The lived experience of postpartum depression and psychosis in women: a bottom-up review co-written by experts by experience and academics

Paolo Fusar-Poli[1-4], Andrés Estradé[2], Keshnie Mathi[5,6], Constance Mabia[5-7], Nur Yanayirah[5-8], Valentina Floris[1], Elisa Figazzolo[1], Cecilia M. Esposito[9], Milena Mancini[10], René Rosfort[11], Ana Catalan[2,12], Helen Baldwin[13], Rashmi Patel[14], Giovanni Stanghellini[15,16], Matthew Ratcliffe[17], Mario Maj[18]

[1]Department of Brain and Behavioral Sciences, University of Pavia, Pavia, Italy; [2]Early Psychosis: Interventions and Clinical-detection (EPIC) Lab, Department of Psychosis Studies, King's College London, London, UK; [3]OASIS Service, South London and Maudsley NHS Foundation Trust, London, UK; [4]Department of Psychiatry and Psychotherapy, University Hospital, Ludwig-Maximilian-University, Munich, Germany; [5]Global Mental Health Peer Network, Cape Town, South Africa; [6]The Wellness Specialist, Gauteng, South Africa; [7]Generation Mental Health, Nakuru, Kenya; [8]MotherHope Indonesia, Bekasi, Indonesia; [9]Department of Neurosciences and Mental Health, IRCCS Fondazione Ca' Granda Ospedale Maggiore Policlinico, Milan, Italy; [10]Department of Psychological Sciences, Health and Territory, G. D'Annunzio University of Chieti and Pescara, Chieti, Italy; [11]S. Kierkegaard Research Centre, University of Copenhagen, Copenhagen, Denmark; [12]Psychiatry Department, Basurto University Hospital, Biocruces Bizkaia Health Research Institute, OSI Bilbao-Basurto, Centro de Investigación Biomédica en Red de Salud Mental (CIBERSAM) Barakaldo, Bizkaia, Spain; [13]ESRC Centre for Society and Mental Health, Department of Health Service and Population Research, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK; [14]Department of Psychiatry, University of Cambridge, Cambridge, UK; [15]Department of Health Sciences, University of Florence, Florence, Italy; [16]D. Portales University, Santiago, Chile; [17]Department of Philosophy, University of York, York, UK; [18]Department of Psychiatry, University of Campania "L. Vanvitelli", Naples, Italy

This is the first bottom-up review of the lived experience of postpartum depression and psychosis in women. The study has been co-designed, co-conducted and co-written by experts by experience and academics, drawing on first-person accounts within and outside the medical field. The material initially identified was shared with all participants in a cloud-based system, discussed across the research team, and enriched by phenomenological insights. The subjective world of postpartum depression is characterized by a sudden onset ("being hit with a ton of bricks"), unbearable loneliness and sadness that are often suffered in silence, inability to feel positive emotions, grieving over the loss of self, feelings of being bad mothers (haunted by a suffocating burden of guilt due to that), inability to concentrate, lack of control of thoughts ("feeling like a tightrope walker without control over thoughts and emotions"), insecurity (up to needing to be nurtured and mothered themselves), and thoughts of death ("contemplating death as a glimmer of hope to escape the living nightmare"). In addition to these themes, the subjective world of postpartum psychosis is characterized by difficulty in articulating thoughts ("feeling the brain in a centrifuge"); perceptual abnormalities and unusual beliefs disrupting the sense of personal unity (with, in a few cases, thoughts of harming themselves or their baby, so that women may feel that they are "sinking in the depths of hell"); losing trust ("ploughing through the fog and losing trust and safety"), and stripping down relationships. Much of the isolation, guilt and disorientation experienced in these conditions relates to sociocultural and family environments, especially a gulf between how women feel and a web of norms and expectations surrounding motherhood. In most cases, stigma is related to a lack of knowledge of what postpartum depression or psychosis are. Stigma and lack of knowledge are core drivers impacting health care in terms of seeking professional help, accessing mental health services, and receiving pharmacological or psychological treatments. The narratives described in this paper should inform clinical practice, research and public health education. This study brings voice to the unspoken and unheard, and fosters relational connections within which different mothering experiences may be expressed and understood. This is vital to challenging negative sociocultural attitudes towards postpartum depression and psychosis, and providing the most supportive care to women experiencing such pervasive psychiatric disorders at a critical, fragile time in their lives.

Key words: Postpartum depression, postpartum psychosis, lived experience, first-person accounts, mood disorders, psychotic disorders, mental health care, recovery

Perinatal (i.e., occurring during the pregnancy or in the first twelve postnatal months) mental disorders represent a significant clinical and public health concern[1], being associated with substantial personal burden, impact on bonding with the baby; later physical, cognitive, emotional, behavioral and social developmental outcomes in the offspring; complex treatment challenges, high economic costs, and – in the most severe cases – increased risk of maternal suicide[2-4] and of the very rare outcome of infanticide[5].

Alterations of mental health in the perinatal period range from mild and self-limiting depressive features (i.e., “baby or maternity blues”), that are highly frequent (up to 40-50%)[6] but represent physiological adaptations, to clinically significant and impairing depressive or psychotic disorders.

Globally, about one in four women experience perinatal depression. The prevalence is higher in low- and middle-income countries[7], in women who experienced intimate partner violence, and in those with a previous history of mental disorders[8].

Perinatal psychosis is considered a rare disease[9], with only about two in a thousand women affected globally. The prevalence is higher in women with a previous history of mood disorders[10]. Notably, psychotic symptoms may present as extreme features in postpartum depression, and these episodes may be the initial presentation of a psychotic bipolar disorder[11,12].

As the risk of developing these disorders peaks in the first few weeks after delivery[13] (e.g., the relative risk for the first onset of affective psychosis is 23 times higher during postpartum than at any other period[9]), they are also termed “postpartum” depression and psychosis. Because of the risk and high impact on the mother-baby dyad (postpartum psychosis is considered a psychiatric emergency[1]), screening women for these conditions and preventive interventions are clinically recommended[14-16].

Yet, postpartum depression and psychosis remain poorly managed globally. This is partly due to the poor understanding of the qualitative nature of these experiences, as they are typically siloed in academic investigations lacking first-person perspectives or, on the other hand, in autobiographical accounts lacking in-depth analyses.

To the best of our knowledge, this is the first bottom-up review of the lived experience of postpartum depression and psychosis. Experts by experience co-designed, co-conducted and co-wrote the study, leveraging an established methodological template developed by our group to investigate the lived experience of psychosis, depression, and mental disorders in adolescents[17-19].

Experts by experience of different ages and ethnicities, from multiple continents (Europe, Asia and Africa), were invited to participate through the Global Mental Health Peer Network (https://www.gmhpn.org). The Web of Science, PubMed and EBSCO were searched from inception until February 2024, using the terms (postpartum* psychosis OR postpartum*

depression) AND (qualitative OR etnograph* OR phenomenol* OR "lived experience").

