25 %, without PPD in the medical history. The most common psychiatric illness following childbirth is PPD which not only impairs the mothers, maternal mortality is also linked to poor access to medical care and suicide. Meanwhile PPD also affects children's social, physical, cognitive, emotional and behavioral development (Pope & Mazmanian, 2016; Hahn-Holbrook et al, 2018). The overall global prevalence, according to Dennis and Dowswell (2013) is 13 % which is consistent with statistics from Sweden of a prevalence around 8-15 % (approximately 10 000 women annually) according to Statens beredning för medicinsk och social utvärdering (SBU, 2014). Our result shows that the prevalence of PPD in women with D-MER is approximately 14 %. This being the case, emphasizes the need for knowledge to neither confirm nor dismiss PPD in these women without thorough investigation as to what caused wich symptoms and when. Pope and Mazmanian (2016) describes that PPD is characterized by low mood, sadness, worthlessness and/or hopelessness as well as disturbances in appetite, energy and sleep. They also state differences to "baby blues" being a briefer and involving emotional disturbances like dysphoria, tearfulness and irritability which are common for the majority of women the first days after delivery. It is therefore understandable as to how D-MER can be dismissed as "baby blues". One of the women interviewed reported to have developed other issues due to D-MER, for example eating disorder and obsessive-compulsive disorder. Pope and Mazmanian (2016) described that PPD also increases the risk for comorbidity of both physical and psychological disturbances. Several women with D-MER as well as BAA have reported suicidal thoughts and thoughts about hurting their baby. This is reinforced by Pope and Mazmanian (2016) stating that it is more common in women with PPD to experience suicidal thoughts and thought of self-harm and/or harming the infant, for example PPD is associated with disturbance in bonding between mother and child and deficient parenting. Dennis and Dowswell (2013) reinforces that PPD can manifest itself as dysphoria, emotional lability, guilt and suicidal ideation and emphasizes that left untreated

it can turn into depression and tragically also suicide. This increases the understanding of the fact that D-MER, according to the women, easily gets dismissed as PPD when in contact with health professionals.

Overall there is disappointment among the women that there is not enough research on D-MER which they hope for to bring a general awareness and explanation on the condition and by that help others through support. The midwives agreed on the fact that there is too little research on this condition and emphasize difficulties recognizing D-MER by the fact that the women probably raise these feelings at Child health care services and also, that other common postpartum difficulties can disguise D-MER, for example “baby blues”, PPD and common breastfeeding issues with latching on for example. A problem with common breastfeeding issues is that the knowledge is inadequate which Coats et al (2014) explains by that they are brought up in antenatal classes, but that problem solving isn't raised. Sriraman (2017) emphasizes that there is no surprise in the lack of knowledge and comfort regarding support in breastfeeding since there is little to none education about lactation anatomy and physiology for students, it seems to be more a “learn on the job” kind of attitude towards breastfeeding in general. This is consistent with Lagan et al (2014) findings of t that women, even though having positive experiences also from health care staff, many reported different support and advice on breast, as well as formula feeding which could lead to both conflicts and confusion. The different advises was reported from midwives as well as other professions. Recent studies also emphasize that making sense of breastfeeding difficulties can help the mothers manage their experiences (Watkinson et al, 2016). Gustafsson, Nyström and Palmér (2017) emphasizes that midwives wish to help mothers reach their breastfeeding goals but that one issue can be their own desire to succeed in enabling breastfeeding. This meaning that struggles with supply adequate help balancing own responsibility, the mothers wishes, and the infants need, opens up for feeling like a failure because of shortages in their own knowledge and skills beyond lack of guidelines, resources and different advice between colleagues. One can wonder when psychological difficulties in association to breastfeeding will be researched on and recognized? Since "Ten Steps to Successful Breastfeeding" from WHO and UNICEF in 1991 research has shown that mothers in the twentieth century experiences breastfeeding more difficult explained by higher degree of tension, insecurity and anxiety than mothers in the early nineties (Holmberg, Peterson & Oscarsson, 2014). With the amount of knowledge as well as research about unusual conditions having negative impact on breastfeeding known to this day, the impression is that there is a long way to go.

Method Discussion

Mixed Method

This study used a mixed method design. Teddlie and Tashakkori (2009) proposed the term *inference quality*, being overall criteria for evaluation of quality of conclusions and interpretations that has been reached by using mixed methods. This refers to the accuracy of the mixed methods conclusion and implies the

quantitative concepts of internal validity and statistic conclusion validity, together with the qualitative concept of credibility. They also suggest the term *inference transferability*, which includes the quantitative concept of external validity and the qualitative concept of transferability, meaning how valid the mixed method's conclusions are in similar populations, contexts and environments. The first, qualitative phase focused on exploration of the unknown condition that is D-MER through interviews. The findings were then used in a second, quantitative phase in the form of a survey as described by Polit and Beck (2012), enabling qualitative data to be quantified, meaning that patterns of a phenomena can emerge with greater clarity and emphasizes that this is positive for valid conclusions of a study. Borglin (2016) described the benefits of mixed method research based on Creswell (2003), as primarily being complementary, practical, increases credibility and is incremental in terms of knowledge. Creswell and Plano Clark (2011) also stated that mixed method is motivated when researching new or badly defined concepts and/or conditions because there is a possibility to use the result from one approach to amplify the other, when neither of quantitative or qualitative method separately are enough to answer the objectives or research problem or when quantitative results are hard to interpret, and qualitative data can help with this. Mixed method offers a possibility of that knowledge when one method is used in the other method, which leads to both descriptive and affirmed objectives can be addressed and answered at the same time. This study therefore includes both interviews and surveys because of the ability to partly eliminate each separate method's weaknesses while the strengths remains by having representation of both numeric and textual data, which can lead to increased credibility (Borglin, 2016). This method provided the possibility to answer all of the study's purposes. Since D-MER is an unknown condition with scarce amount of research, it was considered justified to do a comprehensive data collection, not only because of the negative impact D-MER has on women in their lives, but also for the scientific need, meaning that the method is well-motivated based on its purpose. Nevertheless, doing three studies at once increases the risk of missing details during analysis with such a limited amount of time which is to be considered as a weakness. Teddlie and Tashakkori (2009) described that in concern to unknown aspects of a phenomenon, purposes can be answered and presented as both textual and numeric data. They also advocate to use the same main objective for both methods whereas Creswell and Plano Clark (2011) recommended using separate questions for both methods that are later combined into one mixed research question. Based on the framework for a master's thesis, the study could have been limited to both the number of participants and surveys used consideration to the author's inexperience of the method which can be seen as a limitation. On the other hand, the study has been under strict guidance from supervisor with experience from the study design, as well as constructive criticism from fellow students during seminars for the purpose, which would be considered as a strength, however, it should be taken in consideration that there is a possibility of missing details during analysis due to time limitation.

