Received: 13 September 2018 | Revised: 17 January 2019 | Accepted: 12 February 2019

DOI: 10.1111/jocn.14820

ORIGINAL ARTICLE

WILEY Journal of Clinical Nursing

The forgotten mothers of extremely preterm babies: A qualitative study

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Funding information
Funding for this research study was received from the University of Technology and University of Hertfordshire.

Abstract

Aims and objectives: To explore the experiences of mothers of extremely premature babies during their Neonatal Intensive Care Unit stay and transition home.

Background: Mothers of extremely preterm infants (28 weeks' gestation or less) experience a continuum of regular and repeated stressful and traumatic events, during the perinatal period, during the Neonatal Intensive Care Unit stay, and during transition home.

Method: An interpretive description method guided this study. Ten mothers of extremely premature infants who had been at home for less than six months were recruited via a Facebook invitation to participate in semi-structured telephone interviews exploring their experiences in the Neonatal Intensive Care Unit and the transition home. The data were examined using a six-phase thematic analysis approach. The COREQ checklist has been used.

Results: Two main themes emerged: (a) things got a bit dire; and (b) feeling a failure as a mother. Participants had a heightened risk of developing a mental disorder from exposure to multiple risk factors prior to and during birth, as well as during the postnatal period in the Neonatal Intensive Care Unit and their infant's transition to home. Mothers highlighted the minimal support for their mental health from healthcare professionals, despite their regular and repeated experience of traumatic events.

Conclusion: The mothers were at high risk of developing post-traumatic stress symptoms and/or other mental health issues. Of note, study participants relived the trauma of witnessing their infant in the Neonatal Intensive Care Unit, demonstrated hypervigilance behaviour and identified lack of relevant support needed when their infant was at home.

Relevance to Clinical Practice: This study highlights the need for nurses to include a focus on the mothers' psychosocial needs. Supporting maternal mental health both improves maternal well-being and enables mothers to be emotionally available and responsive to their extremely preterm infant.

KEYWORDS
mental health, Neonatal care, preterm, psychosocial adjustment, qualitative study, women's health

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1 | INTRODUCTION

Annually, there are at least 15 million preterm births internationally, with the number of preterm and extremely preterm infants increasing (World Health Organization, 2018). Mothers who give birth to extremely premature infants (born alive at 28 weeks' gestation or less) (World Health Organization, 2018) are regularly confronted with traumatic events during pregnancy, labour, birth and while their infant is in the Neonatal Intensive Care Unit (NICU) (Hess, Teti, & Hussey-Gardner, 2004). Many mothers experience an acute stress disorder (ASD), which may then lead to post-traumatic stress disorder (PTSD) (Jubinville, Newburn-Cook, Hegadoren, & Lacaze-Masmonteil, 2012). ASD has a duration of three days to one month after exposure to a traumatic event, and is distinguished from PTSD by this time frame (Diagnostic and Statistical Manual of Mental Disorders [DSM-5®] (2013)). Symptoms of ASD include involuntary, intrusive and recurrent distressing memories, sleep disturbance and hypervigilance (Diagnostic and Statistical Manual of Mental Disorders (2013)).

Of note, traumatic experiences can continue as mothers transition home with their babies, resulting in emotional challenges (Petty, Whiting, Green, & Fowler, 2018) and low maternal self-confidence (Jotzo & Poets, 2005). Mothers frequently experience heightened caregiving requirements to maintain their infant's health, with a constant need for vigilance, but experience a lack of professional and social support while in hospital and the community. The mothers have described this as being a safeguard for their infant (Griffin & Pickler, 2011).

The main focus of care by healthcare professionals from the time an extremely premature birth is threatened is on the infant due to their often precarious health status. This may therefore lead to a subsequent lack of focus on the mother's mental health, placing her at significant risk of developing a mental disorder from the sudden, unexpected and overwhelming experience of having an extremely preterm infant (Beck & Harrison, 2017; Jubinville et al., 2012). Given their gestational development, preterm babies commonly require major interventions within a NICU (Aftyka, Ryojad, Rosa, Wróbel, & Karakuta-Juchnowicz, 2017).