We included qualitative studies providing first-person accounts that involved women with a diagnosis of postpartum depressive or psychotic disorder (postpartum psychosis generally refers to a manic, mixed or major depressive episode with psychotic features, a brief psychotic disorder, or a psychotic disorder not otherwise specified[20]), as operationalized by each individual paper. Notably, the nosological status of these disorders remains contentious, partly because of the "mercurial nature"[21] of their symptoms, which vary widely and have rapid fluctuations. While the ICD-11 includes a distinct diagnostic category, the DSM-5 recognizes them as specifiers of depression or psychosis. We did not include baby or maternity blues, and mental disorders occurring in men transitioning to fatherhood (e.g., postpartum depression in fathers)[22].

Researchers produced a thematic synthesis of selected papers and generated a preliminary list of descriptive themes and sub-themes. Further sources external to the medical domain, including autobiographical books (see Table 1), websites, blogs, and social media material written by experts by experience were also considered within the synthesis.

We stratified the material across four overarching descriptive sections (each including themes and sub-themes): "The subjective experience of postpartum depression", "The subjective experience of postpartum psychosis", "The lived experience of women with postpartum depression or psychosis in the wider society", and "The lived experience of women with postpartum depression or psychosis in receiving mental health care".

Experts by experience and academics collectively interacted to draft and review the manuscript via a shared Google Drive platform, and enriched it with phenomenologically informed perspectives[30-46]. All experts by experience actively participating in the manuscript elaboration were offered reimbursement for their time, adhering to available guidelines[47], and were invited to be co-authors. As in previous papers of this series[17-19], first-hand quotes are cited and reproduced verbatim in italics. Commentaries from co-author experts by experience are anonymized as "personal communications".

While this study outlines the most paradigmatic ways by which postpartum depression and psychosis manifest, we neither assume that the reported experiences are exhaustive nor that they are systematically applicable to all women. On the contrary, we acknowledge the fluctuating presentation and kaleidoscopic variability[12] of the lived experiences reported.

THE SUBJECTIVE EXPERIENCE OF POSTPARTUM DEPRESSION

In this section, we describe the subjective experience of postpartum depression across several characteristic themes.

Being hit with a ton of bricks

Many women feel that postpartum depression emerges suddenly out of the blue, and hits their lives with unprecedented violence: *"It hit me like a ton of bricks. I never would have imagined that could have all happened so suddenly"*[30]. As most of them never experienced a severe mental health problem, they typically have no idea of what is happening and cannot understand what they are going through: *"You are normal and then the next thing, you know, you're crazy"*[30]. This experience is particularly shocking in those women who tend to be neat and precise in their management of interpersonal relations and life events[31,32]: *"I've planned everything in my life, I've been used to doing it this way forever"*[33].

Women often try to describe the sudden and profound change in their mental status by referring to darkness (*"I was in the total dark the whole time"*[30]) or suddenly being in a cold place (*"My living nightmare put me in a very cold place"*[30]). Images of water, waves and the sea – like they are drowning and no one is rescuing them, leaving them in the depths of a dark and cold ocean – are sometime used: *"I felt like I was in the middle of the sea and no one was able to understand"*[30].

Being enveloped in unbearable loneliness and sadness that are suffered in silence

Most women with postpartum depression report an unbearable loneliness: *"It is just a very lonely illness"*[30]; *"The emptiness, the endless loneliness"*[27]; *"One thing you're not prepared for is the feeling of loneliness"*[34]. This experience may relate to both the depressive symptoms themselves and the associated personal or social situation. It typically peaks during the night: *"I felt totally alone. If the whole world were in my front room, I would still have felt this terrible isolation. The loneliness was even more evident at night"*[26].

Common feelings are an immense sadness (*"I couldn't stop crying, and I was just feeling this overwhelming sadness"*[35]), which is different from previous transient experiences of low mood (*"This was a sadness of a shockingly different magnitude. It felt as if it would never go away"*[29]), and a profound despair (*"I would get up in the morning and… this awful feeling of loneliness and sadness and doom and gloom would come over me. I would just get worse as the day went on"*[36]).

Central to these women's experience is a sense that their negative feelings are unspeakable[36,37]. No words can explain the contrast between their feelings and the new motherhood: *"Where do you find the words to explain that you can hold a new life in your arms and still feel no hope for the future?"*[27]. Most women suffer in silence, because they feel that no one can understand: *"I didn't have anyone to talk to and no one actually knew about me*

being diagnosed with postnatal depression, my mum or anyone, no one knew, not even my partner"[38]. Consequently, a common experience is the mismatch between their inner suffering and their apparent smiling façade: *"My smile is like a two-way mirror. I can see out, but no one can see in. No one sees what is going on behind the smile"*[27].

Those who have migrated away from their families, friends and communities into a new foreign country, where they have no established social network, may be particularly vulnerable to loneliness and silent suffering following the birth of their child: *"Have got nobody to help"*[39]; *"No one was nearby to assist. I had no one to turn to. I think I had no security, no sense of safety"*[40]. However, feelings of loneliness are commonly reported by women with available social and emotional support, as they feel that their experiences are intrinsically uncommunicable, or that most of their attempts to share their suffering with their family members remain unsuccessful[41]. This profound loneliness may amplify feelings of disconnection regarding the self, the baby, and the social and material world (see below).

Feeling like mechanical robots stripped of all positive feelings

Women with postpartum depression typically report being unable to feel positive emotions: *"I cannot see anything that makes me happy. People talk about how happy I am to be a mother, but I do not feel anything"*[42]; "*I always pictured being happier with the baby, and now I don't really feel anything"*[43].

They also describe a lack of enjoyment in their usual interests or hobbies, which become unimportant to them: *"Having zero enjoyment for life, as it was dark, it was a dark space… Nothing made me smile, and nothing made me happy, nothing made me enjoy anything"*[44]. They feel that nothing makes sense anymore, not even the little things that usually made them happy: *"It is like you are sitting in a dark bubble"* (*personal communication*). For example, they may no longer desire to have sexual relationships with their partners, or feel angry towards them: *"I wanted nothing to do with sex. I just wanted him to leave me alone and not touch me"*[41]; *"No intimacy. We did not have any sexual relations"*[45].

In some cases, women with postpartum depression feel neither positive nor negative emotions. This experience is described as the "feeling of not feeling"[46], a profound and pervasive sense of the absence of feelings that should be there. The lack of any emotion can be extreme to the point that they may feel psychologically dead: *"Please, someone come in and confirm I'm still alive"*[24].

This is particularly distressing because women experience a profound disconnect to the emotions regarded as "normal", such as feeling joy or love when cuddling, feeding or bathing their newborn baby. They may feel like mechanical robots stripped of any emotional feelings as they are caring for their newborn: *"It was like a withdrawal of emotions. I didn't feel real... I*

went through the motions of my life without any of the joy"[41].

These experiences are associated with a profound desire to escape from their body and a sense of discomfort with how their body has changed: *"I want to escape my body. I don't recognize it anymore. I have lost any resemblance to my former self"*[27], which is frequently amplified by feelings of disconnection and depersonalization, and a profound sense of loss of self (see below). Women may feel deprived of their previous emotional repertoire in relation to the new focus and demands posed by the baby, as well as all the changes in their body, and may have the impression of only being a *"walking womb"* or a *"baby carrier"*[48].

