

More Than a Walking Diagnosis: Identity and the Long Aftermath of Perinatal Suicidal Behaviour

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More Than a Walking Diagnosis: Identity and the Long Aftermath of Perinatal Suicidal Behaviour

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Abstract

Suicide ranks among the leading causes of maternal death in high-income countries, and Australian population-based data show that maternal suicide deaths continue throughout the five years after childbirth. Researchers have rarely examined the years after a perinatal suicidal crisis. We asked how women experienced diagnosis and misdiagnosis, what the crisis left behind, and how women described the self they built afterwards. In Australia, forty-three people took part in interviews, a practitioner survey and five lived-experience co-design sessions; participants in those sessions also shaped the study. The 27 women with lived experience of their own perinatal suicidal behaviour were interviewed approximately 2 to 20 years after the birth associated with that behaviour (median approximately 5 years). With those groups, we defined perinatal suicidal behaviour as an umbrella term for suicidal ideation, planning, suicide attempts and self-harm during pregnancy or in the three years after birth. We used reflexive thematic analysis to construct patterns of shared meaning within a

critical realist orientation. We constructed three themes: the long search for understanding; what the crisis changed over time; and transformation rather than recovery. Many participants waited years for an explanation. When clinicians gave a diagnosis that fitted and validated the woman's experience, women could understand what had happened and enter a care pathway. An incorrect or dismissive label, most often borderline personality disorder, fragmented their self-understanding; participants said the label changed how clinicians engaged with them. In the second theme, participants described effects on parenting, relationships, healthcare engagement, employment and identity that persisted for years, while follow-up care lasted weeks. In the third theme, participants rejected recovery language. They described instead a self they had built, with growth held alongside grief. How clinicians gave a diagnosis affected whether women could build an account of what had happened, which participants described as the starting point for making meaning of the crisis. Perinatal services could treat a diagnosis as the start of a conversation, extend follow-up across years, and set care goals other than a return to the woman's former self.

Keywords: perinatal mental health; suicidal behaviour; diagnosis; misdiagnosis; identity; motherhood; lived experience; reflexive thematic analysis

Introduction

Suicide ranks among the leading causes of maternal death in high-income countries (Chin et al., 2022). An Australian population-based study followed maternal deaths from suicide, accidental poisoning and undetermined intent for five years after childbirth in New South Wales; about three-quarters of the suicide deaths occurred after the first year (Makarious et al., 2026). If women continue to die by suicide for years after birth, some may also experience distress over this period. This paper examines women's experiences after perinatal suicidal behaviour.

In clinical practice, clinicians usually recognise perinatal suicidal behaviour through a mental health diagnosis. Women can struggle to obtain an appropriate diagnosis, particularly women from ethnic minority or Indigenous groups, women with low socioeconomic status and adolescent women (Prady et al., 2021). Women present with varied symptoms and experiences (Howard & Khalifeh, 2020), yet Australian screening guidance centres on the Edinburgh Postnatal Depression Scale, a questionnaire that screens for symptoms of depression during pregnancy and after birth (Highet & the Expert Working Group and Expert Subcommittees, 2023). A diagnostic label can affect treatment, identity and safety (Howard & Khalifeh, 2020; Petreca et al., 2026). Qualitative researchers have also found that unmet expectations of motherhood and inadequate recognition by services can shape women's pathways into perinatal suicidality (Biggs et al., 2023).

Researchers have paid little attention to women's experiences after perinatal suicidal behaviour. The literature to date focuses on the crisis period or ends when authors consider women to have recovered (Biggs et al., 2023; Kobylski et al., 2026; Reid et al., 2022). A systematic review of interventions for perinatal suicidal behaviour defined the perinatal period as pregnancy and the first postpartum year and identified five eligible studies. The only study that compared an intervention group with a control group followed women until 7 to 8 months postpartum (Scarth, Derakhshan, et al., 2026). We found no qualitative study that examined how the crisis affects women's identities, relationships, parenting and engagement with healthcare, or how it affects their families in subsequent years. Studies that have examined later effects have focused on children (Mebrahtu et al., 2020). Researchers studying people who had survived a suicide attempt outside the perinatal context found that participants deliberately made meaning from their experiences and continued to negotiate their relationship with those experiences (Scarth et al., 2021).

This qualitative study forms part of a larger co-designed programme on family support for perinatal suicidal behaviour. Four related analyses examine concealment of perinatal suicidal behaviour and the conditions in which women can disclose it safely (Scarth, Wereta, et al., 2026); traumatic birth and its relationship to suicidal ideation and suicide attempts (Scarth, Dudeney, et al., 2026); the care provided by partners, fathers and kin, their capacity to provide it and their unmet needs (Scarth, Vella, et al., 2026); and the model of care that participants specified for the whole family across pregnancy and the years after birth (Scarth, Levin, et al., 2026). We used each participant excerpt in one analysis only.

We examined how women experienced diagnosis and misdiagnosis before, during and after perinatal suicidal behaviour; what effects the crisis had over time; and how women described the self they built afterwards.

Methods

Design and Orientation

We conducted the programme in Australia within a participatory action research orientation, which treats people with lived experience as co-researchers who shape the research from design through analysis (Cornish et al., 2023). The co-design groups met before any interview took place. The mothers' group met eight times between June 2025 and October 2026, and the male family members' group met once. Group members wrote the three interview guides, set the eligibility window and specified the safety procedures; interviews followed between March and June 2026. Five lived-experience co-design sessions, four with mothers and one with male family members, shaped recruitment, instruments and analytic priorities. The sessions also generated data. One mothers' session focused on the effects of perinatal suicidal behaviour over time, and some members of the co-design groups

also participated in interviews. To protect their identities, we do not report how many members did so or link session and interview identities. The sessions produced group discussions of shared experience, while the interviews produced individual histories. We analysed both sources together (see Data Analysis) and attribute each excerpt to its source.