Qualitative method

According to Polit and Beck (2012) recommended sample size for qualitative data when saturation occurs. After the first half of interviews the participants started to repeat their experiences for the most part, but due to the scarce amount of research on D-MER it felt adequate to continue with interviews until nothing new appeared regarding symptoms, all of which can be seen as strengths. Polit and Beck (2012) stressed the importance of power calculation when estimating the sample size of the quantitative data. However, this applies when previous research findings are available with large samples and when doing statistics. In this case, the only available studies on D-MER are case-studies and this study aimed for quantitative data. Polit and Beck (2012) also stated that there is no simple formula for how big a sample size should be to run a study but big samples is always recommended if it is practically possible. Big sample increases the likelihood to represent the study population. If the population is relatively homogeneous, as in this case regarding experiences of D-MER, a smaller sample size could be adequate according to Polit and Beck (2012) as power increases if the population is not homogeneous adding other variables. In our study, participants are heterogeneous women regarding sociodemographic factors e.g. age, country. The participants were given a code in form of a letter that then were compiled in a matrix for a clear overview of results. Since exclusion criteria for women was not having experience from D-MER in past or present, in combination to the condition being so unknown, it can be a weakness because of the risk of missing many women who indeed suffers from D-MER but does not know about the term yet. Polit and Beck (2012) described that data collection as free from bias as possible increases studies credibility so it can be seen as a strength that the content analysis initially by the authors was conducted separately followed joint discussion to reach consensus. The data analysis aimed to present all results without own interpretation as described by Polit and Beck (2012). Considerations was made in regard to both authors having positive and negative experience of breastfeeding, one of the authors also had personal experience of D-MER. When interviewing the women in the qualitative data collection the author without experience of the condition therefore asked the questions about D-MER and the one with experience asked about demographics and gave information. This to ensure objectivity and to have the same interviewer asks the same questions every interview which can be seen as a strength. The results were analyzed with content analysis and SPSS which both are commonly used tools for qualitative respectively quantitative data analysis (Polit & Beck, 2012) which is a strength. The result was categorized on the basis of commonly used statements from participants. This could be seen as a weakness since it opened up for own interpretation by the authors because the evaluation of the results determined under which category what result should be placed. All but 2 interviews were held in English, since the study aimed to reach participants worldwide. This was considered a strength because it enables described experiences from different countries, however, both healthcare- and support systems differ between countries making it difficult to draw conclusions regarding healthcare professionals' ability to provide support. This study enabled women worldwide to participate through the international Facebook-

support group, however, weaknesses is that participation was only possible if access to computer, internet- as well as sufficient English skills. Apart from Indonesia (middle-income country), only high-income countries participated, meaning there was no representation from low-income countries. Considering the native language of the authors is Swedish, a Swedish-English dictionary was used when needed for translation, for example when translating the Swedish interviews, and the Swedish answers and citations in both surveys. This can be considered as a strength because it reduces the risk of misinterpretation.

Quantitative method

Strengths of this study are that the use of internet surveys is an increasingly common method for data collection. It is cost efficient and easy to both participate in and design, offers anonymity, enables a large geographical spread and the possibility to reach many of the wanted participants (Billhult & Gunnarsson, 2016). In this study we were able to reach more than 4000 members in the group "Barnmorska- aktuellt och intressant", more than 1100 individuals in the D-MER support group and over 23000 members in the Swedish breastfeeding support group. Acceptable response rates according to Billhult and Gunnarsson (2012) would be 70-75%, meaning 2800-3000 respondents from the midwife group and 630-675 women from the D-MER support group. Since the surveys were published in three Facebook groups, one can assume that the members have some computer skills and access to a computer or other device, which is a prerequisite for this method of data collection to be seen as easy to participate in. Weaknesses identified are, that although internet surveys can reach many people, it can also have a large loss of respondents, and the sample may not be representative. This was apparent in this study where only 3,9% of the members in the midwife group responded, however, not all members of this group are "active members", meaning it is difficult to anticipate the true loss of participants when not knowing how many had seen the survey. All midwives, even if they´d never heard about D-MER before was able to participate. Still, as unknown as the condition is, it could have affected the low rate of response. It can also be explained due to difficulty wanting to admit lack of knowledge from midwife perspective as well as not having the time to fill in the survey, 115 completed the survey but 47 did not. It is also to been seen as a weakness that no other midwives than those who were members in the Facebook group was approached. Furthermore, it would have been more representative to approach international professionals outside the Swedish system as well as other professions as CNS within the Child Health Services in Sweden, since those are the ones that follow the families postpartum. The choice to only include Swedish midwives was based on lack of time. Another aspect to consider is that participants can answer in a way that is not desired by not answering questions at all or respond, "Don't know" and that they may have different levels of education and skills which could affect their answer (Billhult & Gunnarsson, 2016). They also describe that there may be problems when the researchers themselves designs the questions in a survey, as these can be written in a way, so the answers do not match the study's expectations and purpose.

However, we could not use surveys with completed questions since D-MER has not been subject of extensive research and there was scarce information about the condition. We did not pilot-test either of used questionnaires but instead carefully reviewed and tested the survey together with our supervisor before publishing it in the groups. We discovered after publishing that some midwives did not discover that when trying to skip a question the alternative of answering "Don't know" would appear. In those cases, some midwives answered "Yes" and wrote in the open follow-up question that were unsure or just put in a question mark. In the D-MER survey, we discovered one week after publishing, that the follow-up question for those answering if they more than one child, did not appear. This resulted in a loss of answers, but changes were made to the survey and we therefore have representation in our result. Exclusion criteria for midwives was only; not being licensed midwife which can be seen as a strength since that meant that every midwife, working anywhere or retired regardless of age, gender, knowledge or experience of D-MER could participate. However, one need to take into account that it is unknown how many of the members in the Facebook group they were recruited from, actually are licensed midwives since the group previously granted membership to individuals with other professions linked to midwifery, for example doulas and obstetricians. Nor can it be guaranteed that the participants actually are midwives. In addition to this, this survey was not distributed to midwives who were not members in the Facebook group. This is a major sample loss since the number of licensed midwives in Sweden was 11493 in 2014 according to Socialstyrelsen (2016b). It is also a weakness that the survey only was avaible for participation in Sweden, meaning that this study's findings is lacking in generalizability due to neither other countries represented nor availability for other health professionals supporting breastfeeding women.

According to Skärsäter and Ali (2016) there can be unclear guidelines in Internet-based research. A basic rule is to assume the ethical rules that exist and apply them in the virtual room. It is also described that there are websites with ethical guidelines to use. Furthermore, Skärsäter and Ali (2016) also described that collected data is treated confidentially, considering, inter alia, technical problems such as data hackers, stolen computers, data crashes and bugs. It is also seen as a complicating factor that the law about internet-gathered data is difficult to understand e.g. copyright and data protection (Skärsäter & Ali, 2016).

Inference quality and transferability

Polit and Beck (2012) described enhancing integrity for mixed method studies include *inference quality* meaning the believability and accuracy of the conclusions. Teddlie and Tashakkori (2009) disclosed that mixed method design implies both validity from quantitative concept as well as credibility from qualitative concept. Also, *inference transferability* meaning how valid the mixed method's conclusions are e.g. to which degree found conclusions can apply to other, similar populations, contexts and/or environments is described by both Polit and Beck (2012) and Teddlie and Tashakkori (2009). The lack of knowledge on D-

MER made it appropriate and about time to raise awareness on this condition. Using mixed method as design enabled perspectives from both affected women as well as midwives which was according with the purpose and research questions. The *inference transferability* of this study is strengthened by its demographical spread globally. This includes spread by country and age, which therefore enables found conclusions to apply to both women with experience from D-MER in general, as well as a general lack of knowledge among midwives in high-income countries. The *inference quality* of this study, meaning the credibility of qualitative data is strengthened due to triangulation where qualitative data was the basis for quantitative data, hence quantification, by the results from the surveys being true to the results of the interviews, this is to be seen as a strength.

Social benefit

This mixed method study raised awareness on D-MER, confirms that knowledge on D-MER is inadequate and that the need for proper knowledge is needed to enable support for breastfeeding women with D-MER. Knowledge of health benefits from breastfeeding, for both mother and child, is well researched on (Socialstyrelsen, 2016a; AAP, 2012). The result shows that without knowledge and adequate support women can stop breastfeeding earlier than recommended, as well as wanted. Combination of lacking and different support from health care professionals is experienced as negative (Lagan et al, 2014) which emphasizes the importance for further research on problem solving in breastfeeding, for example D-MER, that can occur in breastfeeding women.

Clinical benefit

Acquiring knowledge raises awareness about D-MER. In health care settings where professionals provide services for breastfeeding women, support can have a positive impact on duration, frequency and experience of breastfeeding. Therefore, it is vital for both women and children's health to improve public health regarding beneficial aspects of breastfeeding for both mother and child, in short- and long turn from a global perspective.