However, it is important to note that other women still experience intense love for their baby, although this may involve a deeply felt mix of responsibility, inadequacy, vulnerability, isolation and guilt.

Grieving over the loss of self

Although the birth of a child always evokes an identity shift, this process is much exaggerated in women with postpartum depression: *"Why was I now a shadow of my former self?"*[23]. They lose their sense of self and feel like strangers or aliens: *"I wasn't myself anymore. I became a stranger, an alien. I lost myself"*[30].

Women may feel that they are not the same person they were before the depression hit (*"I know me, I know the 'me' in me. So I have never been like that since I had my baby"*[49]), and they are scared that they cannot offer their true self to their baby: *"It's very scary. You are afraid you are not the same person. You are afraid your child isn't going to have you for a mother"*[30].

They feel that they will never recover their old selves (something that is also often reported in the context of bereavement[39]), and grieve for this loss: *"There's this photo of me shrinking back with dead eyes, looking around not talking to people. Totally, this was not like me. Where was I?"*[30]; *"I did go through a period of feeling like I was mourning the loss of my old life"*[50]. They are frequently frightened that their lives will never be normal again and that happiness is gone forever: *"My big fear was that I wasn't going to get better… that I never would quite get over it"*[41].

At the same time, there appears to be no prospect of consolidating a new identity either (you can't be who you were and you can't be someone new)[51]: *"I feel incapable, I wish I could go back and reset everything. I wish this child had never been born, it would have been better for everyone"*[33]. The loss of self is exacerbated by a sense of grief surrounding their uncooperative or defiant body (e.g., because they are unable to breastfeed or to wake up to the baby's cries, or unable to stand for long periods with the baby), which is felt as not doing enough to take care of the baby's development: *"I felt like my body just wasn't doing what it*

was meant to be doing"[35].

These experiences may ultimately lead to pervasive feelings of depersonalization, like being unreal or in a dream (*"not with it"*[52] or *"out of the self"*[52]), and of detachment from their own life: *"As being in a daze, feeling distant, seeming as if a cloud descended on me, everything looking cloudy and distorted"*[53]. Women frame their experience as feeling alien to their core, internal or authentic selves, as if *"a large part of it doesn't feel real. It's like the baby's here and I'm taking care of him, but it's like I'm numb"*[43].

Haunted by a suffocating burden of guilt for being bad mothers

Women with postpartum depression frequently experience a suffocating burden of guilt over being unable to give their babies the love or care needed, because of the overpowering sadness and despair: *"I'm overwhelmed with guilt"*[24]; *"I feel the guilt of not being able to feel love for my daughter"*[33]; *"I feel only one guilt. I can't feel love for him. I am an asshole. I feel nothing for this child"*[33]; *"To give birth to a child and not be able to take care of it, what kind of person am I then*?"[45]; *"What's wrong with me? Am I going crazy? Why can't I enjoy being with my baby? Will I ever be normal again?"*[41].

These thoughts typically stem from the gap between their expectation of being mothers (i.e., internalized images of "the perfect mother") and the reality of motherhood with depression: *"I thought… I wanted this baby; I'm going to be so happy; everything is going to be perfect. I'll be baking cookies and making soups, and the baby will be sleeping, and I'll nurse him… I had this image that everything would be perfect. When it wasn't, I was shocked"*[36].

A woman with postpartum depression may feel like she *"has no maternal instinct"* and *"can't even take care of herself, let alone a baby"*[27]. For example, she feels unable to bond with her baby ("*Why couldn't I bond with my baby?"*[26]) or feels *"desperate to breastfeed"*[54] her baby to comply with her moral expectations: *"I felt as if I had some moral obligation as a mother and if I didn't breastfeed him I was badly letting him down"*[54]. The inability to breastfeed the baby becomes an inconsolable source of guilt[55]: *"I cried inconsolably many times because of the pressure of breastfeeding"*[42]; *"I am consumed with sadness at the idea of having to forgo breastfeeding. Society places such a high premium on it"*[28].

Similarly, women may feel incapable of comforting their newborn (*"When my son was crying, I wanted to leave him alone in the room, lock the door and walk away"*[56]), because they already struggle to survive (*"I found I had nothing left to give to the ones who needed me the most. I had to stop and save myself"*[27]). These experiences are sometimes associated with fears of psychologically harming their infants (*"I knew I couldn't take care of him, but… I didn't want him to suffer. The guilt made it even worse and the fact I couldn't love him normally made*

it even worse"[41]), and the conviction that they could cause depressive features in the baby (*"I think the baby also felt the sadness because you don't pay attention at the time the child needs it"*[57]).

As the notion that mothers "should" be able to take care of children transcends cultures[36], women are reluctant to admit that they are *"drowning in [their] own mind in the happiest time ever"*[58] and that they cannot reach the "relaxing and happy" moral standards of mothering[56]. Because of this dichotomy between expectations and reality[59], they are unlikely to admit these experiences and ask for help, and instead mask their difficulties to maintain their role: *"I gave the impression that things were really great and I was so happy and everything was going fine. And that's what they saw when they came to see us, a lovely baby and a nice house"*[60]. This inevitably places further pressure on themselves and amplifies the contradiction with their poor image, fostering further stress, sadness, guilt, poor self-esteem and self-worth: *"I wasn't worth anything, just like garbage"*[30].

In fact, women frequently experience heartrending feelings of being horrible mothers and failures: *"I was too terrified to hold my baby and I cried even more than he did"* (*personal communication*). These feelings are experienced as physically exhausting (*"The language of postnatal depression was corporeal… a failing of my body"*[25]). They may long for some rest during the night, but sleep is frequently disrupted (*"A very restless night again"*[23]) and their minds keep racing[41] (*"I would lie awake at night having a lot of obsessive thinking"*[41]).

Shrouded in fogginess and unable to concentrate

Women with postpartum depression typically describe intense ruminations and an associated inability to concentrate and think clearly, referred to as *"the fogginess and fatigue [that] would set in"*[41]. They feel that their mind is filled with cobwebs, uncontrollable thoughts and emotions that decrease their concentration: *"I felt like I had cobwebs in my brain. I wished I could put a broom in there and brush away the cobwebs"*[30].

Feeling disorganized and unable to make decisions is also commonly reported: *"I felt like there was just confusion in my head… I was overwhelmed by the simplest thing so easily"*[50]. This severely limits their ability to perform ordinary activities: "*It was difficult to manage daily tasks"*[50]; *"If I went grocery shopping… I would do it, but it would take me four hours to unload the bags and put them away. It was as if I just wasn't efficient at anything. Everything was a big, big deal to do"*[41].

Being a tightrope walker without control over thoughts and emotions

Some women report feeling like a tightrope walker with no safety net below: *"Each day*

when I was deep into my depression, I felt like I was walking a tightrope trying not to fall off and lose my mind"[30]. This feeling of being on edge may resemble *"a see-saw balancing act"*[61]. The experience is related to a loss of control over ruminative and intrusive thoughts and negative emotions (*"I could not control my emotion and behavior"*[62]), which may emerge suddenly (*"Sometimes this losing control just suddenly comes over you no matter what. You never know when it's going to come"*[30]).