The co-design groups developed the definition of perinatal suicidal behaviour used here: an umbrella term for suicidal ideation, planning, suicide attempts and self-harm during pregnancy or in the three years after birth, regardless of the type or outcome of the pregnancy. We follow the terminology recommendations of De Leo et al. (2021). We use “mother” for the birthing parent because all participants used it. We attribute excerpts from the mothers’ co-design sessions as “(mothers’ co-design session)”. We attribute practitioner survey excerpts by participant number, role and source, for example, “(P37, health professional, survey)”.

We used a critical realist orientation (Bhaskar, 1986/2009). We treat the events that participants described as real, while recognising that their accounts and our interpretations provide partial and fallible knowledge of those events. We treat a diagnosis as a real event with real consequences, and we use participants’ accounts of its effects on identity as evidence about those consequences. We co-constructed the account from diagnosis to rebuilding the self. We state when a claim rests on our inference rather than on participants’ words.

Participants and Recruitment

Forty-three people took part. Thirty-eight people completed 37 semi-structured interviews, including one joint interview with a couple. Three perinatal health professionals completed a written survey, and two lived-experience co-design members participated only in a session.

People aged 18 or over were eligible if they had lived experience of perinatal suicidal behaviour as defined above, either their own experience or that of a woman they supported as a family member or friend. Perinatal health professionals were eligible if they had worked directly with perinatal suicidal behaviour. We based eligibility on each participant's account of the suicidal behaviour. We neither required a psychiatric diagnosis for inclusion nor treated one as a reason for exclusion, and we did not verify diagnoses against clinical records. The diagnostic histories reported below comprise participants' accounts of diagnoses that clinicians gave them and conditions that some participants identified in themselves. We analyse these histories as experiences of receiving, or being refused, an explanation. The eligibility criteria did not include current mental state, and we excluded no one because of current illness or current suicidal ideation. The co-design groups, whose members all had lived experience, made this decision. They considered exclusion on the basis of current mental state paternalistic and held that people should decide whether they were ready and able to participate. The explanatory statements described this approach, which the ethics committee approved. The interviewer checked each participant's readiness during an initial conversation and again at the start of the interview. The safety procedures described under Data Generation and Ethics applied to everyone.

We recruited through networks formed by the co-design groups, participant referrals, perinatal mental health and suicide prevention organisations, social media and the study website. We assessed the size of the participant group using information power, an approach that links the number of participants needed to the study aim, sample specificity and depth of the material (Malterud et al., 2016). The specific aim and difficulty of reaching the groups reduced the number needed. We sought up to 15 participants per group and reviewed that target against the depth of participants' accounts. Recruitment of women with lived experience exceeded this target because recruitment was still open and each additional

participant brought a perspective the group did not yet include, such as rural, Indigenous or migrant experience, or involvement with child protection services. Interview participants received a \$50 supermarket voucher; practitioners who completed the anonymous survey received no reimbursement.

We describe the participant group's demographic characteristics in prose because several participants were the only person with a particular combination of cultural background, role and history; a table could identify them. Twenty-seven women had lived experience of their own perinatal suicidal behaviour. Two men who participated as kin made suicide attempts after their period of caring (Scarth, Vella, et al., 2026). Nine participants took part primarily as family members or carers, while seven took part as perinatal health professionals, including two senior perinatal psychiatrists. Thirty-five participants described themselves as women and eight as men; their recorded ages ranged from late adolescence to over 70. Participants included Aboriginal and Torres Strait Islander people, Māori people, white Australian-born participants and people from culturally and linguistically diverse backgrounds.

Participants reported extensive and often contested diagnostic histories, which Table 1 summarises for the perinatal period. We interviewed the 27 women approximately 2 to 20 years after the birth associated with their suicidal behaviour (median approximately 5 years), so the time since that experience varied widely. Some participants reported current treatment for mental illness at the time of interview. Because we did not formally assess current mental state, we cannot report how many participants were unwell when interviewed. Sixteen participants had roles in both the perinatal workforce and lived-experience communities. Ten mothers and two male family members reported one or more suicide attempts. For nine participants, the interview focused primarily on a family member's suicidal behaviour.

Table 1

Events During Pregnancy and the Three Years After Birth, and What Clinicians Recognised

(*n* = 27)

Pattern in participants'		
accounts	<i>n</i>	Examples from the accounts
Described a traumatic birth or a serious obstetric or neonatal event	19	Haemorrhage, emergency caesarean, pelvic floor injury, neonatal resuscitation, neonatal intensive care
A clinician identified the birth as traumatic at the time	2	Premature birth, haemorrhage
The birth was recognised as trauma only later, by the participant, a peer or a clinician outside maternity care	9	Through peer work training, a news article, a physiotherapist or a neurologist
The physical injury was missed or not disclosed	3	Pelvic floor injury identified months later by a physiotherapist
Received a psychiatric diagnosis in this period	22	Postnatal depression, postpartum psychosis, PTSD, OCD, bipolar disorder, ADHD
Received a diagnosis in this period that they dispute or describe as a misdiagnosis	6	Borderline personality disorder, bipolar disorder, anxiety
Received no new diagnosis in this period despite suicidal behaviour	5	Pre-existing depression or anxiety left unchanged, or symptoms concealed

Pattern in participants' accounts		
accounts	<i>n</i>	Examples from the accounts
Identified in themselves a condition that no clinician had diagnosed	11	Autism, ADHD, OCD, complex PTSD, postnatal depression, birth trauma
Concealed symptoms because they expected their child to be removed	19	First Nations women, women who grew up in Out of Home Care systems, women with a history of complex trauma
Described harm caused by a service in this period	18	Refused assessments, dismissal, a child protection investigation after disclosing suicidal thoughts, racism in care

Note. Counts describe the material analysed and do not measure how strongly the material supports a theme. The participants are the 27 women with lived experience of their own suicidal behaviour. PTSD means post-traumatic stress disorder; OCD means obsessive-compulsive disorder; ADHD means attention-deficit/hyperactivity disorder. Participants reported their diagnoses, which we did not verify against clinical records.