While parental stress is not uncommon due to the demands of a newborn infant, for parents of extremely preterm infants this stress is compounded by such events as the unknown survival chances of their infant (Ballantyne et al., 2017), and being present during regularly occurring emergency situations within the NICU (Ditzel, 2016) for both their infants and others in the unit. As the extremely preterm infant needs remain a priority for NICU staff, the mother and her role may be overshadowed (Jubinville et al., 2012) resulting in her physical and emotional needs being neglected. This paper explores the experiences of mothers with extremely preterm babies and their resulting emotional distress.

2 | BACKGROUND

Maternal mental health is now well accepted as a significant factor in enabling infants to reach optimal growth and development (Austin & Highet, 2017). Of concern, approximately 20% of mothers develop a mental disorder during the perinatal period (O'Hara, Wisner, Asher, & Asher, 2014). In many countries, maternal psychosocial assessment is conducted during the antenatal period and several times during the first year after giving birth, although assessment approaches are not consistent in all jurisdictions (Austin et al., 2017; Haran, van Driel, Mitchell, & Brodribb, 2014). In Australia, it is recommended that all women receive a psychosocial assessment, for example, as early as possible during pregnancy, at six-to-eight weeks and six-to-eight months postpartum (NSW Department of Health, 2009). Assessment includes women's previous experiences of mental illness, family history of mental illness, available social supports, domestic violence, and childhood emotional and physical abuse (Austin & Highet, 2017). For some women, these assessments identify the need for early intervention to address potential or existing mental disorders (Austin et al., 2017); this is particularly important for women who experienced traumatic experiences during their perinatal period (Austin et al., 2017), notably birth of an extremely preterm infant (Beck & Harrison, 2017).

A mother's mental health status is known to have a significant impact on the mother and infant relationship development and the infant's future mental and physical health (Royal College of Midwives, 2012). The mother's mental health status potentially places an extremely preterm baby at high risk of developing significant chronic and acute health problems (Beck & Harrison, 2017; Galeano & Carvajal, 2016) including mental health status in adolescence and adulthood (Glynn et al., 2018).

Given the critically ill nature of an infant, it is unsurprising that the focus of care is on the infant rather than the mother during this time. NICUs in Australia provide tertiary- and quaternary-level services for newborns, including those who are extremely premature and require continuous life support, other complex care, surgery and treatment (e.g. Office of Kids & Families, 2016). These units are therefore extremely busy clinical environments with high use of technology; for mothers, this can be overwhelming and at times frightening (Ardal, Sulman, & Thomson, 2011). Internationally, perinatal depression and

What does this paper contribute to wider global clinical community?

- Supporting the mental health of the mothers of extremely preterm babies not only will improve maternal well-being, but there are positives for the infant who has a caregiver who is emotionally available and responsive to the infant's unique needs.
- Midwives, nurses and other health professionals require increased awareness of the psychosocial needs of mothers with extremely preterm infants.
- Improved health professional education needs to be provided that focuses specifically on this group of mothers so that support is tailored to their particular needs.

anxiety are common (Buist & Bilszta, 2001; Shah, Clements, & Poehlmann, 2011). Critically, these disorders are magnified in mothers of extremely preterm infants (Buist & Bilszta, 2001), including a heightened risk of developing a mental disorder (Pace et al., 2016) related to their parenting experiences during the first postnatal year (Alkozei, McMahon, & Lahav, 2014; Shah et al., 2011). Mothers of premature babies also have higher prevalence of depression, anxiety and PTSD, and experience these conditions for longer durations (Baum, Weidberg, Osher, & Kohelet, 2012). Importantly, mothers of preterm babies describe the transition from the NICU to home as the most difficult of their lives, and can experience anxiety up to two years postdischarge (Griffin & Abraham, 2006).

