



NARRATING PERINATAL OBSESSIVE-COMPULSIVE DISORDER THROUGH BLOGS

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Abstract

Purpose: To describe women's experiences of perinatal obsessive-compulsive disorder (OCD) as written in their blogs.

Study Design and Method: This qualitative descriptive study examined perinatal OCD blogs identified using Google search engine. Krippendorff's thematic content analysis method for qualitative data was used. The unit of analysis included segments of the bloggers' descriptions of their perinatal OCD. Clustering and dendrograms were used to group the data into themes.

Results: Forty-three different posts from women in the United Kingdom, United States, Australia, and South Africa were analyzed. Five themes were identified that described women's experiences of perinatal OCD as told in their blogs: (1) Starting to tighten its grip during pregnancy, (2) Keeping horrific secrets all to themselves, (3) Tortured with terrifying images and thoughts, (4) Driven to compulsive

behaviors to protect their infants, and (5) Long difficult road to recovery but so worth it.

Clinical Implications: Perinatal OCD is a hidden problem that can have negative consequences for mothers and for their infants and families if not diagnosed or if misdiagnosed. There are effective treatments for OCD, but first nurses and other health care providers need to identify the women who are struggling with this anxiety disorder. During the perinatal period nurses can screen women for OCD. Developing a trusting relationship with pregnant and postpartum women is critical for nurses so that their patients can feel safe enough to share their horrific secret thoughts.

Key words: Blogging; Obsessive-compulsive disorder; Perinatal; Postpartum period; Qualitative research

Perinatal obsessive-compulsive disorder (OCD) is a hidden problem that can have consequences if it is not diagnosed or if misdiagnosed (Challacombe & Wroe, 2013). Postpartum depression has received the most attention by clinicians and researchers leaving perinatal OCD concealed in the background. Fawcett et al. (2019) conducted a meta-analysis of 19 studies of OCD during pregnancy and 9 studies of postpartum OCD. The prevalence rate is reported to be 2.3% during pregnancy and 2.2% during postpartum. Miller and O'Hara (2020) conducted a longitudinal study with 228 women who completed an online questionnaire packet at 2 and 12 weeks postpartum. At 2 weeks after birth and 12 weeks after birth, 30% and 23% of the sample respectively met criteria for clinically significant levels of OCD symptoms, obtrusive thoughts, or neutralizing strategies.

Fairbrother et al. (2021) assessed prevalence of OCD among 580 women in Canada across pregnancy and postpartum. The structured clinical interview for DSM-5 (American Psychological Association [APA], 2013) was conducted by telephone in late pregnancy and twice postpartum. The point prevalence for OCD diagnoses was 2.6% at 6 weeks prior to birth, 8.3% at 10 weeks postpartum, and 6.1% at 20 weeks postpartum. In a systematic review of 14 studies of OCD symptoms during pregnancy and postpartum, aggressive obsessions were more frequent in postpartum OCD than during pregnancy. On the other hand, washing/cleaning compulsions were more common during pregnancy than during postpartum (Starcevic et al., 2020).

Impact of Obsessive-Compulsive Disorder on Pregnancy and Outcomes

Uguz et al. (2015) examined the impact of OCD during pregnancy on gestational age and birthweight of the infants. The sample consisted of 28 women with OCD and 35 women without OCD. Five of the women with OCD (17.9%) gave birth to low birthweight infants compared with one woman (2.9%) without OCD. Preterm births occurred in four women with OCD (14.3%) and one of the control women (2.9%).

Researchers have found that OCD can negatively affect mother–infant relationships. In a sample of 37 mothers with and 37 mothers without postpartum OCD along with their 6-month-old infants, women underwent a SCID-IV (First et al., 1995) interview. Challacombe et al. (2016) found that mothers with OCD were troubled by their obsessions and compulsions a mean of 9.6 hours/day. Mothers with OCD were less likely to breast-feed and were rated as less sensitive in their interactions with their infants than the comparison group of women. At 12 weeks postpartum, Miller and O'Hara (2020) reported a significant difference in maternal responsiveness toward their infants in mothers with and without OCD symptoms. Women with OCD symptoms displayed lower responsiveness toward their infants than mothers without symptoms. In a sample of 143 mothers, Ratzoni et al.