Conclusion

The most prominent symptoms of D-MER are feeling anxious, restless and nervous. Followed by emotional disturbance (dysphoria), dread, sadness and depression. For the majority of participating women, D-MER affects breastfeeding, motherhood and bonding to some extent. The women wanted more awareness on the issue, to be believed in and to get adequate help, both through support group for those affected, through

distractions they have learned from experience along the way, as well as from health care professionals caring for breastfeeding women. Midwives described having a lack of knowledge on D-MER and also emphasized the need for research on the condition. Until the cause behind the symptoms is determined, it is difficult to separate D-MER from BAA and Embodied Emotions due to similar symptomology, duration and frequency. The main conclusion therefore is that awareness towards negative experiences of breastfeeding is important for women, as well as for midwives and other health professionals caring for breastfeeding women.

Proposals for continued research

It would be interesting to investigate, identify and understand the mechanisms that cause D-MER. Further research is needed to find out the exact mechanism of the symptoms. Even though this study aimed to describe experiences of D-MER, the amount of research in total is very scarce so further qualitative studies to highlight the condition and its consequences in both short and long-term level is well needed. Majority of the women felt it is important to segregate D-MER from postpartum depression. Therefore, it would be valuable to confirm and / or dismiss comorbidity of conditions with similar symptomology. This, and previous, research has shown that symptoms have been experienced in other situations in life. There may therefore be of value to further research linking hormones to others exposes than those connected to childbirth and/or lactation. This, and similar studies have included participants with different backgrounds. Still, it is uncertain as to who are at risk of being affected, and how many people are in present so further studies including participants with different sociodemographic, and socioeconomic variables is of value. Also, studies regarding women's attitudes towards breastfeeding before and during pregnancy could be beneficial. It would also be valuable to compare the average new mother and mother with D-MER to see similarities and/or differences in breastfeeding experience for greater conclusions.

Summary

The purpose of this study was to describe experiences and knowledge on D-MER. The results here, identified and described symptomology and experiences of D-MER from both women and midwife’s perspective. Consequences of D-MER are broad. For majority, it affects breastfeeding, motherhood and child bonding to some extent. The results raise awareness on this neglected condition and increased knowledge on D-MER provides guidance for healthcare professionals on to how to help those who suffer of D-MER. Acquiring knowledge and raising awareness will have a positive effect on overall breastfeeding

duration, frequency and experience with positive health outcomes for mother and child, in short- and long term, globally.

Declaration of independence

Writers Jaqueline Pettersson and Andréa Packalén have contributed equally much to all parts of this thesis.

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Attachments

Attachment 1: Semi-structed interview

The participation is voluntary, you can at any time during the interview or process cancel your participation. Feel free to interrupt and/or ask me/us to repeat the questions. The interview will take apx 25min. Can you state your full name? Do you agree to participate in this study and interview?		
How old are you?		
Where do you live?		
Are you smoker?	If yes	How frequent?
		Were you smoking during pregnancy and breastfeeding?
How many children do you have ?	Did you experience the symptoms with every child?	If no, which one/ones did you experience it with?
Do you have a history of anxiety or depression?		
Can you describe your experience of D-MER?	feelings	
	symptoms	
Did you experience the feeling every time you breastfed your child?		
Did anything make the feelings better or worse?	hungry	
	angry	
	stressed	
	nicotine	
Can you tell me how you felt before a breastfeeding session?		
Did you receive any medical help, or did you seek help from a medical professional?	If yes	What kind of help or treatment
	If no	Why didn't you seek help and what did you do instead?
If you look back, is there anything you would have changed?	Decisions	
	Actions	
Has this experience affected your breastfeeding in any way?	duration	
	frequenscy	
	bottle/extraction	
How long did you breastfeed		
Do you feel like this experience has affeced your motherhood	how you viewed yourself as a mother	
Do feel like this has affected the attachement between you and your baby		
Do you have anything to add?		
Thank you for your participation, do you have any questions?		

Attachment 2: Midwife survey

Do you consent to participate in this survey? **Obligatory question**	Yes	Next question	
	No	Survey ends	
Are you a reg. midwife? **Obligatory question**	Yes	Next question	
	No	Survey ends	
How old are you?	Open question		
Number of years as an active midwife?	Open question		
Where do you work?	Multiple options		
Do you know of the term "D-MER"?	Yes	Please describe what you know	Open question
		How did you first encounter D-MER?	Alternatives
	No		
Do you know the symptoms of D-MER?	Yes	Please list the symptoms you know	Open question
	No		
Have you met anybody that experienced D-MER?	Yes	Please describe your experiences	Open question
	No		
During your career as a midwife, how often have you met a person who experienced D-MER?	Alternatives		
Have you heard of any treatment of D-MER	Yes	Please describe what treatment	
	No		
According to your experience, do you think that D-MER can affect breastfeeding in any way? **Obligatory question**	Yes	Please describe how	
	No		
	Don't know (only visable when trying to skip question)		
According to your experience, do you think D-MER can affect the attachement between mother and child? **Obligatory question**	Yes	Please describe how	
	No		
	Don't know (only visable when trying to skip question)		
According to your experience, do you think D-MER can affect the transistion into parenthood? **Obligatory question**	Yes	Please describe how	
	No		
	Don't know (only visable when trying to skip question)		

Attachment 3: D-MER survey

1. I have read and understood the information letter. I understand that all data will be handled confidentially. By replying "Yes" to this question, I accept participation in this study. I'm aware that my answers are anonymous and that there is no link between my personal data and the answers to the question in this survey. Do you accept participation in this survey?	Yes	
	No	Survey ends
2. How old are you?	Open question	
3. In which country do you live?	Open question	
4. How many children do you have?	1 child	If only 1 child, question 21 is hidden
	2 children	
	3 children	
	4 children or more	
5. Are you a smoker?	Yes	
	No	If no, question number 6,7 and 8 are hidden
6. If yes, how frequently do you smoke?	Several times a day	
	Once a day	
	Once a week	
	Once a month	
	Less than once a month	
7. Did you smoke during pregnancy?	Yes	
	No	
8. Did you smoke while breastfeeding?	Yes	
	No	
9. Do you drink alcohol?	Yes	
	No	If no, questions number 10,11 and 12 are hidden
10. If yes, how frequently do you drink alcohol?	Every day	
	Once a week	
	Several times a week	
	Once a month	
	Twice a month	
	Less than twice a month	
11. Did you drink alcohol while pregnant?	Yes	

	No	
12. Did you drink alcohol while breastfeeding?	Yes	
	No	
13. Do you have a history of anxiety, depression or other disturbances?	Yes, anxiety	
	Yes, depression	
	Yes, both anxiety and depression	
	No	
	If other, please specify	Open question
14. Did/do you have postpartum depression or postnatal anxiety?	Yes, postpartum depression	
	Yes, postnatal anxiety	
	Yes, both postpartum depression and postnatal anxiety	
	No	
15. Have you ever suffered, or do you suffer of D-MER?	Yes	
	No	
16. Please choose which symptoms you experienced, you can choose several:	Emotional disturbance (dysphoria)	
	Anxious, restless, nervous	
	Homesick	
	Nausea	
	Depressed	
	Melancholy	
	Angry	
	Sad	
	Dread	
	Shameful	
	Suicidal	
	Thirsty	
	Loss of appetite	
	Physical pain	
	If other, please specify	Open question
17. Which were the most prevalent symptoms, please name three:	Open question	
18. What word would best describe D-MER symptoms?	Continous	

	Intermittent	
19. When did the D-MER symptoms start during breastfeeding? Please write time, for example 1 min. from latching	Open question	
20. For how long time did the D-MER symptoms continue while breastfeeding? Please write the time, for example 1 minute:	Open question	
21. Did you experience D-MER with all of your children?	Only visible for those who answered more than 1 child in question number 4	Yes
		No
		Don't know
22. Have you experienced the D-MER symptoms every time you breastfed (or pumped milk to) your child?	Yes	
	No	
	Don't know	
23. Did you at some time extract milk by pumping?	Yes	
	No	If no, question number 24 is hidden
	Don't know	
24. If yes, did you feel any difference in symptoms of D-MER when pumping compared to breastfeeding?	Yes, it was worse when pumping	
	Yes, it was less when pumping	
	No, I didn't feel any difference	
	Don't know	
25. Did anything improve the D-MER symptoms?	Yes	If yes, question number 26 is visible
	No	
	Don't know	
26. Chose which of following options that made it easier, you can choose several:	Keeping yourself occupied with cellphone, TV, friends and family etc.	
	Knowing what it was	
	Breathing through it	
	Positive thinking	
	Eating or drinking while breastfeeding	
	Having slept well	
	Ice water	
	Physical stimulation as scratching or foot massage	