Developing a support network of experienced mothers who can provide regular parenting information has been identified as necessary for most new mothers, and is protective against postnatal depression (Leahy-Warren, McCarthy, & Corcoran, 2011). This peer support reduces mother's concerns and provides care enabling her to rest and recover during the early months of motherhood. For mothers of extremely premature infants however, an appropriate support system may not be easy to access, and mothers may be reluctant to trust others to care for their infant. Given that maternal mental health is key to the long-term health and well-being of developing preterm babies, exploring support needs and other potential initiatives to improve outcomes is important.

3 | METHOD

3.1 | Study aim

The study aim was to explore the experiences of mothers of extremely premature babies during their Neonatal Intensive Care Unit stay and transition home.

3.2 | Design

To address the study aim, an interpretive description method was used to enable development of the study questions, reflection and critical analysis (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Interpretive description has a focus on practice phenomenon (Thorne, 2008) and is useful for small-scale studies (Thorne et al., 2004). Interpretative description enables a focus on an exploration of what we know and what we do not know about the phenomenon of interest (Thorne, 2008)—in this case, the experiences of mothers of extremely premature babies during their Neonatal Intensive Care Unit stay and transition home. It is acknowledged that the study design and interpretation of the data were influenced by the nursing experiences and understanding of the researchers. Hegelund (2005, p. 656) comments that:

> Because the researcher does have his or her background of knowledge with her all the time, and because this cannot, nor ought it to, be switched off, it will affect (also in the sense of give meaning to) what he or she sees and concludes.

However, as advocated by Clarke (2009), to facilitate transparency and rigour, a reflexive approach underpinned the study. In addition, one member of the research team who was purposely not directly involved in the data collection or analysis and was therefore available to independently scrutinise each stage of the research.

The study gained ethical approval by the University of Technology Sydney Human Research Ethics and Research Committee. Data were de-identified prior to analysis. The COREQ checklist (see Supporting Information Appendix S1) was used to guide construction of this article. (Tong, Sainsbury, & Craig, 2007).

3.3 | Recruitment

Mothers were invited to participate if they had an extremely preterm infant, had been at home with their infant for less than six months and spoke English. Recruitment occurred using the Miracle Babies Foundation Facebook site. This association interacts with and supports parents of preterm and other babies who have spent time in NICU. Twelve mothers responded within the first week of recruitment; ten were interviewed, with the remaining two not able to be re-contacted. Prior to being interviewed, each mother was emailed an information sheet and consent form. Those agreeing to be interviewed returned their consent form via email.

3.4 | Data collection

Semi-structured interviews were conducted via telephone by the first author. This approach enabled participation from different Australian locations. At commencement of the call, participants were reminded that the interview was being digitally recorded, and verbally confirmed their consent to participate. Interview questions focused on: events leading up to the birth; their experience in the NICU; the parenting education they received prior to their infant's discharge home; the parenting challenges they experienced at home; and the support they received from family, friends and health professionals. Each interview ranged from 30–40 min in duration. The infants were often present during the interview. On occasions, recording was stopped to allow the mother to care for her infant. Data saturation was identified at nine participants, and additional interview was conducted for confirmation.

3.5 | Analysis

A six-phase analysis framework was used to conduct a thematic analysis: data familiarisation; coding; searching for themes; reviewing each theme; defining and naming themes; and writing up the findings (Braun & Clarke, 2014). Transcripts were read and re-read, and coding was conducted manually, facilitating identification of multiple themes by the first and second authors. Each theme was

TABLE 1 Participant details

Mother	Maternal age (years)	Mother's birth country	State	Gestational age (weeks)	Birthweight (g)	Length of stay (days)
1	38	Australia	WA	24	700	91
2	30	Tonga	NSW	25	700	133
3	28	Australia	NSW	27[a]	1,100[a]	84
4	26	Australia	WA	25	710	105
5	33	Australia	Qld	27	990	77
6	30	Australia	WA	27	1,160	62
7	30	Australia	WA	27	870	70
8	39	USA	NSW	27	1,000	73
9	31	Italy	NSW	24[b]	490	140
10	32	Australia	NSW	26	1,020	91

Notes. NSW: New South Wales; Qld: Queensland; WA: Western Australia.
[a]Twins, both same weight. [b]Twins, other twin died in utero at 23 weeks.

reviewed internally and considered within the context of the study purpose, to identify the final emergent themes and their subthemes. Field notes were referred to during the analysis.