Data Generation

The first author conducted all interviews except one. She checked the automated transcripts against the audio and removed identifying information before analysis. An interpreter conducted the remaining interview in the participant's first language, with the first author present to provide support, so that he could speak privately. All but two interviews took place by Zoom between March and June 2026 and lasted about 60 to 180 minutes. The first author began each interview by checking the participant's readiness and ended it with a

debrief. She offered participants a wellbeing plan beforehand and a check-in afterwards. Zoom produced automated transcripts of the online interviews, and the first author transcribed the two in-person interviews by hand. Google Translate produced an English version of the interpreted interview, and the interpreter checked the quoted passages against the recording.

The co-design groups developed the semi-structured interview guides, which set out topics while allowing the interviewer to follow each participant's account. The guides asked about participants' experiences over time, disclosure, contact with services, and what helped or hindered them; a screening section recorded diagnoses (the guides are available from the corresponding author). The guides did not ask directly how clinicians communicated diagnoses or what participants' lives had been like since. Participants raised both matters, and the first author followed them up during interviews; the mothers' session on longer-term effects addressed the second matter directly. Perinatal health professionals could instead complete an anonymous online survey that covered the same topics as the interview guide. We did not ask practitioners about their own lived experience; when they disclosed it, our attributions reflect that disclosure. The demographic screening item in each guide retained the conventional twelve-month wording. Eligibility rested on the three-year definition, and we did not include or exclude anyone based on that item.

Ethics

The Monash University Human Research Ethics Committee approved the study (Project ID 50913, qualitative interviews; Project ID 49134, co-design workshops). The University of Melbourne first approved the co-design study in May 2025. We asked participants who had enrolled under that approval to provide consent again under the Monash approval. All interview and co-design participants gave written informed consent to

participate and to the publication of material from which we had removed identifying information. The first author sent each interview participant the explanatory statement and consent form and received the signed form before the interview. Co-design members gave written consent to the first author before their first session. Practitioner survey respondents gave consent by completing the anonymous survey, which presented the explanatory statement on its landing page. Participants took part voluntarily and could decline any question or withdraw at any time.

We used a stepped distress protocol for all interviews, surveys and co-design sessions. Depending on the participant's needs, the protocol ranged from pausing to offer support to contacting emergency services. No acute risk incident occurred. We excluded descriptions of suicide or self-harm methods from the material analysed, and none appear here; we report suicidal behaviour by type only. We edited excerpts to remove identifying details. We marked omissions with (...), pauses in speech with ... and clarifications with square brackets. Several participants were the only people in the material analysed with a particular characteristic, so we generalised some details and reported some sequences without dates.

Data Analysis

The first author analysed the data using reflexive thematic analysis, a method for developing patterns of shared meaning across participants' accounts (Braun & Clarke, 2021), within the critical realist orientation described above (Fryer, 2022). We chose reflexive thematic analysis rather than approaches that use a predefined coding framework or measure agreement between coders because we asked how participants made sense of a diagnosis and what followed. The participatory design also suited an approach in which the researcher examines how her own perspective shapes the analysis, and Braun and Clarke (2021, 2025) describe the method as compatible with critical realism.

The first author developed codes from the data, which made the coding inductive. The co-designed questions and the session on longer-term effects also shaped what she examined, so the coding was also deductive. She first coded what participants said directly and then interpreted the assumptions and meanings beneath their words. She moved repeatedly among Braun and Clarke's six phases rather than completing them once in a fixed sequence (Braun & Clarke, 2021). The first author began familiarising herself with the material while generating it. She coded the entire dataset in MAXQDA (VERBI Software) without using its automated coding functions, revised codes as her interpretation changed and wrote analytic notes to develop possible themes. She reviewed each possible theme against the whole dataset and asked whether it described a pattern of shared meaning organised around one central idea, rather than a topic that several participants had raised. Writing formed part of the analysis, and she revised the theme structure while drafting. We analysed the interview, survey and co-design material together and examined where participant groups agreed and disagreed.

Reflexivity and Quality

We calculated no measure of agreement between coders because reflexive thematic analysis does not treat such agreement as evidence of quality (Braun & Clarke, 2021). We interpreted agreement between participants cautiously. Many participants had worked in or around perinatal services, and some had met through the co-design groups. Their agreement therefore shows shared priorities, but it cannot establish that they reached the same conclusions independently.

The first author is a mother and a researcher-practitioner with extensive experience in mental health, family violence, suicide prevention and support after a suicide death.

The co-authors contributed to and challenged the analysis. They include clinicians, academics, peer workers and lived-experience researchers involved in co-design. All authors are mothers.

Two features of the programme affect how readers should interpret Themes 2 and 3. The five members of the mothers' co-design group are both co-authors and participants. The first author presented possible themes to this group in a session where members interpreted the analysis, then refined the themes in response to their readings. We did not seek consensus or treat the group's interpretation as confirmation. A member of that group first proposed the critique of recovery language that organises Theme 3. We therefore report the transformation framing as one that lived-experience partners developed, and in Theme 3 we identify when a participant responded to it.

Overview of Themes

We constructed three themes that together describe a sequence in participants' accounts. A diagnosis or another form of understanding helped participants explain what had happened. That explanation allowed them to make meaning from the crisis, which they described as part of living well afterwards.

Theme 1. The Long Search for Understanding

Many participants described the absence of a diagnosis as a lengthy and frightening experience because they did not understand what was happening to them. We interviewed all 27 women at least two years after the birth associated with their suicidal behaviour, so their accounts show how long they searched for an explanation; the Limitations section considers how this interval may have affected recall.