	Support from health care professional	
	If other, please specify	Open question
27. Please specify the three things that helped the most:	Open question	
28. Did anything worsen the D-MER symptoms?	Yes	If yes, question number 29 is visible
	No	
	Don't know	
29. If yes, please specify what made the symptoms worse:	Open question	
30. When mentally preparing to breastfeed, how did you feel about knowing D-MER would appear? Please write the three most profound feelings:	Open question	
31. Did it happen that you forgot you had D-MER between breastfeeding/pumping sessions?	Yes	
	No	
	Don't know	
32. Did you experience symptoms like D-MER while pregnant?	Yes	If yes, question number 33 is visible
	No	
	Don't know	
33. If yes, during which trimester of your pregnancy did you first notice the symptoms?	1st trimester (0-3 months)	
	2nd trimester (3-6 months)	
	3d trimester (6-9 months)	
	Don't know	
34. Have you experienced symptoms like D-MER prior to pregnancy and childbirth?	Yes No Don't know	If yes, question number 35 is visible
35. If yes, can you describe in what/which situations the symptoms appeared?	Open question	
36. Do you feel like D-MER affected your breastfeeding experience in any way?	Yes	If yes, question 37 is visible
	No	
	Don't know	
37. How did D-MER affect your breastfeeding?	I weaned prematurely because of D-MER	
	I bottle fed with formula because of D-MER	

	I did not breastfeed as frequently as I wished	
	I chose not to breastfeed siblings due to D-MER	
	I did not enjoy breastfeeding my child	
	Don't know	
	If other, please specify	Open question
38. Did you seek help from any medical professional for ex. doctor, midwife, lactation consultant	Yes	If yes, questions 41 is visible
	No	If no, questions 39 and 40 are visible
39. If no, why did not you seek help?	Open question	
40. If no, what did you do instead?	No	If no, questions 39 and 40 is visible
41. If yes, were you satisfied with the help you received?	Yes	If yes, question 42 is visible
	No	
	Don't know	
42. If yes, can you describe what helped you?	Open question	
43. Do you feel like D-MER has affected how you view yourself as a mother?	Yes	If yes, question 44 is visible
	No	
	Don't know	
44. If yes, please describe in what way	Open question	
45. Do you feel like D-MER has affected you bonding experience to your child(ren)?	Yes	If yes, question 45 is visible
	No	
	Don't know	
46. If yes, please describe in what way:	Open question	
47. Has D-MER affected your relationship with your partner?	Yes	If yes, question 48 is visible
	No	
	I don't have a partner	
	Don't know	
48. If yes, please describe in what way:	Open question	

Attachment 4: Content analysis

EXPERIENCE OF D-MER									
Negative emotions and physical symptoms prior/while breastfeeding					**Symptoms intensity shown fluctuations over time and disrupted by stopping breastfeeding, eating, drinking, sleeping or socializing**				
It is out of her control, it is not something her mind can control (D39)	Noticed it at first as a yucky chemical feeling, like shame, when pumping (N1)	Once it triggered other symptoms connected to her panic attacks, she had to run to the bathroom constantly due to nausea (C4)	Profound, strange feeling of a black cloud passing over her and making her want to sob (K10)	When it hits, the thought in her head seems to turn into something terrible (K7)	Notice it sometimes more than others but do not know why (N4)	It is gotten better but still feels it to some extent all the time (D18)	The intensity varies, at night it can be more due to less frequent feedings (I17)	Getting more sleep eased the symptoms so sleep deprivation made them worse (G3)	Uncomfortable when touched by older sibling during breastfeeding (E10)
It was not enjoyable as people said, felt dread and that something bad was going to happen, uncomfortable, anxious and irritable. Just wanted the feeding to be over (L2)	Severe anxiety, loss of strength and inability to control her thoughts (I7)	D-MER amplified and made the actual thought in her had seem bad, when realizing what was happening she tried to stop think about it (K13)	Felt extreme nausea, anxiety and loss of appetite (D5)	Felt a horrible way of anxiety and painful letdowns every time she pumped or breastfeed, got worse over time (M1)	Feels it for the most times but sometimes less severe when able to think about it ahead (J4)	In the beginning the letdown could feel really intense when too much time went between feedings. Now they do not feel as strong anymore (D22)	Less noticeable during the night, more at day and horrible when pumping (E7)	Not feeding makes the feelings better, when the baby's been given formula she feels a lot better but that is not what she wants (L6)	Hunger or thirst seemed to be amplified by D-MER so having water nearby distracted and helped her (K12)
If she gets it when eating, the food tastes bad and she compares it to eating when given word of the death of someone close (I8)	Does not feel anger just different levels of sadness (K15)	She felt nausea and anxiety before letdown (D2)	The pain she's feeling during letdown is physical, like every milk duct is stabbed with a knife or stung by millions of bees (M7)	Can't control the thoughts that are coming during that short period (I9)	Decreased in severity over time (J9)	Four months postpartum it has decreased in severity (K9)	She did not feel any difference in intensity over time or comparing pumping to breastfeeding (H16)	Nothing made the feelings better or worse (C5)	Even though she feels it less when distracted, she prefers not to be because she feels that the breastfeeding goes better when focusing on it (K16)

Happens when breastfeeding, nipple stimulation and letdown and causes feelings of sadness and worry (J1)	She experienced a loss of appetite kind of nausea every time she breastfed (D16)	Diffuse, strong feeling of discomfort, physical nausea and wanting to crawl out her skin (F1)	Whatever's in front of her can impact her thoughts when it happens (I10)	It is an overwhelming feeling of anxiety, sadness and worry in the beginning of breastfeeding (J3)	Different between the siblings. With firstborn more sporadic and later in. with second baby from the start and every time but now decreasing (C3)	Being less intense now, though still varies in intensity, the feeling has become more of a light melancholy (K11)	Felt it every time she pumped or fed but felt no difference between the two (M5)	Stopping breastfeeding stopped it (A7)	When talking to others while breastfeeding she did not notice the feelings (K17)
Felt homesick, depressed, sad and anxious when breastfeeding (G1)	Felt an emotional unsettling, a hole that drained all joy, a void, sometimes agitation and anxiousness, felt confused (B1)	If eating food, whatever's on her plate can turn into something horrific when it happens (I11)	Felt overwhelmed and chocked at the pure rage (A5)	Transient rage, waves of depression and suicidal thought (A1)	The symptoms are getting worse with her second now, she wonders if it is connected to longer feedings or the number of letdowns (M10)	Less symptoms when more frequent feedings (D19)	Feelings got more and intense over time (A4)	It felt worse when it also was more frequent (F4)	The symptoms have the same intensity, she found out recently that lying on her side in bed helped enormously with the anxiety, the pain was the same, but that has been the only thing that has lessen the intensity (M6)
People use the dementor analogy from Harry Potter, and it describes it well as all joy had been sucked out and would never return (B2)	She gets terrible nightmares and wakes up because of milk leaking (I18)	Weird thoughts can linger after the attacks, like that something will happen her baby (I34)	All of a sudden it could feel like something was wrong, like the world was going to collapse (B6).	Felt pinch in her chest before every letdown (B5).	Symptoms more severe with firstborn but more sporadic, with second one less severe but every time (C9)	The feelings are still similar when the severity differs (K14)	The feelings are little less intense when pumping, do not always have a letdown then (K33)	Nothing made it better or worse (A8)	Felt D-MER most of the time in the beginning but now it seems to have gone away (G2)
The feelings are so strong that she's disgusted of what is happening inside her (I30)	Can feel sad afterward due to the thoughts that appears even though the feeling itself is gone (I16)	Felt like killing herself and throw the baby in that minute (A6)	Felt homesick when breastfeeding (E1)	When speaking to her boyfriend and the attack happens she can raise her voice and say things she does not mean (I31)	Now when it has decreased in intensity she feels really good in between, and it has never stopped her	Only pumped a couple of times and not for so long, haven't felt it then but wonders if she would've if she pursued it (L14)	Felt it especially when baby latched on again, when D-MER comes much milk is being released (I5)	Over time it happened less frequently, now almost never, sporadically (F5)	If it went more than 2 hours between feedings in the beginning it made the symptoms stronger and worse (D20)