Women may feel trapped (*"I had no control and that was a scary thing. I felt trapped. I felt like there was absolutely no way out of this hell. These horrible feelings weren't going to leave no matter how hard I tried"*[41]), and these experiences may amplify their feelings of guilt (*"You are a bad person because you've got something you can't control"*[30]) or of being defective (*"You think you're defective. Something is terribly wrong with me"*[59]).

Sadness may be periodically shattered by uncontrollable and unexpected panic attacks, during which women may feel like they are losing their minds, along with bodily experiences such as tingling hands, difficulty in breathing, digestive problems, sweating, palpitations, and chest pain. These experiences can be so intense that they feel on the edge of dying: *"It's terrible. It's like the worst thing you can imagine. Think of how you would feel if your husband or child had been hit by a car and killed"*[41].

Being besieged with insecurity and needing to be nurtured and mothered themselves

Because of the experiences described above, women typically perceive intense feelings of insecurity, fragility, vulnerability, helplessness and dependency, and of no longer being able to relate to the social world: *"I felt totally insecure. I'm a basket case. I felt like I needed all the help I could get"*[30]. The responsibility of motherhood is overwhelming: *"The responsibility seemed absolutely enormous"*[41]. As they feel unable to control their thoughts and feelings or restore their previous self, they cannot rely on themselves to care for another tiny and helpless human being: *"Don't wake up. Don't wake up. I can't cope with you on my own"*[28].

At times, women with postpartum depression may themselves seem to revert to an earlier stage of development, to a place in time where they felt safe and could depend on a caretaker[52]: *"I just wanted to be looked after"*[63]. They may need to be nurtured themselves, frequently by their own mother (*"I was like an infant. I had to be with my mother all the time"*[41]). These experiences may cause profound feelings of devaluation, amplifying an inner sense of failure and intensifying the perception of a corroded sense of autonomy: *"I was like a baby because I had to be taken care of and couldn't be left alone"*[41].

As women become very dependent on others, they may identify with their baby, to the point that he/she becomes an extension of themselves and they have difficulty in separating their emotions from the baby's perceived ones: *"I feel that my feelings are directly related to*

him because if he has a good day, then I have a better day"[64].

Contemplating death as a glimmer of hope to escape the living nightmare

The profound and disruptive experiences of postpartum depression described above amount to a *"living nightmare"*[41]. A subset of women may experience thoughts of ending their lives and leaving this nightmare, as if death is the only escape: *"I've never been that low where I just thought death was the way to go"*[30]; *"It was terrifying. I felt there was absolutely no way out of it. I was very suicidal. I loved my baby, but I thought if this was the quality of life that I was going to have, there was no way. No way anybody can endure the kind of pain I was going through"*[41]; *"I think that the worst part of my entire depression was that it locked me [in]. I wanted to crawl into a hole and die"*[30].

For a few of these women with postpartum depression, a further dreadful feeling is an extreme and unspeakable irritability (*"It's like a rage, it's all-consuming, like a fury, like a volcano"*[65]), associated with thoughts, frequently of obsessive nature, of harming their baby (*"After a while, my sadness became aggression"*[45]; *"I could have strangled him at times"*[65]). Thoughts of infanticide can accompany suicidal thoughts: *"I had been tempted to jump out of the window, taking the baby with me"*[62]. This may be related to feelings of a distorted and abnormal sense of responsibility toward the baby: *"I felt that it wasn't fair on [the baby] to have a terrible mother, but it also wasn't fair on him not to have a mother. And so, to take him with me was the only option"*[65]; *"I believed that he was my responsibility and he would be disadvantaged by not having a mother, so it was better to take him with me"*[65].

Mothers typically feel horrified that they could harbor such feelings (*"It is shocking really, wishing he was dead"*[66]), and are physically and mentally consumed with guilt (*"I felt such tremendous guilt that I just wanted to hurt myself"*[41]). However, most of them do not tell any health professional about their thoughts of infanticide, because they are concerned that their baby would be taken away: *"You don't come straight out with it to your GP or your psychiatrist"*[65].

THE SUBJECTIVE EXPERIENCE OF POSTPARTUM PSYCHOSIS

Because of the substantial clinical overlap between postpartum depression and psychosis, most of the experiences described in the previous section also apply to postpartum psychosis. The current section focuses on additional aspects of the lived experience of this latter condition.

Feeling the brain in a centrifuge

Many women with postpartum psychosis experience a sudden and severe escalation in their mood state, and a rapid fluctuation of mental states[11], typically shifting from depressive to euphoric feelings (*"It was a nice experience… and immediately rang my husband to tell him!"*[21]), with racing thoughts and flying ideas that are difficult to control, and profound disorientation (*"For ten days I was filled with sorrow. Then suddenly, as if someone had thrown a switch, I was wildly agitated, full of ideas, all of them pressing to be written down"*[21]; *"Without any warning sign, suddenly, my thoughts were unstoppable and flew around. My brain was in a centrifuge"*[66]).

Racing thoughts are typically associated with hyper-talkativeness and hyperactivity (*"I was speaking really, really fast and just trying to do everything, clean the house and just do everything at once and be super mum"*[67]) and grandiose feelings (*"I feel connected with all people in the world via invisible wires. I became God"*[66]). The surroundings may appear uncanny and bear obscure meanings (*"I can move and talk, but the environment feels strange. Something I have never felt before, an almighty feeling"*[66]).

Some women may attempt to write notes to themselves to keep track of their racing thoughts: *"I felt if it wasn't all written down, I would forget it, as my mind was switching from one subject to another every minute"*[21]. Several women report that the manic shifts were preceded by lack of sleep (*"I was very awake and alert at night even just in the maternity ward"*[67]), even for a prolonged period (*"11 days after he came home that was 11 days of zero sleep"*[67]).

Feeling trapped in a split mind

These manic experiences are frequently associated with perceptual abnormalities: *"I had to breastfeed him with no eyes, just large black eye sockets. I would hear voices through the baby monitors"*[21]. At the same time, women may start noticing unusual connections in their environment or life, which becomes self-referential (*"I thought everyone on the TV or radio was talking to me and everything had hidden meanings. I became obsessed with colors and each color would mean something to me"*[21]), eventually leading to delusional beliefs, such as persecutory ideas (*"They were coming for me. They were watching and they knew. Knew what? I don't know"*[21]; *"They are going to euthanize me there [at the mother-baby unit], aren't they?"*[21]; *"I was certain that my husband… was out to get me and take our child"*[68]; *"I thought the house was bugged, and people were listening"*[67].

The storm of hallucinations and delusions has a *"knock-on effect"*[69], disrupting and fragmenting the sense of personal unity so that the women may feel trapped in a split mind

and a dying self: *"Your whole being, how you see yourself, the kind of person you are, and your whole sense of identity is completely devastated really"*[70].

Hallucinations and delusions are unprecedented experiences to many of these women (*"If I'd known about [psychosis] it would have helped to understand a little"*[71]), extremely challenging to explain (*"It's very difficult to get your head around that"*[72]) because there is typically no insight (*"At the time, it felt that those things were really happening"*[72]).