Years Without an Explanation

Some participants moved from service to service for months or years before anyone explained why they were experiencing suicidal distress. One senior perinatal clinician attributed part of the delay to women concealing their distress because they feared the consequences of disclosure:

You're really good at hiding it (...) if you look at the (...) root cause there is society's attitudes, and fear of the baby being taken away. (P34, senior perinatal clinician)

Some participants received no diagnosis at the time; understanding came in retrospect:

I've never been diagnosed with it, but I think I'm a classic case of it. I just didn't have time to reach out for help (...) And my doctor has now said, looking back (...) you definitely did have it. (P20, mother)

Caring responsibilities and work left these participants little time to seek help. Clinicians confirmed their experiences years later, which helped participants understand what had happened but came too late to guide treatment at the time.

For some participants, understanding their perinatal suicidal distress came only after their child received a diagnosis, which prompted them to reconsider their own history:

It's only after having both my girls that I've realised that I'm neurodivergent (...) since my eldest daughter has been diagnosed with autism and ADHD, that I'm clearly autistic as well, as having ADHD. And just the fact that you have to keep going and reviewing your life with these different lenses is so much work in itself while you're trying to raise the next generation. (mothers' co-design session)

Participants and practitioners most often described clinicians as missing or misdiagnosing postpartum psychosis, partly because women concealed their experiences.

One participant explained: "Women with psychosis will present as being really well (...) you

mask it because you're so scared, because your brain's really playing tricks on you" (mothers' co-design session). One survey respondent proposed recognising postpartum psychosis in the Diagnostic and Statistical Manual of Mental Disorders, which she said "would make a big difference" (P37, health professional, survey).

Clinicians gave a second group conflicting diagnoses over several years, with each diagnosis replacing the previous one; participants described the sequence itself as a problem. One participant reported diagnoses of severe postnatal depression and depression with psychotic features, followed by a possible diagnosis that she thought did not fit:

originally, diagnosed with a severe, postnatal depression (...) And then, yeah, further down the track, a depression with psychotic features, or (...) postpartum psychosis, so it comes under that umbrella. And then a (...) sort of a query around bipolar type 2, which (...) it fits and doesn't fit, I think. I'm not completely convinced or wedded to that. (P3, mother)

Another participant described how a later diagnosis changed her understanding of all her earlier experiences:

we should have booked you in for an autism assessment. And it was then that I kind of went away and started looking up (...) late diagnosis women, autism, how much I realised, hello, I don't have just anxiety and depression. Like, this is (...) full body dysregulation, this is sensory difficulties, cognitive issues. (P22, mother)

Her earlier diagnoses of depression and anxiety had "stuck with me (...) pretty much my whole life", and an emergency department psychiatrist whom she never saw again had "floated" a diagnosis of borderline personality disorder (BPD) (P22, mother).

Participants described waiting for an explanation and receiving conflicting diagnoses as frightening. Several participants said their distress deepened during that period or during treatment that did not help.

When the Diagnosis Fits: Relief, Understanding and Validation

Participants often described a diagnosis that fitted as changing how they understood their experiences:

It was life-changing, for good, for once, because everything actually made sense (...) the best thing to have ever happened. (P1, mother, of an attention-deficit/hyperactivity disorder [ADHD] diagnosis)

Another participant described a similar but more understated relief: “The panic disorder, I didn’t realise it had a name. But it made sense” (P23, mother).

A diagnosis often helped by validating an experience that someone had dismissed. One mother contrasted a hospital where staff did not believe her with a service that explained her experience as postpartum psychosis:

They actually believed me (...) they validated how I was feeling. (P15, mother)

In these accounts, participants needed both an explanation and validation. Participants who received only one did not describe the same resolution.

One participant listed what she needed alongside the diagnosis:

The right doctor, the right diagnosis, the right medication, and the right kind of relationship and rapport then, helped things. (P3, mother)

Participants who received a diagnosis that fitted without a safe therapeutic relationship did not consider the diagnosis sufficient. Those who had the relationship without the diagnosis described the same limitation.

The explanation that fitted did not always come from a clinician. Several participants obtained this language from peers, and one participant found it in a stranger’s account online. For birth trauma, recognition sometimes took more than a decade (Table 1); a companion analysis reports that process (Scarth, Dudeney, et al., 2026).

Another participant found a BPD diagnosis helpful. A psychiatrist gave the diagnosis after one session and did not agree with her general practitioner's suspicion of ADHD. She then adopted the BPD label:

instead of being like, oh, shit, I've got borderline, I was like, oh, yes, I've got borderline, right! How does a borderline brain work? (...) so when I have these emotions, my brain's actually better at making these than other people's brains (...) [and] worse at dealing with them. Right, okay, what can I do to combat that? (P17, mother)

She described how the label corrected her understanding: "having the diagnosis of borderline taught me (...) that as much as this is how my brain works and how I'm thinking, perhaps this is not actually the reality of every situation that I'm in". She interpreted the diagnosis in her own terms: "to me, borderline is more a trauma response of how my brain forms" (P17, mother).

On our reading, her experience suggests that whether a diagnosis helped or harmed depended on the support and explanation that accompanied it. The woman needed a way to understand the diagnosis, the clinician needed to remain engaged, and the clinician needed to offer the diagnosis as an explanation rather than an irrefutable statement about her as a person. When clinicians did not meet these conditions, participants experienced the diagnosis as harmful and stigmatising.

Participants did not always welcome an explanation. The participant whose diagnoses had changed from postnatal depression to possible bipolar type 2 felt that a clinician had labelled her too quickly: "he was quite quick after one and a half sessions to label it, you know, to say, I think you've got bipolar type 2, which I wasn't ready to hear at that point either" (P3, mother). She described timing as equally important as accuracy.

Another participant, who had survived extensive complex trauma, described resisting a BPD diagnosis:

my old doctor was trying to gently push me down that path when my son was 5, and I said, have you looked at complex (...) PTSD with autism? (...) I feel like that suits me a lot more than (...) a BPD diagnosis, because half of it isn't relevant. I don't experience that. (P20, mother)

As a very young mother with little support, she disclosed traumatic experiences, researched her own condition and contradicted a clinician because she believed that a BPD label would reduce the care she received.