(2021) reported higher OCD symptom scores were significantly negatively associated with maternal bonding at 4 months after birth.

Multiple instruments are available to screen for general OCD symptoms. A few of the most frequently used ones include the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS; Goodman et al., 1989), the Dimensional Obsessive-Compulsive Scale (DOCS; Abramowitz et al., 2010), and the Obsessive-Compulsive Inventory-Revised (OCI-R; Abramowitz & Deacon, 2006). There is only one scale developed that measures OCD symptoms during the perinatal period, the Perinatal Obsessive-Compulsive Scale (POCS; Lord et al., 2011), which consists of two Likert subscales: a symptom severity subscale and an interference subscale. The first scale to assess symptoms of postpartum Parent-Infant Relationship Obsessive-Compulsive Disorder (PI-ROCD) and its risk for impaired maternal bonding (Ratzoni et al., 2021) was recently published.

Only one qualitative study was located where 10 women who endorsed moderate-to-severe OCD symptoms on the POCS (Lord et al., 2011) participated in a follow-up interview regarding their experiences of perinatal OCD (Garcia et al., 2021). Inductive thematic analysis revealed three themes: obsessions, compulsions, and other symptoms. The top two most commonly reported obsessions were around baby safety and cleanliness. The top two most common compulsions included baby safety and constantly seeking information about perinatal OCD on the internet. Other symptoms reported by mothers included fear, panic, anxiety, suicidal ideation or self-harm, shame, guilt, and irritability or anger. More qualitative research is needed to fill the gap in the knowledge about women's experiences of perinatal OCD. Blogs may provide unique insights into understanding experiences of illness in addition to what traditional narratives alone can yield (Producers & Gough, 2021).

Blogs

Narratives in blogs are different than narratives obtained with individual interviews under a researcher's observation. A strength of blogs is that they are unsolicited and are driven by the concerns of persons rather than researchers' concerns (Producers & Gough, 2021). Given that blogs allow communication through writing instead of speaking, researchers may gain valuable information about persons' experiences that may not be shared as candidly when persons are being interviewed face-to-face with researchers (Rodriguez, 2013). Blogs provide narratives over time where patterns in recovery from an illness can be plotted.

Examples of recent qualitative research using blogs include experiences of caregivers for persons living with dementia (Anderson et al., 2021), and orthorexia nervosa, which is an obsession with healthy or "clean eating" (Greville-Harris et al., 2020). Murphy et al. (2020) conducted a scoping review of research exploring the experiences of persons with mental health difficulties using blogs. Eleven studies met the inclusion criteria. The-

matic analysis revealed positive themes of blogging including catharsis, enhanced coping strategies, and social connectedness.

Blogs provide an alternative platform from which women can reconstruct their OCD experiences. The purpose of this qualitative research was to answer these questions: What are women's experiences of perinatal obsessive-compulsive disorder as described in blogs and what does the process of recovery, as described in blogs, look like for women with perinatal obsessive-compulsive disorder?

Definitions

Obsessions are defined as "recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and in most individuals cause marked anxiety or distress" (APA, 2013, p. 237). Persons try to ignore these thoughts and images and may try to neutralize them by performing a compulsion which can be a thought or an action.

Compulsions are defined as "repetitive behaviors or mental acts that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly." (APA, 2013, p. 237). The purpose of the acts or thoughts is to prevent distress or some feared event. These acts or thoughts are not realistic and cannot prevent the dreaded situation.

Methods

Sample and Data Collection

Blogs were identified using the Google search engine and the following key terms were used: blog, OCD, perinatal, postpartum, and pregnancy. Criteria for choosing blogs included the blog being available in public domain without registration or password, written in English, and by women describing themselves as experiencing perinatal OCD and their recovery. Blogs were not restricted by date or by bloggers' country of origin. Blogs were excluded if they were written by health care professionals or by an organization and were solely informational and did not include personal experiences of perinatal OCD. Blogs published by associations or organizations were included only if there were posts of first-person accounts of perinatal OCD.