Sinking in the depths of hell

In a few cases, postpartum hallucinations or delusions plague women and sink their minds into a psychological hell: *"In the depths of hell"*[21]; *"I thought I was on my way to hell on earth"*[68]; *"Going to the gates of hell"*[41]. They may feel that something horrible resides in their mind, because voices tell them to harm themselves (*"Inside me is a dark force. A dark shadow that looks like me outside of me. If I kill myself, will the shadow go away?"*[66]) or their baby[66].

In postpartum psychosis, infanticidal thoughts are usually secondary to psychotic symptoms and are thus at higher risk of being acted out than in postpartum depression: *"Intrusive thoughts and a voice… telling me to [harm my baby] were what plagued me every time"*[21]. As a consequence of such terrifying experiences, some women may have intense depersonalization feelings (*"I stood outside myself looking in, detached but present"*[21]) or feel mentally drained (*"I lay powerless, helpless, tense, terrified, exhausted"*[21]).

Ploughing through the fog and losing trust and safety

Many women experience psychotic symptoms as an extreme deviation from their usual self, likening their feeling of lost identity to *"ploughing through the fog"*[72]. This feeling may be accompanied by the loss of trust in others, including professionals and family members: *"I didn't trust anybody. I felt like people were just playing games with me, nurses, police"*[69]. This lack of trust leads to women keeping things to themselves, afraid to reach out to others around them: *"I would never have reached out; it's like you've entered a different world, nothing is safe, and you can't trust anyone"*[69].

Stripping down relationships

The above experiences substantially impact how women relate to their family members. Some of them report an increase in conflictual interactions (*"We fought a lot when I was raging with psychosis"*[69]) and reduced communication (*"During psychosis… we didn't have normal chats like we would've done… that was really missing"*[69]).

Psychotic symptoms are critical challenges to interpersonal relationships (*"It kind of strips down your relationships"*[69]), possibly leading to their dissolution. However, in some cases, women may seek reassurance and physical touch: *"I'd want him to hold me, hold my hand, constantly reassure me. Like I was when I was a kid. To help with feelings of paranoia, fear, safety"*[69].

Stigmatizing experiences are frequently reported, and may even be more disruptive than those occurring in postpartum depression: *"Not only the stigma of being mentally ill, you have got the stigma of being a mentally ill mother, a bad mum"*[71]. Some women whose friendships are affected detrimentally perceive this as a mixture of fear and ignorance: *"I felt a bit stifled with my friends*"[73].

Attempting to reassemble a fragmented self

Soon after the acute psychotic episode, women may self-reflect and experience a shattered sense of themselves or their identity as a couple: *"What is going on? What on earth just happened?… It was more a sense of shock, like what on earth?"*[69]. The shock is often *"followed by a really bad depression"*[69] (*"The depression afterward, the deep, deep depression afterward, was just such a blow"*[70]). In this context, recovery is often experienced as a problematic journey characterized by an up-and-down transition towards feeling better, feeling that they have missed out on what has been lost through their condition[74], and taking years to return to a recognizable version of themselves: *"It took a long time to rationalize what had happened to me"*[70].

The recovery process is a non-linear trajectory that requires collecting up the pieces of the fragmented self, making sense of it and integrating the experience[75]: *"I knew that things had to change so I didn't get ill again... being more aware of what I need. I'm easier on myself now, and I have a healthier lifestyle. Exercise and sleep are really important"*[69].

Several women reflect on how the experience of postpartum psychosis influences their decision-making regarding personal choices: *"The experience lives with you… for a long time"*[72]. At the same time, mothers often report that the baby was intrinsic to their recovery ("*He was the key reason, he was the reason I wanted to get better"*[76]; *"It made me continue my life"*[76]). On the other hand, many women report that separation from the baby would have been detrimental to recovery: *"I think if I had my baby taken away at that stage, then I would not have recovered"*[76].

THE LIVED EXPERIENCE OF WOMEN WITH POSTPARTUM DEPRESSION OR PSYCHOSIS IN THE WIDER SOCIETY

The experience of postpartum depression and psychosis in the family

The experience of these disorders is shaped in significant ways by the responses of partners, family, friends, and health care professionals. Many women report uncaring and *"disempowering"*[72] relationships with the partner ("*I wanted my husband to take care of me. I felt very alone*"[40]), who did not provide the emotional support they needed ("*I felt he didn't give me a lot of emotional support*"[36]).

Women can feel invalidated when family members deny the existence of mental problems: *"In my house, people don't accept the fact that depression exists"*[77]; *"I told my husband that I might be suffering from postpartum depression, but he didn't believe me"*[42]. In some cases, women even experience stigma from their husband: *"He never comforts me, only blames [me]"*[78]; *"[My husband] says that I am not a good mother and I am hurt by that"*[78]).

In other cases, women find that their mother or mother-in-law attribute their depressive symptoms to external causes that can be fixed: *"My mother also can't understand. She thinks that because my parents-in-law are helping me with my baby, I don't have the pressure of looking after the child"*[79].

Intergenerational differences in values and beliefs may exacerbate these experiences: *"This is the battle you can never win. Grandparents represent the tradition that cannot be adjusted"*[56]*.* For example, in the early postpartum period, women may be expected to devote themselves to meeting certain traditional mothering values of their mother and mother-in-law[56]*,* leading to constant and exhausting arguments over childcare authority. They may experience stigmatizing attitudes from their parents or family members (*"They… believe that the baby will inherit this disease"*[42]) and fear their blame (*"In my town, if a new mother became [mentally unwell] after giving birth, she would be blamed by her family"*[42]*).*

However*,* several other women report that their family provided the main social and emotional support, including their husband[80] (*"[My husband] never blamed me. I cannot imagine how to go through the darkest time without my man"*[56]; *"[My partner] helped build my confidence with the baby and going out and about to see people, talking me through situations"*[69]*),* grandparents and mother (*"I talked to my grandma and my mom… I told them I felt depressed and they helped me"*[81]) and mother-in-law (*"My husband… his mother, my mother-in-law, were doing so much"*[72]).

The experience of postpartum depression and psychosis in the social and cultural context

The profound sociocultural differences in experiences of motherhood (e.g., a month's rest for the mother post-birth: *"In my country, after childbirth, we rest for 40 days"*[40]) are reflected in varying experiences of postpartum depression or psychosis[82].

In several cultures, women and their family members are likely to not recognize these conditions. For example, in some areas in India, postpartum psychosis is termed as a religious fate (*Devva hididide*, possessed by a ghost; *Devaru bandeti*, possessed by god[83]). A core belief shared by different cultures is that perinatal depression and psychosis are not specific and diagnosable mental disorders: *"I didn't think that this thing was a disease, but here [in Canada], the doctors are saying it is a disease"*[40].

Women may instead feel that their mental problems are due to external factors such as financial difficulties, relational problems, lack of sleep, perceived negative changes in their physical appearance, feeling overwhelmed by multiple responsibilities, overthinking, stress, or lack of a supportive community[49,84,85]. However, a chemical imbalance within their body related to pregnancy is sometimes considered: *"I think, perhaps it is some sort of chemical hormone or imbalance"*[86].