					from breastfeeding (K20)				
always want ice cold water when breastfeeding because she feels extreme thirst (E9)	It was an awful feeling (A10)	Felt out of control and suicidal without knowing why (A32)	Felt nervous and it triggers the fight or flight response but goes away almost immediately (C 1)	Bizarre feeling of wanting to shake baby off and commit suicide (A31)	Feelings of anxiety and doom-and gloom feeling were the worst between 1 week and 6 months postpartum (D17)	Noticed some correlation between thirst and severity of symptoms, water nearby helps a bit (J5)	With her second child she did a cesarean and were put on pain medications afterwards. When she stopped taking them the D-MER symptoms came, at first less severe compared to later on (M9)	D-MER was at its strongest for some months before gradually lessen in intensity and frequency (F8)	In the beginning it felt better when breastfeeding often (D21)
Felt a tidal wave of depression for a minute just when baby got on the breast (A17)	Feelings of anxiety that lasted for a little bit (E2)	Had experience the sensation prior to pregnancy, came across the description of D-MER prior to birth and wondered whether she'd have it (J20)	Experienced D-MER for 30 seconds up to a couple of minutes before the painful letdown (B4).	Felt annoyed and frustrated over the experience, it felt like an atomic bomb inside(E26)	Pumping felt less intense (A27)	Haven't found anything that makes it better or worse, it feels like part of her existence at this point (D23)	If she'd had a really stressful day with high anxiety built up, she could start crying and not being able to stop while breastfeeding (M18)	Feels it for the most times but sometimes less severe when able to think about it ahead (J4)	In the beginning the letdown could feel really intense when too much time went between feedings. Now they do notdo not feel as strong anymore (D22)
Have experienced the symptoms this pregnancy too when being intimate with husband, feels horrible about it because she thinks it is going to happen when	Every time it happens it is connected to milk release and the feelings disappears after 30-40 sec (I15)	Happened every time in the beginning, less more recently. Sometimes when the baby is not breastfeeding, maybe in connection to milk release and	Realized within the first couple of days something was not right (D1)	Noticed it within the firsts weeks (L1)	Less noticeable during the night, more at day and horrible when pumping (E7)	Not feeding makes the feelings better, when the baby's been given formula she feels a lot better but that is not what she wants (L6)	Hunger or thirst seemed to be amplified by D-MER so having water nearby distracted and helped her (K12)	Decreased in severity over time (J9)	Four months postpartum it has decreased in severity (K9)

breastfeeding again (H29)		it is very unpleasant (L3)							
Wondered at first was what happening, just felt horrible (L4)	Realized within the first couple of days something was not right (D1)	It would last about 5 minutes, in the beginning pretty much the whole feeding, now much shorter, it depends and is variable (L5)	Amazed by the mood swings that only lasted a minute or two (D9)	It started within 3 days postpartum (D3)	She did not feel any difference in intensity over time or comparing pumping to breastfeeding (H16)	Nothing made the feelings better or worse (C5)	Even though she feels it less when distracted, she prefers not to be because she feels that the breastfeeding goes better when focusing on it (K16)	Different between the siblings. With firstborn more sporadic and later in. with second baby from the start and every time but now decreasing (C3)	Being less intense now, though still varies in intensity, the feeling has become more of a light melancholy (K11)
Noticed it every time she breastfed or pumped, an awful feeling for about 30sec-1 min that would start with letdown and then disappear (N2)	Noticed the association between symptoms and letdown quickly, could be happy and then just feel dread for 30sec-1 minute (D4)	The feelings started 2-3 weeks before baby was born and came on very suddenly occasionally during the day (H1)	She experienced D-MER every time she breastfed (B18)	Blind-sided by the symptoms (A15)	Felt it every time she pumped or fed but felt no difference between the two (M5)	Stopping breastfeeding stopped it (A7)	When talking to others while breastfeeding she did not notice the feelings (K17)	Seems to have gone away now, it is still not pleasurable but not horrible (G25)	Sleep deprivation and stress made it worse (B26)
Felt it pretty much every feed, starting to not happen every time (C2)	Felt it every time when breastfeeding (A3)	Handful of times without symptoms in total 36 months of breastfeeding (D15)	It is apparent just in the beginning of breastfeeding but disappears within 30 secs or so (F19)	A wave of dread and sadness that would last for about 30 secs to a minute and then stop (H2)	D-MER was less noticeable when breastfeeding than pumping due to being distracted and happy to feed her (N3)	The stronger episodes she calls attacks and the milder ones' brain freezes (I13)	Feels it less during the night when not totally awake (K18)	Being dehydrated or hungry, or if the baby was very hungry and by that stressed or frazzled her made it worse (B27)	Do not think it is a difference in symptoms when pumping or breastfeeding just the notice of it (N5)
The feelings came connected to milk letdown, several times a day (I4)	Happens when latching on, lasts up to 30 seconds, then decreasing (F2)	It happened every time both while nursing and pumping (H5)	It happens even when she's not breastfeeding (I6)		Oxytocin spray made D-MER symptoms more extreme (E5)	When she stopped breastfeeding D-MER ceased while the postpartum	Strangers, people who did not understand and were unkind about it made it worse (B30)	Associate the feelings more negatively to pumping because she does not like it anyways (N9)	When feeling really tired or dehydrated the symptoms gets worse (E8)

					She knew the negative feelings were connected to breastfeeding because it always happened before the letdown (B7).	depression did not (B16) There was a clear correlation between the ucky feelings, painful pinch milk letdown, every time and dozens of times a day (B9).	Could not understand the feelings (A13)		

CONSEQUENCES OF HAVING A D-MER CONDITION							
1.Weaning **2. Not weaning but women continue breastfeeding under stress**			**Negative impacts on mother child attachment**		**Women's self-stigma and feeling of guilt in relation to breastfeeding was created by judgmental attitudes of the surrounding people**		
Does not think it has affected her breastfeeding even though it was hard, but its transient and nursing is good for the baby (N15)	D-MER did not affect breastfeeding because she was determined to pursue (G11)	Did not affect her breastfeeding (C12)	D-MER impacted the bonding. Making the decision to wean opened up the opportunity for others to feed them so she made sure there was lots of bonding in every other way possible by telling them to snuggle and hold the babies when feeding them (B61)	Feels that this has affected the bonding, is learning that feeding by bottle also can be a bonding experience, but then, she's never experienced that bonding, so she has to teach herself that too (M28)	People thought she just gave up when making the hard decision to quit breastfeeding (E19)	Could not relate to others talking about how great they felt when breastfeeding instead it made her feel like a bad mom for not having the same experience(B38)	It was bad (M4)