4 | RESULTS

Study participants were from three Australian states, and their ages ranged from 26–38 years. Their infant's gestation ranged from 24–27 weeks. There were eight singleton babies and two sets of twins (one participant had one of her twins died in utero) (see Table 1 for further participant details).

All ten mothers experienced varying degree of distress from the rupture of their membranes or the first onset of labour. Eight of the babies were readmitted with respiratory infections to hospital within a week of discharge from the NICU, and one infant was readmitted after four weeks for feeding problems. Another infant returned to hospital for planned hernia surgery at four weeks post-NICU discharge; unfortunately, he developed complications and had an extended stay in hospital. Only two babies had not been readmitted to hospital at the time of interview.

Mothers had a heightened risk of developing a mental disorder due to multiple risk factor exposure prior to birth, during the birth, across their newborn's admission to NICU, and their transition period home with their infant. Only one participant was provided with the three recommended psychosocial assessments: four mothers did not have any assessment, two had one assessment, and three had two assessments. The women who had assessments only recall having the Edinburgh Depression scale administered, and did not know whether they had a full psychosocial assessment. Most assessments were conducted in hospital or during the antenatal period with only two mothers noting their assessment after discharge home. Only one mother had regular psychiatry consultations after her infant's discharge home, although this was for a pre-existing mental disorder. One other mother had consultations with a psychologist, and another was seen by a social worker once while in the NICU. These women were not offered further sessions.

Two themes emerged from the data, each with related subthemes (see Table 2). Themes and subthemes are described below, with verbatim de-identified quotes used as exemplars to elaborate or illustrate the key issues experienced by participants.

5 | THINGS GOT A BIT DIRE

Participants commonly spoke of being stressed and emotionally distressed. For some mothers this started during pregnancy, continued through labour, birth and for many months postbirth. One mother described it as: "… things got a bit dire (M6)," as she talked about her experiences. This phrase encapsulated the life and death struggle for their newborn. The breadth and depth of these traumatic experiences are highlighted in the following subthemes: trauma of the unknown; life and death struggles; and being separated.

5.1 | Trauma of the unknown

Exposure within the NICU as a mother of a critically ill infant, as well as vicariously experiencing other babies' life and death struggles, was a source of continued emotional trauma. Women spoke of not knowing what would happen or was going to happen. This "unknown" created for the mothers an environment of constant stress and anxiety. As noted above, this emotional distress frequently commenced during pregnancy. One participant reported her experience of finding out one of her twins had died in utero but knowing she had to carry on with her pregnancy while grieving the loss of her second infant.

> At about week 21, it started to become pretty evident that things weren't looking great. But we didn't expect that the worst would happen. At about week

TABLE 2 Themes and subthemes

Themes	Subthemes	Example quotes
Things got a bit dire	Trauma of the unknown	It's really stressful because all you want is for your child to be okay. You're not going to know that, and no one is going to give you the answers for that. (M3)
	Life and death struggles	It was 48 hr past, and [my baby] had a brain haemorrhage. The consultant that did the ultrasound thought that would be a grade 2, grade 3 brain haemorrhage, which potentially meant that, in the next week, we'd have to make a decision about his care. Again, totally shocked and overwhelmed with emotion, and definitely didn't want to be in that position to make the decision. Luckily, after a week, that subsided, and we carried on with the journey. (M9)
	Being separated	So after [baby] was born I wasn't even able to see him for 6 hr later because they didn't have any porters or anyone to take me down to … I was in pain for the first few days and couldn't stand up to do any of his care. (M8)
Feeling a failure as a mother	Lost mummy moments	I feel like I failed as a human being able to keep this baby inside me. I had one job and I failed at that … We were never told what to expect by anyone. So I just felt like I lost a lot of those mummy moments. (M8)
	Slipped through the cracks	They put us in a ward … everyone had their babies. No one told us what it meant to have an extremely premature baby. In my mind my baby was going to die … It was hard for me to hear their babies cry … I should never have gone to the postnatal ward … I don't think anyone with an extremely premature baby should ever go there. It was cruel and awful and even in that time in NICU I think I was … our child was quite a healthy baby … I think we slipped through the cracks and a lot of things (M8)
	You can't leave them with anyone	Being in [hospital] was a very isolating experience … then to come home and be so far from everyone, emotionally that was quite hard. (M4)
	Losing control	No … no I'm fine now I don't know if it was the initial shock. I did talk to the home nurse who came to visit she offered a group … I had a really high powered job and then I was stuck home with [baby]… As I said I'm fine now … I did have some things I had to work through … So I'm fine (M8)