Due to space limitations, only a couple of the most long-standing blogs are highlighted here. Taming Olivia (<https://tamingolivia.com>) is an example of an engaging and innovative blog as well as a long-standing blog started as *Delicate Change* (<https://delicatechange.blogspot.com>) and later changed to *Not Your Mama's OCD* (<https://notyourmamasocd.com/>). Also included in the sample were women's perinatal OCD narratives that were posted on different websites such as Postpartum Support International (<https://postpartum.net>).

As the narratives posted in the blogs were in the public domain, the University's Institutional Review Board (IRB) determined this project did not meet the definition of human subjects' research and a protocol did not have



Reported prevalence rates of obsessive-compulsive disorder during pregnancy and postpartum range from 2.3% to 2.6% and 2.2% to 8.3%, respectively.

to be submitted for IRB approval. When quotes are included in the results section, bloggers' identities were protected by removing all names and identifying information from the data.

Data Analysis

Krippendorff's (2019) content analysis method for qualitative data was used to analyze the blogs. Content analysis is "a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use" (Krippendorff, 2019, p. 24). Krippendorff's thematic analysis was used. The unit of analysis was considered as the segments of the bloggers' descriptions of their perinatal OCD. Each segment was placed on a file card to help in sorting them. Next clustering was done to identify data that could be grouped together

Perinatal obsessive-compulsive disorder is a hidden problem that can have adverse consequences for women, infants, and their families.

as a theme by sharing some quality. A graduate assistant in the PhD program in nursing who completed two courses in qualitative research methods reviewed the clusters of segments and confirmed their correct placement in the themes. Krippendorff suggests that creating dendrograms, which are tree like diagrams, can assist in visualizing the data as they are clustered into themes.

Results

Content analysis revealed five themes that described women's experiences of perinatal OCD as told in blogs. Some women had preexisting OCD prior to childbirth and for them perinatal OCD was not their first battle with this anxiety disorder. Women posted in their blogs from the following countries: United Kingdom, United States, Australia, and South Africa. Forty-three different posts provided more than enough qualitative data to reach saturation. Comments that other women shared in response to blog postings were included in the data set. The data set consisted of 151 double-spaced typed pages from the blogs. Five themes were identified.

Starting to Tighten its Grip during Pregnancy

Obsessive-compulsive disorder did not wait for some women until after they gave birth but instead first reared its ugly head during pregnancy. As one mother described, *OCD is a demon, and nobody deserves to be in its grasp. It robbed me of my pregnancy.* This woman revealed that she could not take photos of her bump or buy any clothes for her unborn child due to her obsessive thoughts that she would have a miscarriage or give birth to a stillborn. As their pregnancies went on, some women got to the point where their compulsive behavior led them to frequently go to the maternity unit to check and make sure their unborn infant was still alive. The vicious cycle would start again once the women returned home from the maternity unit as they timed every movement of their fetus.

Other women spent endless hours in rituals they deemed essential for the survival of their unborn baby. They cleaned everything in the house, including walls and doors, until their hands were bleeding. For a few women, this brought their relationship with their partner near the breaking point. Here is one mother explaining her struggles with OCD during her pregnancy: *Toxoplasmosis and listeria became the next tangible thing OCD could use to control me. I stopped eating, couldn't sit anywhere in my house comfortably (I have cats). I*

couldn't wear anything unless it had been washed at 60 degrees C. I had to buy new clothes frequently. I could only bring myself to eat from a plate if it had been scalded first. I couldn't sleep in my own bed without buying a new sleeping bag every few days. I didn't trust tap water so I could only have hot drinks. My hands bled and blistered from burning water and overuse of soap... Each night I went to bed dreading the morning when the horror would start all over again.

Keeping Horrific Secrets All to Themselves

Women shared that at first, they kept their dark thoughts to themselves for fear that people would think they were crazy and their babies would be taken from them. This mother explained, *In the hospital shortly after giving birth, bizarre and frightening thoughts appeared in my head accompanied by terrifying images. I drew the obvious conclusion...The best thing I could do was definitely not tell anyone about it. Secrets - keep these horrific thoughts secrets.*

Another mother admitted, *I thought if anyone knew what thoughts were running through my head, they wouldn't want to be anywhere near me and would want me locked up and take my baby away.* As the OCD worsened, this woman recalled that she started having dark thoughts that maybe she needed to be *put down* for being such a horrible person with these disgusting thoughts. When she finally got the courage to go to the doctor, at first, she told him she was only experiencing bad general anxiety. She was too scared to say what was happening in her head and reveal her secret.