In some US regions (e.g., Northern California), predominantly black women may experience postpartum mental disorders as a manifestation of weakness that may be cured through prayer: *"You have to stay strong… Whatever emotions you have, you push them away because you don't want to seem weak. And just pray about it"*[87]. This view is associated with high expectations that mothers handle their mental health problems on their own: *"In African-American culture, the idea is of being able to handle your own problems and black women being strong… and no time to talk about being depressed"*[40]. According to traditional gender roles, women are expected to take up the multiple responsibilities of household work, nurturing the children, and attending to family social relations, without complaining of the pain or discomfort[36]: *"You bring the baby home. You need to eat; the family needs to eat; you have to clean the house; you have to wash the children, take them to school, take them to Arabic reading [classes]"*[40].

In some Asian countries (e.g., China), mothers may be ashamed of asking their husband to share the housework or take care of babies, because of the traditional roles of men and women: *"He has no time to share housework with me. I feel exhausted and usually upset*"[42]. In some US regions, Latina women also perceive high family expectations that they are responsible for all parenting duties and cannot take time out for their mental health[87], while White and Asian mothers may experience shame induced by social media portraying "perfect mommies": *"The kind of social media… perfect mommy scenario where you feel like it's normal*

to get everything done"[88].

In some cultures, postpartum mental disorders may be perceived as a personal deficit or failure as a mother. For example, women in Hong Kong are expected to fulfil their social role "with grace and dignity". Failure to meet the traditional maternal role may be experienced as motherhood betrayal: *"loss of face and shame"*[89].

In Western countries, ethnic minorities of women with postpartum depression or psychosis may experience additional multiple layers of challenges[40], such as low social support resulting from migrating away from their extended family, dissolution of their partner relationship, or significant life histories of trauma and poverty, which exacerbate their symptoms[87].

THE LIVED EXPERIENCE OF WOMEN WITH POSTPARTUM DEPRESSION OR PSYCHOSIS IN RECEIVING MENTAL HEALTH CARE

The lived experience of undergoing screening

Many women feel reluctant to undergo mental health screening for postpartum depression or psychosis, due to their lack of knowledge of these conditions or because they struggle to identify or put into words their experiences (*"I don't know what it is supposed to be, how you're supposed to feel, look or whatever, I don't know. I have no idea"*[40]), or are concerned about stigma (*"I'm very much aware that black people are more likely to be labelled as having psychiatric problems. Therefore, I don't want people labeling me"*[40]).

Other women express dissatisfaction with the use of "tick box" screening questionaries (*"I was told to fill in a paper. The nurse looked at the paper and said that it showed that I was depressed, no more response"*[45]), because they do not take into consideration the need for interpersonal bonding (*"I'd rather have a coffee and a chat with someone than put circles round numbers while the baby's crying"* [89]). Other women feel that their health care providers' attitude during screening is unsupportive since it overemphasizes physical over mental health problems: *"Many doctors… don't tell you anything beyond physical examination"*[79].

Women may also identify room for improvement in how clinicians discuss and manage the diagnosis of postpartum depression or psychosis[87]. However, these experiences are highly variable, and many other women express trust in their mental health screening program to promptly identify and treat their emotional problems.

The lived experience of accessing mental health support and receiving care

Women with postpartum depression or psychosis can experience various individual, interpersonal, institutional or socioeconomic barriers which interfere with seeking help and accessing mental health care.

Regarding individual barriers, many women do not proactively seek help due to not recognizing their mental health needs or not understanding the treatment processes: *"I just was in such denial that I didn't really know that it was postpartum depression"*[87]. Often, it is not until symptoms worsen to a severe level that they, or their surrounding social network, become aware of the need for mental health support[87]. For example, in some cultures, traditional healing practices such as chanting, fasting or prayer are frequently used for the treatment of postpartum psychosis, depending on local beliefs[83].

As to interpersonal barriers, many women experience a lack of education and knowledge of postpartum depression or psychosis in their family, which is perceived as a critical obstacle to the recognition and acceptance of their problems: *"If you teach him some knowledge about post-partum depression outside of the hospital, then he will believe me in the future"*[42].

Concerning institutional barriers, several women struggle to get attentive health care support: *"I was frustrated, and the doctors wouldn't listen, so I pushed them. I admitted myself to the psych unit at the hospital"*[36]. Multiple mothers recount challenging instances in which health care professionals misdiagnosed their psychotic symptoms: *"People often think it's just postnatal depression, and they don't understand it at all"*[71].

Socioeconomic barriers are particularly relevant in low- and middle-income countries, where women may face high health care costs or social discrimination: *"We are sometimes not able to come back for medication because we lack the money"*[90]. Another common barrier is lack of time due to infant care and other responsibilities, finding the multi-step process of engaging in mental health care unfeasible[87]: *"It's not very convenient [to go to the doctor], [we] have to take care of the children"*[79].

However, the most pervasive barrier to mental health access is the fear of losing their baby: *"My biggest concern is that people will think that I'm not normal and… that I'm not able to take care of my child and then they're going to take my child from me. That's the biggest reason why I didn't go and seek help"*[40].

Finally, stigma is experienced as a core barrier to accessing mental health services: *"I think there's a huge stigma about postnatal depression"*[89]; *"I would feel ashamed… I don't want people to know I'm mentally ill"*[79]. As noted above, stigma may be associated with prevailing societal norms involving the expectation that mothers be happy and strong: *"You grow up with traditions, the customs that tell you you're not to express so much. It's hard to go to counsellors even if you believe they could help you*"[40].

Nonetheless, several other women with postpartum depression or psychosis regard their family environment as a core facilitator of their help-seeking behaviors and access to health care (*"I think having the support network is probably an important part of the recovery"*[69]), and of treatment adherence (*"My family said I wasn't well and that I needed to take tablets"*[70]). At times, mothers may resist help-seeking suggestions made by family members: *"The moment he [partner] said, do you think you need to go talk to somebody or try some medication, I was so offended"*[91]. In these cases, they may perceive the expression of concern or offer of care as a confirmation of their failure as mothers: *"I was obstinate and awkward when help was offered as I took it as another indication of my failure"*[23].

For those women eventually accessing health care, the system and associated care pathways are often experienced as fragmented (*"There were so many people involved, and they just all said different things"*[92]), particularly in low- and middle-income countries (*"The doctors did not attend to me well, and they made me feel so bad… she just took the baby and rushed with her to the nursery"*[84]), or at times dismissive of their needs (*"I think they could have at least listened"*[86]).

Hospitalization, when occurring, may be experienced as terrifying: *"It was atrocious"*[92]. Contributing factors include the sense of isolation (e.g., not seeing partner or family for several days; being cut off from the baby, which increases the subjective suffering and guilt); the misrecognition of postpartum psychosis (*"They kept treating me like I was just depressed… but it was something more than that"*[92]), and the facilities feeling like "*scary*"[93], *"horrible"*[92] or "*jail-like*"[93] places. These feelings are further intensified in women who are compulsorily admitted to hospital because of psychotic symptoms: *"The shocking departure out of my own home with police and ambulance and the whole street out… it's very traumatic to process… if you have been quite well functioning up until now"*[72].