Have being trying really hard to continue and hopes it has not affected her baby's experience but it was hard for her (J16)	D-MER has not affected the breastfeeding duration but have wanted to quit many times (D41)	Breastfeeding has been less of a positive experience than she wanted (D40)	Do not think it affected the bonding, maybe it became stronger because she did this even though she experienced these feelings (N18)	Feels like she's missing a key piece, she knows she's bonding with the kids but since she still associates holding and feeding him with anxiety and pain the happy parts has not gotten to her yet, it definitely affects the bonding (M29)	Hated going out in public and trying to keep a game face on was challenging, trying to find a place to breastfeed in a society that does not look fondly on public nursing amplified stress(B29)	Felt that people did not understand that breastfeeding made her feel bad (B32)	Very much affected how she viewed herself as a mother (A28)
Did not affect the breastfeeding in terms of duration but it affected her experience (K28)	D-MER hasn´t affected the breastfeeding (F15)	D-MER hasn´t affected before breastfeeding maybe due to a milder form of D-MER (F9)	Did put her off initially, worried about the bonding because she felt horrible. It easier with that know that the baby is older and more responsive (L9)	Disconnected to the baby because the breastfeeding experience was so hard (E23)	Did not talk to anyone about it because she felt ashamed of not getting it when others did, and they seemed to enjoy it while she despised it (A16)	She could not relate to other moms talking about how they loved the feeling of breastfeeding (B33)	She's quite logical about things so she does not think it affected her motherhood (L15)
D-MER has not affected her breastfeeding more than any other reason, like worrying if baby gets enough food and so (L12)	It came close to affecting the breastfeeding but did not since she's still nursing (J14)	Felt better after quitting breastfeeding but it was a hard decision (E12)	It definitely affected the bonding to the baby, she could not be around baby for more than five minutes by herself (A30)	The anxiety caused by D-MER together with having problems to get baby on disconnected her and makes her feel that the bonding was affected (E24)	Did not talk to people about negative bits of breastfeeding because she felt pressured to stop (G7)	Felt alone since everyone else had this lovely experience when she wanted to crawl out of her skin and scream (B35)	Negative impact on quality of life due to frequent mood swings (D43)
It has not affected the breastfeeding. However, the decision to eventually give formula for some meals per day has been a consequence of D-MER (M24)	Breastfed her first two for just a couple of weeks and was recommended by ob to not try with third (B52)	stopped breastfeeding at 6 weeks and pumped instead (H6)	D-MER hasn´t affected the bonding (F17)	The feelings made it hard to keep calm with older one when breastfeeding the younger, thinks it affected the older one more (E27)	Avoided telling others because she did not like explaining it since people tended to think it was postpartum depression (K5)	Thinking she was alone with feeling like this around breastfeeding affected her motherhood the most (D46)	D-MER has affected her confidence, relationships and how she views herself as a mother (I28)

It has happened that when baby only wants to be on the breast but not eat she's been playing with her instead to avoid the feeling (I21)	Felt up against it because hardly any professionals knew about it, just weaned which made it stop (A20)	Stopped pumping when baby was ca 2 months old because she could not handle the feeling of dread (H9)	D-MER affected the bonding in the beginning but not anymore (G18)	Feels that she missed out on the experience of bonding while breastfeeding (H26)	Isolated herself because of D-MER since she did not want people to see it or having to deal with questions about it (B37)	Adjusted voice depending on how she was asked about bottle-feeding instead of breastfeeding (B58)	She felt discouraged and down before breastfeeding or pumping because she knew it was going to happen. (H17)
She's been giving food to the baby earlier than recommended partly to avoid breastfeeding, she feels like a bad mom because of it (I22)	When having to give formula due to undersupply of milk she almost hoped she would have an excuse to wean (J15)	Breaks her heart that she quit breastfeeding so soon (H21)	She does not feel that the bonding has been affected (I36)	The bonding was affected because the closeness of breastfeeding was not there (H27)	Feels kind of envious at other moms who are able to relax and talk of the bonding experience. She does not have that, and never will and it is hard to accept that (M27)	If having visitors that holds the baby when it happens, she wants to remove the baby from them (I35)	Anxious between feedings that it would happen again (A12)
If she has severe attacks when feeding it happens that she removes the baby from the breast and lies about it, saying it is the baby that let go (I29)	Blames D-MER for weaning early (H25)	It does not feel natural to remove her baby from the breast and see her trying to relatch (I32)	In the long run she does not think the bonding has been affected but in the beginning maybe due to the general difficulties and not enjoying that time (J19)	Feel that the bonding took longer because of D-MER and that she failed him (H28)	Viewed as a subpar mom and ostracized from mom groups because she made different choices than them(B59)	Asked her husband to help with future questions from family about her decisions about breastfeeding since they weren't easy (B57)	Knowing the benefits of breast milk made her agonize over the decision to stop (B49)
Stopped breastfeeding and gave bottle because it was so intense (A2)	Combination of severe D-MER and depression was too much and caused her to wean early (B14)	Could not breastfeed because she felt overwhelmed (A9)	Inconvenient for bonding (C15)	Does not think it is a yes or a no thing as to if D-MER affects the bonding (D48)	Not being able to relate to others had a significantly impact on the view of herself as a mother (B60)	Husband is really understanding but she does not think he understand it completely (E22)	Did not look forward to it prior to feeding because she knew what was coming (J6)
Stopped breastfeeding to not feel D-MER anymore, that she could control but not the postpartum depression (B15)	Breastfeed and pumped for 2 months then formula (A25)	She thinks she could have breastfed longer if she did not have both D-MER and postpartum depression (B25)	Impossible to believe that it would not affect the bonding in the beginning but when deciding to pursue and go with it, it affected it less and less (D51)	One of her biggest fears is to resent her kid when it comes to bonding (M30)	The D-MER experience isolated her because she had built up anxiety due to people treating her poorly (B36)	Felt she was under pressure from family members and the society to breastfeed (E17)	Happy that she breastfed for 9,5 months but regrets putting that pressure on herself (E18)

Stopped breastfeeding to not feel D-MER anymore, that she could control but not the postpartum depression (B15) Could not handle it due to intensity (A26)	Breastfeed and pumped for 2 months then formula (A25) Weaned early due to D-MER because it had a negative impact on her mental health, connection to family and children, and put her life in jeopardy (B50)	She thinks she could have breastfed longer if she did not have both D-MER and postpartum depression (B25) She's preparing to wean so that some feedings are with formula so that she can have a break from these symptoms (M14)	Less of an impact on bonding with second child (D52)	The attachment was affected a bit with her firstborn when it was at its worst, not knowing what it was and not receiving any help(D49)	She does not consider it a good thing to give formula for a few feedings, she's trying to accept it and feels that it is not a good thing, it is definitely a side effect from D-MER for her (M25)	Assuming feelings were connected to being a new mom (A14)	Would've felt guilty if she'd stopped breastfeeding (D42)
Would have tried to breastfeed longer (B51)			Can't tell if it was D-MER solely that affected the bonding, there was different factors in the beginning (K30)	Feels guilty that she isn't bonding with them the way she should, not giving them the affection needed for development (C16)	Did not get help because she thought this was normal and something new mothers went through (A18)	Would've felt guilty if she did not breastfeed because of expectations (A22)	Expected breastfeeding to be difficult but also to be positive, she never had that and feels guilty about it (G17)
She did not enjoy her baby as much as she could've because nursing was hard (G15)	Before finding out she did not know if she felt like this because she did not like her baby or something (G10)	Was not able to enjoy her baby and wondered whether this was how it was to breastfeed (I3)	Worried about it affecting the bonding in the beginning because she did not enjoy it and expected it to be pleasant. She hated it and felt horrible when breastfeeding (L16)	Because of so much time spent breastfeeding in the beginning it was hard to enjoy her son when dealing with pain, sadness, anxiety and horribleness (G19)	Feared it being something inside her that would transfer to the baby when feeding (K2)	Overwhelming to feel anxiety and nausea on top of general latching issues in the beginning of breastfeeding (D25)	This time around it especially has affected how she views herself as a mother. It feels like a failure to her son that she isn't giving him the same start as her daughter. She feels inadequate in a lot of ways (M26)
Beginning was difficult, overwhelming and tumultuous so she did not realize that she felt bad at the moment she was breastfeeding (K1)	The breastfeeding was not experienced as she anticipated, though not having any physical problems, the feeling of it was really sad and stressed (I1)	The decision to go to formula still makes her feel horrible and very emotional (H10)	Even though D-MER is an unpleasant experience, the motherhood has been more affected by the tough breastfeeding start (F16)	When having surges of anxiety or sadness when she was not nursing was weirder to cope with and harder to differentiate from postnatal anxiety or depression (G22)	It torn me up to not give my children what I could give them (B53)	Didn´t want to talk about it because she felt she was crazy (E3)	Can't say what made her reluctant to breastfeeding in the beginning, D-MER or it being a new thing to adjust to (K19)