Deciding to finally tell her husband, mother, and mother-in-law about her intrusive thoughts was one of the hardest things another woman ever had to do. *Letting them know about the sick thoughts I was having seemed an impossible task without them thinking I was going to harm the baby and that I was some kind of monster mom.* When explaining how she told her partner about her obsessive thoughts this woman recounted, *It was so hard that instead of speaking out loud, I showed him the stories and descriptions of the illness I found on Google and said this is what I have.*

Tortured with Terrifying Images and Thoughts

In blogs women reported a range of time after birth when their obsessions started from as soon as the infant was born to 6 months postpartum. As this mother recounted when she had her first intrusive thought of harming her infant, *I just knew something had happened that couldn't be undone. You can't unthink a thought. You can't go back to the blissful time before your mind threw up the worst thought imaginable.* In their blogs, women explained that the thoughts start as innocent thoughts but can quickly turn into obsessive thoughts and all these different scenarios come racing through your head. Table 1 includes a list of some of the obsessive thoughts and corresponding compulsions that plagued mothers. The anxiety built with each passing day until, as one mother depicted, *I was stuck in my own fearful thoughts, too*

TABLE 1. EXAMPLES OF DISTRESSING OBSESSIONS AND CORRESPONDING COMPULSIONS

Obsessions	Compulsions
Germes infecting the baby	Washing baby bottles till hands bleed Keep all windows closed Don't take children to the park
Infant stopping breathing	Set alarms at night to monitor infant breathing
Throwing the baby down the stairs	Avoid stairs if at all possible
Stabbing the baby Poisoning the baby Using a hammer to harm the baby	Move harmful cleaners, knives, tools to the garage
Throwing boiling hot water over the baby	Stay away from kitchen while holding baby
Drowning the baby	Stop bathing the baby or have someone else bathe the baby
Touching the infant inappropriately	Change diapers as quickly as possible
Molesting an older child	Do not let older children sleep in bed with mother
Becoming a pedophile	Checking internet for stories of mothers who molest their children

afraid to even walk into certain rooms in my home, like the kitchen. In that room was the unrealistic thought of what could happen if my newborn was too close to the microwave.

Women knew their intrusive thoughts of harming their infants or of something horrible happening to the infants were not rational or real, but they could not stop them from replaying over and over in their mind. One woman described her intrusive thoughts as a *terrifying unwanted stranger invading her mind*. Some mothers shared that they were *tortured with these images, urges, and thoughts 24 hours a day*. As this mother explained, *these thoughts can be like a 3D movie reel, filling your imagination with a visual play-by-play of what these horrible incidents could look like, feel like, or sound like. Calling these thoughts "scary" is an understatement*.

An inside peek at one mother's obsessive thoughts focused on her living room, which had a large wooden entertainment center with glass doors on either side. Whenever the mother passed the entertainment center, a motion picture would play. She would see herself holding the infant trying to calm him down. He would be screaming and turning red. Nothing she tried would quiet him. She would throw him as hard she could through the door, glass shattering, and silence followed.

No matter where some women went in their house, the movie vividly played. It could, for example, be in the bathroom where the mother would be on her knees leaning over a full tub of water running over the edge and bubbles rising to the surface. In sudden terror, the mother visualized drowning her baby. As another woman recalled, *It is a special kind of hell to not be able to stop racing thoughts that completely contradict who you fundamentally believe yourself to be*. To try and control their obsessions, women turned to compulsions and so the destructive and constant cycle continued as OCD tightened its grip (Table 1).

Driven to Compulsive Behaviors to Protect Their Infants

For some women they were absolutely convinced that something terrible was going to happen to their infants. Their infants would be harmed by someone either accidentally or deliberately. Their compulsions centered on going to great lengths to keep their infants safe. The constant fear and their resulting compulsions were exhausting and debilitating.