On the contrary, many women feel that mother-baby mental health units are *"amazing facilities"*[93], *"so beautiful… like a spa"*[93], *"better at communicating… and much more organized"*[92]. These units are ultimately experienced as providing a safe respite from mental pain: *"I looked at it as a retreat that might be a miracle"*[94].

The lived experience of receiving pharmacological treatments

Many women may fear pharmacological treatment, primarily due to stigma (*"I wasn't comfortable with accepting medication because I didn't want it to be in my medical record"*[87]), poor knowledge of the medications (*"My concern is that I will just get addicted and it will change my personality"*[86]), fear of side effects (e.g., impacting breastfeeding[93]), and beliefs that the problems can be self-managed (*"I don't want to take tablets. I want to cope with it myself"*[95]).

In addition, several mothers experience pharmacological treatment as a confirmation that they are unsuccessful at coping: *"I remember going on that and feeling like… I'm on an antidepressant; there's such a stigma attached to it. I like to think that I'm stronger, that I don't need something like that"*[91]. However, other women report more nuanced views of medications, and express acceptance or hope (*"I felt pretty hopeful and excited at the potential of feeling better"*[91]; *"Maybe the medication will stop the feeling that [my baby] and I are going to die"*[24]), especially if psychotherapy was not effective (*"I am extremely open to going on medication [after I give birth], because I would love to do anything that I can in order not to have a postpartum depression again"*[87]).

Several women experience relief from their symptoms with medications (*"Since taking the medicine, I can sleep well and eat well. I now think less about my worries. I suddenly feel good. I have a good appetite and I can eat well. I also do not worry about my children like before. The thoughts do not stick in my mind for too long"*[78]; *"When I take the medicine, I feel better. I can laugh… now. Before I took medicine, I couldn't"*[78]), to the point that they may be reluctant to discontinue them (*"I'm too scared to come off them"*[95]). The rapid effect of medicines may be particularly appreciated: *"When it comes to a situation like… postpartum depression, postpartum psychosis, whatever it may be, time is very critical"*[94].

The variability of these experiences is primarily modulated by negative beliefs of the family about medications (*"He [partner] doesn't have a good view on antidepressants… He thinks that they're unneeded or unwarranted"*[91]) and by the quality of the therapeutic relationship and the connectedness between the two parties (*"My first [clinician] treated me like a statistic, a number… but my second one has been so great. She listens, she is very understanding, and she makes me feel the communication is open"*[87]). Furthermore, several women experience a beneficial effect of combining physical exercise with medications: *"You feel tired, so you don't want to exercise. I think it's when you do start to exercise that you realize it actually gives you more energy and makes you feel more positive"*[96].

The lived experience of receiving psychological treatments

Women also describe a diverse range of experiences with psychotherapy. Several of them report positive nurturing experiences[87], such as the possibility of sharing their silent suffering with a therapist and opening up (*"She was so understanding and easy to talk to and willing to listen, that I actually opened up, otherwise I wouldn't have done"*[38]), and the feeling of being supported ("*She was so helpful and thoughtful. She wasn't hard on me like I am on myself and really made me stop and think about how I treat myself"*[97]). They may experience enhanced self-esteem, feel more proactive, manage stress more effectively, and embrace and adopt a positive view of life: *"I am more relaxed and confident. Earlier, I could not speak or*

even go out of my house; now I go out with my friends"[38].

However, other women report negative experiences of psychotherapy, driven by concerns about self-disclosure, lack of individual attention, fear of not being understood or taken seriously. They may also encounter structural hurdles in the health care system, such as limited therapist availability[87] and financial constraints, particularly in low-income countries. Sometimes, women feel that a good therapeutic relationship cannot be established, or that their therapist lacks the appropriate competence or necessary personal qualities, or is not flexible, or that their feelings and beliefs are not valued[38]. Internalized stigma for seeing a therapist may also be present (*personal communication*).

Other drivers of poor treatment adherence or low satisfaction with psychological interventions may include excessive day-to-day responsibilities that are incompatible with rigid psychotherapeutic routines (*"I find it hard to put anything into practice with others around"*[98]; *"I tried, but I could not do that much"*[38]), or finding the sessions too short or unfocused to be helpful (*"I thought the sessions went by too quickly and not enough"*[38]).

The lived experience of peer support

Peer support groups involving other women with similar experiences and problems are frequently welcomed, as they foster the sense of feeling understood and accepted: *"Being able to attend a support group and meet other moms who are experiencing the same thing, it was really helpful knowing that I wasn't alone"*[87]. Participants also appreciate that other women are willing to reciprocate and share their thoughts and feelings: *"I realized they are interested knowing how many children I have, and they will ask things about me too. So, when I start to share with them my personal story like with depression, they are ready to tell me more about their children"*[99]. Peer support helps overcome the sense of loneliness and provides opportunities for interpersonal connection and bonding: *"The thing I looked most for was something that allowed me to meet people, just get out of the house and meet others, like new mothers, people that I could speak to"*[40].

Providing peer support is particularly empowering, because women's confidence and self-esteem are boosted once they become a source of help for others, particularly in low-income countries where access to other sources of support can be limited: *"When you help someone, then you feel happy that you can be a source of support for this depression, I've been there, I experienced it myself"*[99]. Overcoming the sense of grief and loss of postpartum depression or psychosis often involves a personal transformation and the consolidation of a new identity relying on social resources. Peer support can help these women reframe their identity, deriving insights and learnings from their past suffering to help others, assigning positive meaning to previous negative experiences, and promoting self-acceptance: *"You can recover from this*

illness… Postpartum psychosis has made me a stronger, more resilient person. I am alive, and I love my children now more than ever"[21].

DISCUSSION

Becoming a mother is always a major "life-changing experience", involving physical, hormonal and psychological changes. It is foremost a life condition that entails deconstruction and reorganization of one's sense of identity, a "developmental crisis"[100]. Women with postpartum depression or psychosis face severe additional difficulties, and their motherhood becomes a very complex experience. Unlike many other medical conditions, these are "*very silent*"[81] disorders, that are typically hidden or overlooked. Therefore, women's narratives collected in this paper are essential to help other affected mothers recognize themselves and make sense of their experience.

Women who courageously shared their stories of postpartum depression or psychosis in this study are the true storytellers who give voice to many other women: *"This illness needs a voice, and I am happy to talk about my postpartum psychosis journey to raise awareness"*[21]. To our best knowledge, this is the first review of the lived experience of postpartum depression and psychosis that has been co-written by experts by experiences and academics.

We found that the experience of the onset of postpartum depression may be described with the metaphor of "being hit by a ton of bricks", alerting us to the sudden and acute onset of symptoms. Soon after the onset, women with this condition feel enveloped in unbearable loneliness and sadness, that are extremely difficult to communicate and are generally suffered in silence. Affected mothers describe the alienating experience of feeling like mechanical robots stripped of all positive feelings. They perceive themselves as no longer the person they were before, and, at the same time, feel unable to prospectively reorientate their lives towards the future[101].