Was prepared for breastfeeding be a transition and hard but also to feel relaxed and loved up, that did not happen (B34)	Gets psychological help with the feelings of mom guilt and to be ok with feeling that she needed her space when breastfeeding to prevent it from affecting the bonding (E21)	She thinks the nice feelings of breastfeeding makes up for the hard parts, but she did not have that and therefor often wished away those first weeks (G20)	Sees a psychiatrist for postpartum depression and anxiety but also for things connected to D-MER (M13)	Didn´t reflect over D-MER in the beginning because that time was characterized of other breastfeeding issues (F7)	It was hard in the beginning because she had looked forward to breastfeeding but instead felt anxiety (J8)	With firstborn she needed help with the problem itself. With the second help to mitigate because it seriously impacted her mental wellbeing, so she started seeing a therapist (B40)	Overall it has not impacted her overall sense of motherhood but there were times when it did in a discrete way (J18)
Possibly affected how she viewed herself as a mother because of the feelings of dreading to nurse her child (G13)	Does not know if it affected her motherhood (N16)	The other breastfeeding issues caused more trouble for her as a mother, D-MER has more affected her on an individual level (N17)	Hates to admit that it affected her motherhood, but she wanted so badly that nurturing connection to her child when breastfeeding (H24)	The first time she just thought she was crazy and that the feelings were just anxiety of being a first-time-mom (E25)	Thought it was anxiety of a first-time-mom to be but when nursing for the first time she felt it again (H3)	Normal life adjustments as a new mom and adding D-MER on to that make it a led positive mothering experience (D44)	Had to seek psychological help for D-MER because it made her postpartum depression and anxiety worse. The mood swings while breastfeeding made it worse and she's currently on medications hoping to help with that (M19)
Do not think affected her motherhood (C14)	It was exhausting to pull herself up from the experience of D-MER so many times a day (B3)	Affected her motherhood in the beginning when not knowing what it was and made her worry about being a bad mom or not loving her baby (K29)	It just is, does not think about it so much anymore (D26)	Prior to a breastfeeding session there is an inner fight between wanting to do it and not. But the will to breastfeed is stronger than D-MER (I20)	Dreaded breastfeeding because she knew she would feel awful and that it would be painful (G4)	She does not know what went wrong in the brain and body but it is affecting her 3 years later and she still receiving support (A34)	Felt normal before breastfeeding, no anxiety, the feelings are temporary (C6)

To experience depression for the first time combined with the despair and wave of a black hole threw her (A33)	It is not severe enough to make her stop breastfeeding, but enough to definitely interfere with quality of life (D11)	It has affected her at work to the extent that she needed to talk to her boss about it (I14)	Not being able to breastfeed led to feelings of inadequacy as a mother and made her want to give up on it (A29)	Prior to a breastfeeding session there is an inner fight between wanting to do it and not. But the will to breastfeed is stronger than D-MER (I20)	She was sad that it became something she just had to do instead being a time of bonding (J7)	It´s comes as a surprise every time it happens (F10)	It became more of a shore instead of being a time to connect with the baby. She could not feel good about it. (H18)
Knowing the feeling would come was overwhelming and made her sad because she wanted it to be a positive thing (D24)	Feared D-MER happen and felt agitation and anxiety prior to a feeding because she knew what was coming (B21)	Knowing the feeling would come made her tense up a lot prior to feeding (D50)	Almost forgot about D-MER between feedings (E11)	When feeling tired or in a bad mood she's not looking forward do breastfeeding as much because the feelings will come (N8)	It is gotten better now when the symptoms are less severe, she sometimes forgets she has it until it hits (K31)	Loves feeding her baby and sometimes does not notice it until it happens (N10)	she does not look forward to breastfeeding, it is more of an obligation than a bonding experience (M11)
D-MER did affect how she felt prior to breastfeeding, she felt dread, hated it and did not know if she'd continue or not but it has gotten better recently (L8)							

SEEKING HELP FROM HEALTH PROFESSIONALS REGARDING D-MER				
Lack of knowledge and poor services by health personal regardless of their health profession				**Treatment suggested by different health professionals failed to treat D-MER including antidepressants**
The staff questioned her when seeing her nurse in the hospital, she felt she did not have a choice, she nursed the baby for some weeks, it was not what she wanted (B55)	Her physicians insisted on that she had postpartum depression even though she clearly felt a connection between feelings and breastfeeding (B12)	Had to breastfeed after delivery even though it was in the charts that she was not going to because there was not any milk prepared, she felt	No point in telling professionals when there is nothing to do about it (G6)	Tried taking magnesium supplements, things have gotten better but she cannot say it is because of that or just time (L7)

		they treated her as someone who just did not want to (B54)		
People kept saying it was postpartum depression even though she felt the symptoms did not match up (B8).	Wonders if her iron deficiency, the balance between copper and zinc and salt and minerals has something to do with it but her doctor won't look into it (E29)	Mentioned it to several lactation consultants, to the OB at the 6-week check-up, did not get any help (D6)	No one knew about it, was told by GP that her peck muscles were to tight and needed stretching, and from others just that it sounded interesting. Did not get help for 15 months (M2) Told health visitor about it but was just told to contact GP in case it was depression or something (G5)	Out of desperation she tried to help D-MER by trying placental encapsulation, it did not work(B48)
Neither endocrinologist, home doctor, midwife or nurse knew what it was or had heard of it (E14)	Regrets telling the pediatrician because she thinks the doctor thinks she has postpartum depression (K23)	The pediatrician did not know either but listened, googled and printed a publication about it and offered her to go to a psychologist (I24)	She mentioned it both to the midwife during the postnatal period and the health visitor that came to visit but they did not say much and appeared mainly focused on baby's weight and not whether she enjoyed breastfeeding or not (L10)	Medications for postpartum depression helped for that, but not for D-MER (B44)
No one knew about it, was told by GP that her peck muscles were to tight and needed stretching, and from others just that it sounded interesting. Did not get help for 15 months (M2)	The endocrinologist was open-minded and read about D-MER whereas the GP was skeptical and questioning (E15)	The pediatrician did not know either but listened, googled and printed a publication about it and offered her to go to a psychologist (I24)	When seeking help at the baby health center the nurse did not know about it and just recommended psychological care, this upset her (I23)	Being a dietician, she tried to think nutritionally if it being hormonal to understand it (G23)
The endocrinologist was open-minded and read about D-MER whereas the GP was skeptical and questioning (E15) Lactation consultant at hospital did not have anything to say about the symptoms (D31)	The pediatrician did not know either but listened, googled and printed a publication about it and offered her to go to a psychologist (I24) She had a lactation consultant present for the first feeding and told her what she felt but it was dismissed as something normal (H4)	The two professionals she met had not heard of it and one called it postpartum depression (B39)	Health professionals and lactation consultant did not know about it (E13)	Genetic test to see how someone's genotype most likely will respond to certain medications can be helpful when trying to find something that is going to work (B45) The lactation consultant has helped with coping techniques and was the one who encourage her to skip a few feedings after seeing what effect D-MER had on her (M17)
Neither endocrinologist, home doctor, midwife or nurse knew what it was or had heard of it (E14)	Two lactation consultants brushed it off by saying that it hopefully would pass (D28)	They had no clue what she was talking about at her 6-week check-up (D29)	Midwife had heard of the symptoms before but did not know what it was (E4)	She talked to others of it, including a friend who is a lactation consultant who thought she'd heard of it (H7)