One mother recalled that any household objects she deemed too toxic to be inside the house were moved to the garage. Some women set alarms throughout the night so they could wake up and check that their infants were still breathing. Other women never opened the windows in their homes for fear of allowing germs in that could make their infants ill. Some mothers were terrified if any germs were left on the bottles to make their infants ill. They would stand at the kitchen sink washing their bottles until their hands would bleed. Another mother with older children stopped taking them to the park to play for fear of them stepping on dog feces and bringing the germs home. Stopping giving their infants baths out of fear they would drown them was another compulsion mothers described. A mother with twins obsessed that she would love one twin more than the other and that would be harmful to their emotional development. As she explained, to neutralize this intrusive obsession, she made herself *crazy* by ensuring that everything she did for one of the twins was exactly the same as she did for the other twin.

Other compulsions included obsessively checking the internet for stories about mothers who hurt their children to check for comparisons with their own life to make sure they were not somehow similar and at risk of doing the same horrific thing to their children. Other mothers were plagued by mental images of throwing their infants down the stairs so they avoided the stairs as much as they could. If they needed to go downstairs with their infants, they would tightly squeeze them, fearing if they did not, the

Screening for perinatal obsessive-compulsive disorder is an important first step to identifying women who may need mental health referral.

horrible image in their brain would possess their body and the mothers would be incapable of stopping themselves.

Compulsions to interrupt the obsessive thoughts of inappropriately touching their infants or older children were also described. When changing diapers or strapping the infants into car seats, *I always did these things very quickly, almost paralyzed with fear.* Another mother shared that she never let her older son sleep in her bed for fear of molesting him. *Unfortunately, because of these horrid thoughts, I distanced myself from my kids. I was scared that these unthinkable thoughts were going to become a reality and I could actually harm my children.*

Long Difficult Road to Recovery but So Worth It

Writings in the blogs confirmed that recovery is a slow, difficult process but so worth it to be able to finally experience the joys of motherhood. To begin this healing process, women needed to first let go of their secrets and come forward with what they were experiencing. This mother shared what happened the day everything came out into the open. *All my demons had come out into the open and had nowhere to hide so I was able to start to heal... Once I opened up, I was able to tap into the incredible family and friends who wrapped their arms around me until I was able to be alone with my baby again.*

Some women were fortunate to be referred to perinatal mental health professionals to finally receive a diagnosis and put a name to the demon they were struggling with. As this mother stated, *I found an awesome therapist and was diagnosed with severe OCD. I cried for 3 days after being diagnosed. It was such a relief to know this terrible thing had a name and could be healed.* Other women were not so fortunate as this mother recalled, *None of the medical professionals I met within my first year of motherhood identified my symptoms as OCD. I was assessed for postpartum depression and psychosis, but postpartum OCD was never mentioned.*

After searching the internet and finding the blogs where women shared their experiences of OCD, some women diagnosed themselves. Thanks to social media, one woman was introduced to the online OCD community which she described as a community made up of so many of the strongest, kindest, and most passionate people you could meet. Women shared that reading the blogs was so helpful for them to know they were not alone, that other mothers experienced what they did, and that recovery was possible. As this woman recalled, *checking out groups, pages,*

and profiles of people who had perinatal OCD and had similar stories to my own was life changing.

There is no magic cure for OCD, but in the blogs, women shared that cognitive behavioral therapy, Exposure and Response Prevention Therapy, and medication were highly effective treatment options. As this mother depicted, *Now almost 10 months later I am almost recovered. I went through the grizzly and exhausting gold standard of treatment for OCD, this being Exposure and Response Therapy and I am enjoying my time with my daughter.*

During recovery, women shared that being more compassionate with yourself is a must. As this woman explained, *the crucial point for me was when I stopped punishing myself for having this disorder and started being kinder to myself.* Mindfulness and yoga were also helpful for mothers to switch their minds off from the overcrowding of tortuous thoughts and to allow themselves to focus on themselves.