A peer offered one mother ADHD screening after ADHD had changed how the peer understood her own depression. The mother declined:

I don't want to collect any, any more labels at the moment. (P23, mother)

She already had two diagnoses and had received more during a hospital admission. She described a limit to how many further labels she could manage; someone with several diagnoses may experience another as a burden rather than an explanation.

When Diagnosis Harms: Misdiagnosis, Dismissal and an Incorrect Label

An incorrect or dismissive diagnosis can cause harm. Participants described how misdiagnosis weakened their understanding of themselves:

You try and make it fit just so you can make sense of yourself, and then you end up more dissociated and disillusioned from yourself. (P1, mother)

Participants with lived experience, professional experience or both described how a BPD diagnosis changed clinicians' responses. One perinatal professional with lived experience summarised the harmful interpretation that clinicians applied to women with the label: "They're attention-seeking, they're just wanting attention" (P25, perinatal professional with lived experience).

One mother described the negative attitudes that she had seen clinicians hold towards patients with BPD:

[They] don't want to take on a BPD patient, whereas if you've got bipolar disorder or something, it's like, oh yeah, [they] can do that, [they] can take that on. (P3, mother)

This participant also thought that clinicians often missed neurodivergence or applied incorrect labels, and that earlier recognition might have prevented some of the harm women experienced:

there's a lot of neurodivergence and stuff happening in there, too, that's potentially being missed and mislabeled (...) as bipolar disorder, but potentially BPD as well (...) if they'd been diagnosed ADHD in their early 20s instead of being diagnosed with borderline personality disorder, a lot of this other stuff potentially wouldn't [have followed]. (P3, mother)

Participants also described harm from medication reactions that clinicians misinterpreted or from medication that did not suit their condition. One mother presented to hospital four times with akathisia, a state of intense restlessness that she developed after stopping medication in pregnancy: "They had all said to me, no, you've got restless legs (...) [it was] akathisia (...) and they didn't recognise it" (P13, mother). Another participant linked her suicidal period to psychiatric medication that a clinician prescribed on its own when she may have had a different condition for which the medication was contraindicated, meaning that clinicians would usually avoid it: "potentially misdiagnosis, and, not being treated with the right medication, and yeah, I do think the medication certainly worsened things" (P3, mother).

One participant described diagnoses that clinicians revised over several decades. She contrasted an earlier diagnosis that did not fit her experience with the ongoing relational care that helped:

they said that I had (...) chronic manic depression (...) which then went on to be bipolar, but I'm not bipolar (...) no medication ever worked (...) if I took medication, actually, I became worse (...) What worked was (...) going to see the social worker four times a week. (P19, mother)

Members of the co-design group also described the consequences of missed diagnoses. One member said: “for me my suicidality was around psychosis, and that was missed. So my diagnosis was depression. But the psychosis was causing the suicidality” (mothers’ co-design session). Another member described a psychiatrist dismissing her concerns: “I was completely dismissed by my psychiatrist at the time, who put it all down to the fact that my baby doesn’t sleep, so then it was, you know, solve the sleep problem, and then you’ll be fine” (mothers’ co-design session).

Harm Caused by Care

When a diagnosis led clinicians to disengage, minimise a woman’s experience or cause harm through care, participants described their suicidal behaviour as worsening. An incorrect explanation could also remove support that might have interrupted the crisis because clinicians may not develop a treatment plan when they attribute a woman’s distress to her character.

A mother admitted twice to a Mother and Baby Unit stated this claim most directly. Her perinatal mental health clinician requested a specific assessment on her behalf during each admission, but the unit refused both requests. When the interviewer asked what would have prevented her suicide attempt, she said:

if the first place that I went to twice prior to it all happening; if they listened to my perinatal mental health lady. And just had done the diagnosis. Like, just done the ADHD test. Like, it really wouldn’t have hurt anybody, to just do it. Like, and it just makes me angry... That would have stopped it. Yeah. If they’d figured it out, put me

on medication, I would have felt amazing (...) The first time they put me on ADHD meds, it was only 5 milligrams, and I've never felt so happy in 14 years. (P10, mother)

She described a counterfactual, an account of what would have happened under different circumstances, which we cannot test. She described what she needed from the service: "just listen to the people who are sending me there, because she knows me so much better than you do" (P10, mother).

Another participant described how a personality disorder diagnosis left her feeling invalidated and stigmatised during her admission:

They tried to diagnose me with like a personality disorder while I was in the unit, but this was before I was diagnosed with autism, which made more sense in the longer run, but they basically told me I had OCPD (Obsessive Compulsive Personality Disorder) (...) that it was my sort of relentless need for control that was the problem, and I was the problem (...) it really kind of left me feeling like, am I the whole issue here? Like, in my brain, it's like, I'm doing everything I possibly can to like, to support my baby. (P40, mother)

Women experiencing perinatal suicidal behaviour often appear well and conceal their distress because they fear the consequences of disclosure, as a companion analysis discusses (Scarth, Wereta, et al., 2026). Participants suggested that clinicians may therefore miss presentations associated with the highest risk. We infer that a clinician who remains curious may help prevent suicide.

Participants described feeling less isolated and ashamed when a clinician remained curious, provided an accurate explanation and believed them. One senior perinatal clinician offered an alternative explanation intended to reduce shame: "Suicidality is not a failure state

(...) someone's nervous system is daring to let us know how much pain they're in" (P35, senior perinatal clinician).

Having no explanation caused a different harm because participants could not distinguish the illness from their sense of self.

Theme 2. What the Crisis Changed Over Time

This theme describes a mismatch in time. Participants reported effects on identity, family life, parenting, work and relationships that lasted for years, while services provided care for weeks.