The OB did not have a clue (D32)	Physicians dismissing it despite of being provided with information was frustrating (B41)	The only help received was a lactation consultant giving her the name of it (D33)	The first she one she told was her second baby's pediatrician who was very intrigued about it (M16)	The lactation consultant told her that it is a reflex response, it is not psychological and she was only the second person she'd meet with D-MER (M15)
It was extremely helpful to find a therapist who wanted to look into it (B42)	The OB at the 6-week check-up had a friend who experienced it and gave her the name (H8)	Sought a lot of help and found a lactation consultant who know about it (M12)	Mentioned it to Obstetricians/Gynecologists a month or so after given birth, had heard of it but referred her to online resources and she did not seek help after that (J10)	A nurse at OB office only said it can be like this for some women (D30)
The therapist helped to safely manage supplements as treatments to try (B43)	The ob gave her the name and said she could go see a lactation consultant. By then she was already on the way to wean and did not seek other help (H19)	Had read about it before so just continued researching it herself since the lactation consultant did not know much, did not bother seeking more help (N12)	Mentioned it to a lactation consultant who was helping with other problems in the beginning, she had heard of it but did not know much (N11)	Due to complications after the first one was born she has to visit a doctor in another town for a study regularly, he saw what was happening when she breastfed, she explained, he then said that his wife had it and gave her the name, D-MER (M22)

COPING STRATEGIES				
Knowing more about D-MER created mental preparation and acceptance as when they learn it is transient it helped coping with it better			**Strategies**	
Finding out the name for it and to not be alone made it feel better (D45) When googling symptoms, she realized what it was it was a big relief (K3) Felt that the description of D-MER and having knowledge of it was helpful was very true in her case (K4)	Knowing about it made it able to cope (K26) Initially thought it was something linked to postpartum depression since her sister had a severe on, but knowing about it helped much (N7) Realized what was wrong when finding the Facebook support group (A19)	To have a community of people with same experience made it affect bonding less (D47)	Preparing for it happening again by just accept that it happens and there is nothing to do about it, it will pass (H30)	Did not look it up with firstborn, just powered through (C8)

Hopes that more people learn about it since that is the thing that enabled her to keep breastfeeding. (N19)	The clear connection of letdown and feeling was helpful for coping with the experience and when researching on D-MER (B10).	Being able to contribute by telling her story makes her feel better (H32)	Feels that she needs to be able let it come and just breathe, with the goal of breastfeeding longer this time (H31)	Did not seek any help for it (F11)
Only thing that helped is knowing what it is, something chemical and transient that will pass (N6)	Thought she was alone until she found the support group (A36)	Read in the Facebook support group that one could try to welcome the feeling instead of blocking them. She's done this and has not cried as she uses to when breastfeeding (I19)	Has been able to breathe through it (F18)	Did not seek help because she'd never heard of if before and did not know it was a medical condition (C7)
Happy about the support group because D-MER was recognized and to not be alone (D13)	The support group has been great (D12)	Found out about it through google, it is difficult if you do not know anything about it to understand why you're feeling this way (L17)	Tries to think that the milk coming is good and just wait it out (K8)	Haven't sought help for it, at the ob-checkup she had not realized she had it yet (K21)
This time she plans to try longer since the stories from others in the Facebook support group has empowered her (H22)	Might have stopped breastfeeding if it had not eased and if she had not known what it was (G12)	Found out about D-MER online, realized what was wrong and that she was not crazy (E6)	It feels terrible when it happens but tries to think of something else (K6)	Thinks about how the milk coming is a good thing when the feelings come (K34)
Knowing what it was helped her power through (C10)	Finding others with the same experience helped her relax since she realized it was hormonal (G9)	Knowing what it was helped, it made me endure by thinking it will disappear soon, other than that nothing helped (F6	Learned to cope with constant symptoms because she breastfed on demand (D10)	Accepted and dealt with the experience because breastfeeding was so important to her (D7)

Initially had thoughts of giving up breastfeeding but stuck it out with a lot of support from her mother. Can see why others stops and that she would've if it had not gotten better (L13)	The scratching of arms distracted her but other than laying down nothing helped with the intensity of the symptoms (M8)	It was helpful when somebody else could help her through it by saying, hang on, it will pass (B23)	Copes with it by just braising herself, that they will come but pass (D27)	Just accepted it and it became better and better (F13)
Helped to have husband rubbing her feet (J12)	Distractions helped, like sometimes having family around (B19)	Ice water, simple carbohydrates, little things like that helped, things she figured out by herself to go through it (B24)	Husband and family helped by telling her to be calm and breathe, that it would pass (B22)	Having something familiar, fun and light like Friends on TV in the background helped overcome the sadness and worry (J13)
Developed coping mechanisms like scratching her arms to deal with the feelings (M3)	Tries to distract herself with TV or other (J2)	Could put on a happy TV show to distract herself and making her hang on for a little bit and get though it (B20)	Tried to plan around the feeding so that neither she or baby were frazzled, she could distract herself in time and this made it easier to mitigate (B28)	Tried distracting herself with Facebook, Instagram or Pinterest while pumping (H12)
She made her husband aware of what was happening and his support by try and calm her down was very helpful (H13)	Her husband would tell her that it was going to stop soon and having a bit more security and understanding from a spouse helped (H14)	Avoids watching the news when it happens (I12)	She did not find anything that stopped the symptoms it was just her trying to keep distracted from them. (H15)	

WOMEN STRESSED ON THE URGENT NEED FOR OPEN DISCUSSIONS, RAISING AWARENESS/KNOLEDGE WITHIN HEALTH PROFESSIONALS AND RESEARCH INVESTIGATING ABOUT D-MER					
Do not think she would've changed anything (K24)	She would've advocated for herself more and been more confident and empowered to seek further help from	Would not have changed anything, next time have things to help ready (J11)	Thinks it is fascinating that this chemical thing affects how she feels (K35)	It took 15 months to get answers and wishes she had not accepted the previous ones of just needing to relax and done more research on it (M23)	It would be good to recognize D-MER and the consequences of it(G24)

	someone who knew about it (H20)				
Nothing in terms of breastfeeding would've changed, she would've had less anxiety, is happy to have fed her but happy when it is over (N14)	Feels lucky it happened now and not 10 years ago when finding information would've been more difficult (K25)	Would've bottle fed from the beginning because of the mental health issues (A24)	Nobody talks about it which would be good, especially for professionals, because it is a very unpleasant experience (F20)	Would've been good to know this was a possibility beforehand (K27)	Whoever is helping women postpartum should be aware that this is an issue (D34)
Had not changed anything due to D-MER (F14)	There was more available information about D-MER now than when she had her firstborn (B11)	Nobody seems to know much about what you can do about it, it would've been better to know early on to help people from stopping breastfeeding because of it (L18)	Knowing what she knows now she would've sought help in a larger city when she first had it. She wished she had gotten more information that this could happen (M20)	Differentiate D-MER from postpartum depression when screening at check-ups (D35)	People think it is psychological, so she hopes that in the future people know what it is (E20)
If she had known about D-MER and knew she would have it, she would've seen a psychologist parallelly(I26)	Wonders if there is a correlation between her being an emotional person and developing D-MER (K36)	Wishes it was something people talk about, at the doctors, at the birthing classes or just commonly known so it did not have had to take 15 months of suffering (M21)	Thinks it should be a general awareness about this and support for it (D36)	Do not know what she could've done instead but feels it could've been helpful to know that her expectations were high and that this could happen (L11)	Wish she could shake the whole medical community, that there is still so much to be learn and you can't just dismiss what you just understand (B62)
Would've breastfed in calmer environment and talked more with spouse to help with older sibling (E16)	Hoped there would be a genetic explanation for this but it is not in her case (D53)	Awareness of the condition can help others (A35)	Hopes to know the cause of it so she has an explanation (D37)	Would not have changed anything but feels it would've been great if professionals had mentioned it (N13)	Sad that there´s no research on D-MER (D14)
Might have googled it sooner but it would not have changed her behavior (C11)	It is been clear with the experience that this is a biological change in the body (D38)	Wished she'd have known about it earlier (G8)	As a clinical psychologist it was clear that this was a biological thing (D8)	Told a pediatrician for it to be noted and in the hope to participate in a study (K22)	Could be important to know that this could happen, that it is a medical condition, what can help and what the consequences can be (J21)
Would've insisted on support from mental health- or nursing team (A23)	She thinks there might be a connection to intake of B-vitamins (E28)	If she knew she'd have it, she would've sought support (A21)			