The content of thoughts and emotions in women with postpartum depression is typically polarized on a suffocating burden of guilt for being bad mothers, feeling unable to adhere to social norms and expectations, and feeling incapable of taking care of their newborn. These ruminations may trigger cognitive difficulties, mental fog, and lack of concentration or control over thoughts and emotions. Women may summarize these experiences with the "tightrope walker" metaphor or report feeling besieged with insecurity or needing to be mothered themselves. The most disruptive experience of postpartum depression is living in a nightmare and contemplating death as a glimmer of hope to escape it, highlighting the profound depth of despair these women may confront.

Women with postpartum psychosis share most of these experiences but, at the same

time, the occurrence of psychotic symptoms further disrupts their mental and cognitive functions. In a few cases, women feel like they are “sinking in the depths of hell”, because their psychotic symptoms may relate to thoughts of harming themselves or their baby. Compared to postpartum depression, postpartum psychosis is characterized by a more pervasive disruption of the sense of self and more pervasive feelings of unsafety and losing trust in others, and the stripping down of social relationships. Consequently, the journey to recovery from postpartum psychosis is experienced as a perilous effort to reassemble a sense of self that psychotic symptoms have fragmented, and to become a new person.

We hope that these first-person accounts of postpartum depression and psychosis will allow other women to view their experiences through the eyes of the individuals quoted in this study, and encourage them to seek early treatment.

We found that the lived experience of postpartum depression and psychosis is closely intertwined with social and family dimensions. Therefore, they should not be only framed as health problems, but also as core social and relational problems[36]. Much of the isolation, guilt and disorientation experienced in these conditions relates to a gulf between how women feel and a web of societal norms and expectations surrounding motherhood. This results in a crisis in one’s idea of family and the social roles that one would like to embody, disrupting the continuity of the traditions inherited from the family of origin[33].

Our first-person accounts clearly indicate that women’s social situation has a profound effect on how depression is experienced, as well as its trajectory over time. Mental suffering during the postpartum period can involve something approximating what has been termed “disenfranchised grief”[102] (i.e., experiences of loss that are either not acknowledged or actively stigmatized due to predominant social norms, practices and narratives). When grief is disenfranchised, its experience and interpretation are compromised by the extent to which resources for regulation and coping are available in the social environment. Interestingly, “disenfranchised grief” is also a common theme in the first-person accounts of involuntarily childless women, who sometimes remark that society does not recognize their grief over what never was or how their identity has been affected by it[103].

Many women, although not all of them, described experiences of uncaring relationships with their families, lack of social support, loneliness, and isolation associated with deep shame. Direct and explicit stigma from others (i.e., enacted stigma or discrimination), particularly amongst socially disadvantaged groups such as ethnic minorities, was frequently reported[39]. In most cases, stigma was related to lack of knowledge of postpartum depression or psychosis. Most families recognize that they lack the knowledge, resources and skills to serve as supporters for these problems[92]. On the other hand, trying to help with childcare tasks can sometimes unintentionally send the message that the mother is not competent or flawed. This vicious circle self-amplifies stigma, leading mothers and their families towards a

"subconscious agreement whereby neither the mother nor family and friends publicly acknowledge the depression"[36], and everyone suffers in silence. The lived experiences described in this study may be accessed by family members and represent an essential tool to improve awareness of these disorders, and their ability to hear, tolerate and understand the mothers' emotional pain.

The gulf between women's feelings and societal norms, and the associated stigma, also hinders access to resources for understanding and support. Stigma emerges as a common barrier to undergoing screening, seeking professional help, accessing health care services, and receiving available care such as pharmacological or psychological therapies.

We found that stigma may equally be related to a lack of knowledge among health care providers. For example, in some countries, most providers report only some basic knowledge of postpartum depression and psychosis[104]. This is especially marked for postpartum psychosis, which is not only rare but also an "orphan" disease not recognized in the DSM[66]. Consequently, this condition is frequently unrecognized or misdiagnosed as postpartum depression or blues[9], particularly in low- and middle-income countries[83]. Many women affected with postpartum psychosis who die from suicide or who commit infanticide were not diagnosed or misdiagnosed and did not receive adequate treatment[4]. Mother-baby psychiatric units, which provide the safest and most effective support and care for these disorders[105], are available only in very few countries.

Furthermore, knowledge about postpartum depression and psychosis is often not shared by the legal and judicial system, leading to many mothers being compulsorily admitted to mental institutions without adequate care, or receiving excessively harsh sentences when prosecuted[106].

This study should inform clinical practice. Our experts by experience highlighted the need for training of health care workers to support outreach and preventive care[107]. The lived experiences described here will be accessible to many health professionals and therefore inform future training programs, support mental health literacy, help to maintain a compassionate and non-judgmental stance, refine the psychopathological and diagnostic knowledge, and ultimately facilitate culturally sensitive recognition and treatment of these disorders[4,5]. The study can also facilitate the rolling out of screening programs by informing the content of training and supervision for non-specialists and by improving public awareness of postpartum depression and psychosis[75].

The first-person accounts collected in this paper illustrate the extent to which the experiences of postpartum depression and psychosis can be not just "situated within", but "inextricable from" social and cultural environments. Accordingly, this study points to distinctive interventions that may help facilitating self-interpretation and promoting shared understanding[108]. It is also tempting to propose that the management of these conditions might

include challenging predominant cultural narratives of motherhood that leave many women feeling alienated and adrift.

Qualitative meta-synthesis allows for and demands interpretation by researchers. We have mitigated sociocultural biases by establishing a global writing team of experts by experience and academics. As in previous studies of this series[17-19], we acknowledge that the experiences reported are not exhaustive and systematically transportable to all individuals, but more often presenting with phenomenological heterogeneity. Moreover, this study does not distinguish between specific diagnostic subtypes, because this approach would have rendered the analytic task unfeasible. Future studies could focus on the different experiences of the prepartum vs. postpartum period. While we primarily focused on individuals' experiences of postpartum depression and psychosis, future research could further address these experiences in the context of interpersonal relationships (e.g., the couple, family).

In conclusion, this study highlights the vast complexity and range of experiences associated with disorders that are too often misunderstood and stigmatized. The narratives collected in this paper provide a new voice for women's experiences of postpartum depression and psychosis, plus rich insight for their families, health care workers, and other stakeholders. Disseminating the stories gleaned from these lived experiences can be a powerful means to improve literacy and awareness about these disorders, and overcome misunderstanding and stigma.

We hope that this work can help expand options regarding how motherhood is constructed, bringing voice to the unspoken and unheard, and building and maintaining relational connections to create a context within which negative and positive experiences of mothering may be expressed within networks of support. This is vital to providing the most supportive care to women experiencing such pervasive psychiatric disorders at a critical, fragile time in their lives.

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Table 1 Selection of publications on the lived experience of postpartum depression and psychosis considered for this review

Hanzak EA. *Eyes without sparkle: a journey through postnatal illness*[23]
Munday A. *Day nine: a postpartum depression memoir*[24]
Redhouse N. *Unlike the heart: a memoir of brain and mind*[25]
Aiken C, Brockington IF. *Surviving post-natal depression: at home, no one hears you scream*[26]
Osmond M, Wilkie M, Moore J. *Behind the smile: my journey out of postpartum depression*[27]
Wight J. *Rattled: overcoming postpartum psychosis*[28]
Shields B. *Down came the rain: my journey through postpartum depression*[29]