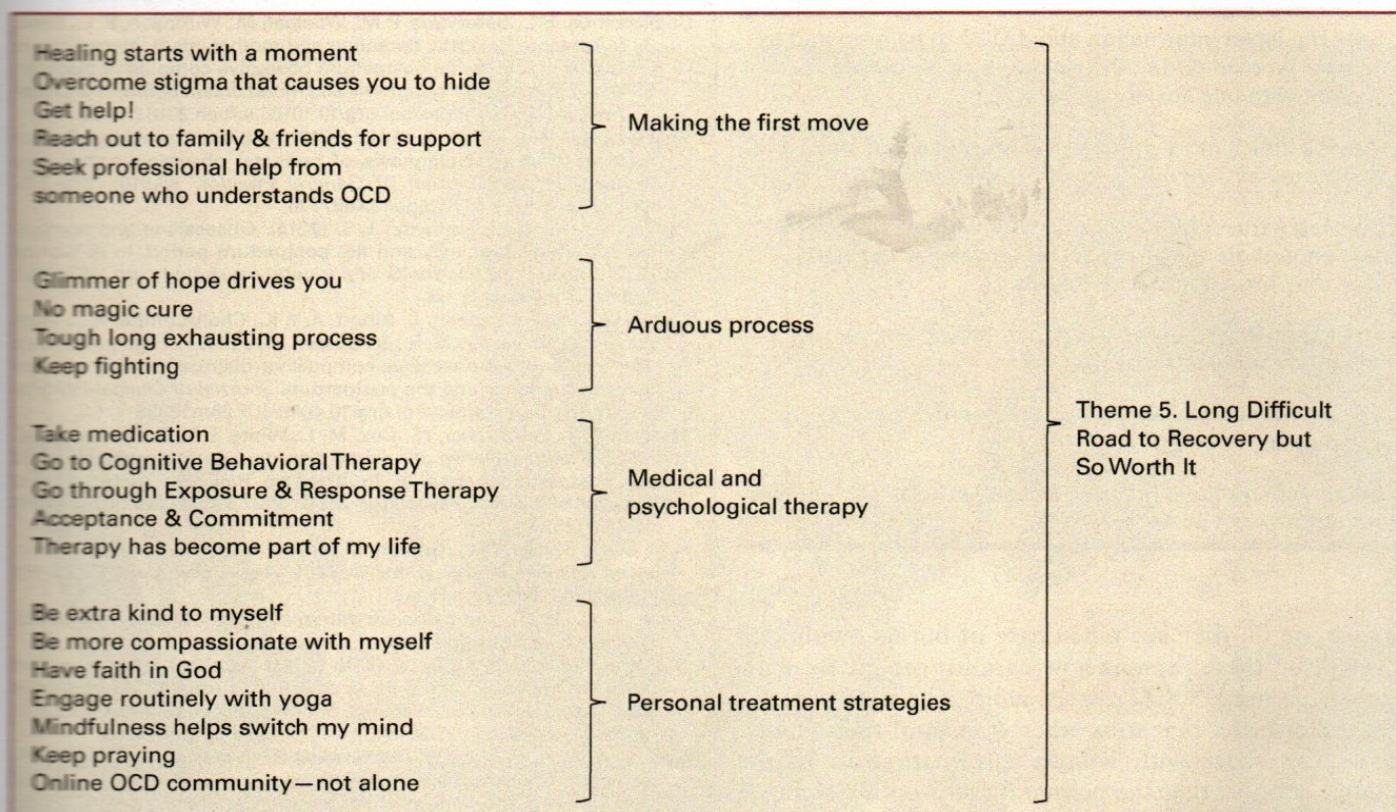
In therapy, women learned that OCD targets what is most dear in your life and that was their infants. When you have OCD and suffer with intrusive thoughts, it is your brain conjuring up the most awful thing it can and proceeds to torture you with it. Women learned that they may not choose or control their thoughts, but they can choose their responses. As this mother recalled, *I was able to fight my thoughts. Rather than backing down and running away from them, I stand with them and challenged them. Go on then. I would laugh out loud and knew I was never going to hurt my children.* As part of their healing process, women wanted to give back once their OCD loosened its grip and to share their stories to help others who were facing the same obstacles that prevented the joys of new motherhood. Figure 1 is a partial dendrogram for the theme *Long Difficult Road to Recovery But So Worth It*.