Changes Across Life

Mothers described lasting changes in their parenting. They monitored their own mental states closely, felt guilt about their parenting and, in some cases, changed their plans for further children. Participants described partnerships that ended or that they rebuilt on different terms; several marriages ended after the crisis, while some partnerships became closer but remained affected. Many participants lost trust in the health system after services caused harm or treated them differently, which made them reluctant to seek care again:

they're never gonna stop asking me about...like trying to kill [my]self. So that's really upsetting. It's very frustrating. I just wish it would stop, like... (P10, mother)

Another mother described lying to hospital staff after a later pregnancy because she feared the consequences of telling them the truth:

The hospital, like the diabetes educator, just laid it on so thick to me...that I was, you know... unequivocally ruining my child's life forevermore because I was... wasn't eating correctly. Yeah, so... so what I did was, instead of telling them, I just lied.

Yeah. I just... I literally just did what I needed to do, and I lied. (P17, mother)

Participants also changed their careers. Some left professions that they could no longer sustain, while others rebuilt their working lives in the perinatal sector, as Theme 3 describes. A third group remained in their profession and concealed the crisis. One participant was well by the time she returned from maternity leave, but explained why disclosure might harm her career:

no one I've worked with has really known that I have bipolar (...) my psychiatrist always said to me, you can't untell people (...) you might always be the one they think of as the girl with bipolar, and we'd better triple check her work, and, oh, well, we won't get her to do that. (P12, mother)

Another participant described the financial consequences: "I lost my business. It's like the financial impact of (...) not working for 2 years. Massive. And depending on other people" (mothers' co-design session). Several participants also described friendships in which people offered support and then withdrew it when participants asked for help.

Participants described changes to their sense of self as the most substantial effect. One mother grieved the mother she had wanted to be:

I had this vision of me just being this earth mother who could breastfeed (...) And, like, I'm, like, rocking on the floor in a mental health facility. Like, this is not what I had planned. (mothers' co-design session)

Gendered Responsibility

Participants described gendered differences in the effects that followed the crisis. Mothers experienced guilt and shame that reflected expectations established long before the crisis.

Mothers felt responsible for the crisis itself, for having been unwell, for what the household experienced and for actual or feared effects on their children. Several men described guilt about specific actions or absences, but no father described the complete

condemnation of self that mothers reported. Clinician participants described the same pattern: years after the crisis, mothers continued trying to show services that they were good mothers at every contact (Scarth, Wereta, et al., 2026).

The mothers' co-design group discussed how guilt affected their parenting:

I feel guilty for something that hasn't even happened yet (...) it's almost framed who I am as a mum, that I haven't let him experience adversity (...) before anything even happens, I'm in there fixing it. (mothers' co-design session)

The group distinguished shame from guilt: "I think guilt is internal, and shame is external (...) all the shame out there from how you perceive the world (...) internalises into guilt". Another mother explained how she rejected the shame while continuing to feel guilt: "I know this wasn't my fault, and I know I didn't choose it (...) so then the shame kind of then just gets debunked (...) but I feel guilty that this was an experience that my child had" (mothers' co-design session).

One member compared expectations of mothers with expectations of someone who has finished a triathlon:

If you signed up to do, like, a triathlon (...) you get to complain afterwards that it was really sore (...) But there's something about having kids that (...) Don't say you're not enjoying it. You asked for this. What is it about us having kids that changes that story for us? (mothers' co-design session)

Effects on Children

Participants whose children were older described how those children processed the crisis later and in their own therapy: "[they are] unpacking that in therapy" (P21, mother).

Families described siblings who became watchful and children who internalised unexplained absences. Parents continued to negotiate what to explain, whether to explain it and how to do so. Co-design members described the effort involved: "I'm constantly doing

the threat scanning, so I'm trying to protect my children against things that haven't even happened and may never happen". One mother described guilt "towards my parents, because they had to look after [child] for so long while I was in hospital" (mothers' co-design session).

Another participant used the experience to shape her parenting deliberately:

I try to reframe it as an opportunity to help my children learn how to deal with shame. Through being able to (...) name it, because (...) for so many of us, it was just a thing you never talk about. (mothers' co-design session)

Participants and clinicians identified child removal as the loss that women feared most after the crisis. Some participants said that, years later, they would still avoid asking services for help because they feared removal, as a companion analysis discusses (Scarth, Wereta, et al., 2026).

Follow-Up Lasted Weeks

Participants described effects that lasted for years and support that lasted for weeks. One mother recalled a public unit that was "very eager to kick people out quite quickly (...) I wasn't super stable at that point on my meds" (P10, mother). Another rejected the idea that recovery follows a clinical timetable: "it doesn't get better at 6 weeks, right? (...) it's 6 weeks, and now you're back to normal, yeah, the hell I am" (P16, mother). No participant described scheduled contact months or years after the crisis.

Without follow-up, participants continued to monitor their own mental health:

Some of my big aftermath is my hypervigilance around my own mental health (...) every time something happens in my life now, I'm like, am I going to lose my shit again? (mothers' co-design session)

The same uncertainty and close monitoring affected decisions about further children. "It makes me question whether I want to have a second child, because I'm scared that, if I do,

I'm gonna go through all of that again", one member said, and another replied, "a right of yours [to have more children] is being taken away" (mothers' co-design session).

Theme 3. More Than a Walking Diagnosis: Transformation Rather Than Recovery

Participants reflected on the relationship between a diagnosis and their identity, and they resisted treating the two as the same.

Diagnosis as Explanation and Constraint

Participants valued language that separated the person from the condition:

It just separates you from it, your identity from that mental illness (...) I can still be a very good mother, and I can still be a person who's experiencing this. (mothers' co-design session)

Participants described a diagnosis as having two possible effects. It could explain what had happened, or other people and sometimes the woman herself could treat her only as the diagnosis. One mother valued freedom from that constraint: "I don't have to fit within anyone's box of 'I'm better now'. It's more, 'I'm a new person now'" (P10, mother). Several participants, including clinicians, preferred explanations that reduced shame associated with diagnosis: "Not the illness model, [so] you reduce the shame, and when you reduce the shame, you make it possible to look and find out" (P35, senior perinatal clinician).