Clinical Implications

Content analysis of women's perinatal blogs confirmed the findings of Garcia et al.'s (2021) qualitative study of the most commonly reported obsessions of baby safety and cleanliness and compulsions of baby safety and seeking information on the internet. What was new that this blog analysis reported was a focus on the long difficult process of recovery for the women. Nurses need to provide continual encouragement for mothers who are on this slow road to recovery. Nurses can help women see the improvement they have made, even if it is in small steps. For example, nurses can assist women to see how they have decreased the number of times they wash their hands every hour. Mothers need to be patient and not expect too much progress too soon. Part of encouragement is to tell mothers that self-care during the postpartum period is a priority and should not be viewed as being a luxury.

Nurses can have a primary role in early detection but first they need continuing education about this perinatal anxiety disorder that may not be known or understood by most health care providers. OCD signs and symptoms,

FIGURE 1. PARTIAL DENDROGRAM FOR THEME 5. LONG DIFFICULT ROAD TO RECOVERY BUT SO WORTH IT



risk factors, prevalence, treatment, and implications for mother–infant bonding all should be part of continuing education provided by health care facilities. First-line treatments for perinatal OCD are Exposure and Response Prevention Therapy, a psychological treatment, and selective serotonin reuptake inhibitors (Brakoulias et al., 2020).

New mothers are screened routinely for postpartum depression in more and more health care facilities but screening for OCD does not occur. Screening women once during pregnancy and again during postpartum may improve detection and allow for referral and treatment. Nurses and other health care providers who care for women during the perinatal period may consider using the POCS (Lord et al., 2011) to screen mothers for elevated symptoms. Researchers have confirmed the comorbidity of OCD and postpartum depression (Fairbrother & Abramowitz, 2016). If a woman screens positive for one of these perinatal disorders, nurses should inquire if that mother is experiencing any of the other disorder's symptoms. If a referral is needed, it is helpful if nurses can share a list of mental health practitioners in the local area who specialize in treating perinatal mood and anxiety disorders.

As perinatal OCD has not received the attention that postpartum depression has, nurses can help to educate women as they provide some anticipatory guidance regarding the signs and symptoms of OCD that may occur during pregnancy and/or the postpartum period. It is important for nurses to normalize some of what new mothers may be experiencing. Nurses can let women

know that it is common for new mothers to experience some unwanted thoughts and can refer them to Kleiman's (2019) book *Good Moms have Scary Thoughts: A Healing Guide to the Secret Fears of New Mothers*. If women are experiencing OCD symptoms, nurses need to focus attention to the mother–infant relationships. Nurses can also share with their patients some of the hints and strategies women wrote about in their blogs that were helpful to their OCD recovery such as relaxation techniques, yoga, exercise, and mindfulness.

Limitations

Some limitations of this blog review should be noted. Only blogs in English and those that did not require a password were included. Some of the posts in the blogs lacked sociodemographic information so not enough information was provided to describe the demographic characteristics of the sample. The sample consisted of women who used the internet regularly, specifically those who write or read blogs, limiting transferability of findings from this analysis.

Conclusion

Reading first-person accounts of patients' experiences with specific physical or mental disorders can provide nurses with a wealth of insiders' knowledge, allowing them to walk a mile in the shoes of their patients. One of the most powerful ways that persons can express their experiences of suffering is through writing narratives (Hydén, 1997). Frank (1995) explained that when

CLINICAL IMPLICATIONS

- Seek the latest information about OCD to be prepared to care for women during the childbirth continuum who present with this anxiety disorder.
- Provide anticipatory guidance to women about signs and symptoms of OCD during the perinatal period.
- Develop a trusting relationship with women so they feel safe enough to reveal any secret, obsessive thoughts they may have about their infants.
- Provide encouragement to women during their slow, difficult process of recovery.
- Screen women during the perinatal period for OCD symptoms.
- Share with mothers the support the perinatal OCD online community can provide.

persons are ill, they are taken care of but as “wounded storytellers” these persons now care for others. By sharing their perinatal OCD stories, women become witnesses to the disorder that robs other women of their voices. Nurses can share with women information about the valuable support that the perinatal OCD online community can provide.

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