A diagnosis posed the greatest threat to identity for participants who understood themselves as capable. High-achieving participants described delaying help-seeking because they did not regard themselves as people who might need it. When clinicians eventually gave them a diagnosis, participants described greater shame because the diagnosis contradicted their previous understanding of themselves.

Loss of Identity and Rejecting Recovery

During the most severe periods, participants described losing their sense of identity: “I often say I feel like I (...) my soul died in that period. Like, there was a death, a spiritual death” (mothers’ co-design session). Participants also rejected the language of recovery because they could not return to who they had been before the crisis. One mother explained why:

I have mixed feelings about the use of the word ‘recovery’ in the perinatal space because it’s actually not possible, you can’t go back to who you were or the life you had before. You can’t give the baby back and your body won’t be the same.

Becoming a mother is inherently transformational, so constant focus on the idea of recovery isn’t helpful. It’s about discovering and finding your new reality with a baby, and having the space and time to work that out. It’s okay to not have all the answers right away, it doesn’t mean that there’s something wrong with you, it’s a normal need to recalibrate. (mothers’ co-design session)

Another mother responded to the co-design member’s statement when the interviewer described it and agreed: “Recovery’s not really the word (...) I don’t have to necessarily recover from this” (P10, mother). Participants’ objection to recovery has consequences for services. In their accounts, services that aim to restore a person’s former self set a goal that cannot be met and may attribute the unmet goal to the patient.

Survival and Rebuilding the Self

Participants who described losing themselves also described building a new sense of self afterwards. One framed survival itself as an opening: “This is my second life (...) I am completely different (...) I’ve survived (...) what do I want my life to look like?” (mothers’ co-design session).

Participants often described rebuilding their sense of self as lonely but necessary:

I think it can be such a lonely process though (...) All my relationships disintegrated (...) it's a lonely place to find yourself in. And having to reconstruct who you thought you were, who you are, and who you're becoming...without anyone around, it's hard. But at the same time, I guess, it almost needed to happen for me because I didn't need any of that external influence, I just needed to really focus on myself. (mothers' co-design session)

Participants described having to rebuild their identities as mothers, and they emphasised how difficult this process was:

I feel like a really big thing (...) was also sort of losing my, like, self-identity, because after all of that, I didn't feel like a mum. But I didn't feel like myself as well, and I just felt like (...) like a complete different person with no sense of self (...). Like, there was that expectation of, you're a mum now, but (...) I think the biggest thing was just bonding with [child]. I struggled so bad with that (...) and with the psychosis, I was so convinced that [child] was someone else's (...) I just did not see myself as a mum at all after all of that (...) I do recognise myself as a mum now. But I guess with, like, my relapses it sort of takes that away sometimes as well, and so I have to sort of remind myself, like...[child] is mine, I am [child's] mum (...) So (...) I do feel more comfortable with that identity of being a mother. But at times, it does get difficult, and it goes down a little bit as well. (mothers' co-design session)

Some participants described gratitude that they had survived into a life they had not thought possible: "I have an overwhelming sense of gratitude, because I didn't think I would survive, and now I am, and I'm thriving" (mothers' co-design session).

Meaning, Growth and Grief

Participants made meaning deliberately over several years, and they described an explanation as the foundation of that process. An explanation that fitted, usually provided through a diagnosis, helped participants organise experiences that had felt chaotic into a narrative; storytelling helped them develop that narrative. Participants described telling their story to partners, to children at the right age, to other mothers and to this study as work that organised the experience and gave it a purpose. This process is consistent with research on storytelling and self-disclosure in growth after suicidal experiences (Scarth et al., 2021).

For some participants, advocacy and work in the sector extended this process. Many participants became perinatal peer workers as a way of using their experience to help others, while also describing the costs of this work. The sessions also showed how participants made meaning together: “there’s five of us sitting in a room, naming this misjustice, and saying it needs to be better (...) what drives me is, like, for this to not happen to someone else. For the learnings, and that’s how I’ve made meaning” (mothers’ co-design session).

Participants described growth alongside grief for what they had lost during their suicidal crisis and early motherhood. One participant linked both responses to the diagnosis itself:

In terms of growth, ADHD, figuring that out caused a huge amount of grief. But also, I’m so glad that I know. But there was such a huge grief in looking back on my entire life and realising that, what could have been different, if only they’d known. If only I’d known (...) how much could have been saved, how much pain might not have happened. (P10, mother)

The diagnosis explained the experience and clarified what the participant believed that an earlier diagnosis might have prevented.

Discussion

Participants experienced diagnosis as an event that affected identity as well as clinical care. Bury (1982) described chronic illness as a biographical disruption that forces people to revise their account of who they are, and participants described diagnosis as having similar effects in two directions. Clinicians gave women mental health diagnoses before, during and after their suicidal crisis, sometimes only years later. When a diagnosis fitted and the clinician validated the woman's experience without attaching shame to the diagnosis, participants could understand their suicidal experience and enter a care pathway. An incorrect, dismissive or absent diagnosis disrupted participants' understanding of themselves and could deepen distress. Clinicians therefore need skills in communicating diagnoses as well as skills in diagnostic accuracy, yet they receive little training in diagnostic communication (Milton & Mullan, 2014; Perkins et al., 2018).

Misdiagnosis harmed participants when clinicians gave them treatment that did not fit their condition and when participants tried to fit themselves to a diagnosis that did not describe them. Participants most often described BPD as changing how clinicians engaged with them, and participants with lived experience, professional experience or both reported this pattern. Researchers have also reported stigma and altered clinical processes for people diagnosed with BPD (Stiles et al., 2023). One participant described a unit refusing an assessment twice and believed that the assessment, and the treatment it would have led to, could have prevented her suicide attempt. One participant had an explanatory framework available when she received a BPD diagnosis, which indicates the value of providing support and explanation when clinicians give a diagnosis (Stiles et al., 2023).

Participants also described timing as important and said they needed time to build trust with the clinician who gave the diagnosis. Researchers have reported a similar finding in

the broader literature on psychiatric diagnosis (Milton et al., 2016; Perkins et al., 2018). One participant did not want further labels because the diagnoses she already had overwhelmed her. Researchers appear to have conducted little empirical work on how accumulating diagnoses affects a person (Brossard & Chandler, 2022).

Participants described effects that lasted for years, varied over time and received little support. They reported effects on parenting, relationships, healthcare encounters, employment and identity. Mothers described substantially greater effects than fathers. Participants attributed this difference to cultural and institutional forces that scrutinise mothers more closely, which is consistent with research on motherhood (Lucas et al., 2019). Mothers wanted support while they rebuilt their sense of self and their parenting, both during the crisis and afterwards.

Participants described rebuilding themselves as transformation rather than recovery, while they experienced growth alongside grief for ruptured relationships and disrupted motherhood. They made meaning deliberately in two ways. They developed an account of why the crisis had happened, then used what they had learned through storytelling and peer work, including advocacy. Participants also held that services set them up to fail when they aimed to restore a former self. They asked for time and space to recalibrate without pressure to present a triumphant ‘recovered’ ending in research or services. Researchers have established an extensive literature on post-traumatic growth (Frey et al., 2019; Scarth et al., 2021; Tedeschi & Calhoun, 2004), and Leamy et al. (2011) framed personal recovery in mental health around connectedness, hope, identity, meaning and empowerment. Participants wanted these things for themselves while rejecting the word recovery entirely. Participants cautioned against applying the term in the perinatal context because they described growth alongside grief, never instead of it. When participants received no explanation or understanding, they could not begin to make meaning from the crisis. Clinicians affect more

than they often acknowledge through diagnostic accuracy and communication (Milton & Mullan, 2014): they influence treatment decisions (Stiles et al., 2023) and whether a woman can develop a coherent account of what happened to her, transform and make meaning from the crisis.

Limitations

Participants gave retrospective accounts, which carry both distance from events and the meaning-making that distance allows. Women were interviewed approximately 2 to 20 years after the index birth (median approximately 5 years), so some accounts describe events from many years earlier, and details of timing and of what services said may be inexact. We report service conduct as participants described it and examined no clinical records. Participants' accounts therefore give no direct record of events. This matters especially in a paper about meaning-making, since the accounts are themselves instances of the process described. We did not formally assess current mental state, so we cannot say how current illness or treatment shaped what participants told us.

We recruited substantially through perinatal mental health networks, and sixteen participants had built working lives in the sector. That bounds the transformation claim. People who made meaning by entering the field are more likely to join research about the field. Fathers in this study took part as carers, so differences between mothers' and fathers' accounts reflect their different roles in the crisis as well as gender. One researcher coded the data. The co-authors and the mothers' group challenged the themes but did not verify them as second coders.

Diagnostic histories are self-reported and we did not verify them against records, which suits the research question, since the paper concerns the experience of being given an explanation. It limits any claim about actual rates of misdiagnosis.

Index experiences span approximately two decades and several service systems, which gives unusual reach into the long aftermath and limits claims about any single current service. Participants included Aboriginal and Torres Strait Islander people, Māori people and people from culturally and linguistically diverse backgrounds; diagnostic experience and aftermath in these communities both require dedicated, community-governed research.

Implications for Practice and Research

Participants' accounts suggest changes that perinatal services could make. Clinicians could treat giving a diagnosis, or preferably a diagnostic formulation that explains how a clinician understands the woman's experiences, as the start of a conversation. They could allow time to explain the diagnosis or formulation, check how the woman understands it and revisit it when it does not fit her experience. Services could consider neurodivergence and postpartum psychosis when a woman describes years of unexplained distress, and clinicians could take care before giving a BPD diagnosis during an acute perinatal crisis. Services could extend follow-up well beyond the weeks of acute care because participants described effects that lasted for years.

Future researchers could follow women for several years after perinatal suicidal behaviour, well beyond the first postpartum year. Researchers could also examine how clinicians communicate perinatal diagnoses and how that communication affects later help-seeking. They could test whether extended follow-up reduces later suicidal behaviour.

Conclusion

Participants described transformation after perinatal suicidal distress as a process that began with seeking an explanation, continued through the crisis and its long-term effects, and eventually involved rebuilding the self. When clinicians offered a diagnosis that fitted

without stigma, participants could use it to make meaning and rebuild. An incorrect diagnosis, or no diagnosis, prolonged confusion and distress for years.

The effects persisted for years, while follow-up support lasted only weeks. Participants rejected recovery language because it did not describe their experiences: they had rebuilt themselves and changed. They asked perinatal services to consider how clinicians communicate a diagnosis as well as its accuracy, validate what women describe and remain involved over time.

Use of Artificial Intelligence and Other Technologies

We did not use generative artificial intelligence to generate or analyse participant data, and we did not use automated coding functions in qualitative data analysis software. During preparation of the manuscript, the first author used voice-to-text for drafting, followed by Microsoft Copilot to support editing and formatting, as part of her disability support plan. The authors reviewed and edited all output and take full responsibility for the content.

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The authors declare that there is no conflict of interest.

Author Contributions

Bonnie Scarth: Conceptualisation; Methodology; Investigation; Data curation; Formal analysis; Funding acquisition; Project administration; Writing – original draft; Writing – review and editing. Julie Levin, Nicola Akeroyd, Hiro Kojo, Courtney Patten, Andrée Balzer: Conceptualisation; Formal analysis (sense-making session); Writing – review and editing. Kylie King: Supervision; Investigation; Data curation; Writing – review and editing. Anne Buist: Supervision; Investigation; Data curation; Writing – review and editing. All authors approved the final manuscript.

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Data Availability

Participants did not consent to the sharing of full transcripts, and several are identifiable within their own communities, so the data are not publicly available. Enquiries about the interview guides can be directed to the corresponding author.

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