> 23, we found out that twin two's heart had stopped, but then twin one was still okay. He was still fine. … At that time, obviously, it was really traumatic trying to deal with the news of one baby passing away but then also having to carry another one full term, which, at that time, we were told it was a possibility. (M9)

Being an expectant mother of twins but then having to manage the distress of losing a child resulted in significant emotional trauma for the mother. An unspoken concern and source of trauma was dealing with her uncertainty about the viability of her live infant.

For another mother, her pregnancy was difficult resulting in the birth of twins at 27 weeks' gestation, following many hospitalisations for hyperemesis gravidarum.

> I was in hospital on the Thursday. And I was in there for hyperemesis gravidarum … That was my 30th admission into the hospital … So, it's been a bad pregnancy … It was an emergency caesarean, but I was 10 centimetres dilated. So, they were just questioning whether I could deliver naturally or not because one of them was breach. So, it was a bit of an emergency situation in the end … I didn't really know what the NICU was. So the whole thing completely, you know I was in shock basically the whole time. (M3)

This mother's last statement of *I was in shock all the time* implies that her experience was not short-lived, but continued as an outcome of having a preterm infant. This experience was compounded when her birthing became an emergency situation with a lack of information about the NICU and what would happen:

> It's really stressful because all you want is for your child to be okay. You're not going to know that, and no one is going to give you the answers for that. (M3)

Extremely preterm babies commonly have significant health problems that exacerbate any maternal anxiety. Often this anxiety was intensified by the "unknown"; if and when their infant was going to experience another emergency episode. One mother accentuated her feelings by repeating the word "very.".

> I was very, very anxious because … he has a heart problem where his heart rate just goes through the roof, and … the nurses couldn't really, if they just looked at [baby], couldn't tell that he was out of rhythm for as long as he was, because he never ever gave signs. (M2)

For this mother, uncertainty about her infant's health and the critical health episodes caused her intense anxiety, especially as nurses were unable to accurately monitor his cardiac status through visual means.

The experiences of ongoing health problems during the first hours and days after birth, and the resulting maternal distress were a common thread throughout the interviews, with survival often unpredictable.

> When poor [baby] was really, really sick, I thought I was going insane, crying every five seconds. (M2)

From the words this mother used, the strong impression was that she was extremely distressed and inconsolable. The mother's statement of *I thought I was going insane* highlights the impact of uncontrollable emotions that can be experienced.

For mothers being in a NICU watching unfolding emergency events happen to other babies also highlighted the vicarious and potential distressing nature of being constantly exposed to such a stressful environment; as noted by one participant:

> so we had a few situations around us that were quite messy, so there was a fair bit going on. (M4)

Having "a fair bit going on" reflects the complexity of a NICU with real life dramas being regularly played out. For the majority of mothers, a NICU is a foreign environment with constant unknowns and distressing situations occurring either to their babies or to other babies. Being in a NICU environment therefore created the potential for mothers to be traumatised and re-traumatised personally and vicariously.

5.2 | Life and death struggles

Life and death situations are a common feature of a NICU. Mother 9 told of her baby's brain haemorrhage that placed them in a situation where they anticipated having to make decisions about their baby's treatment plan. This decision would probably mean the death of their baby.

> It was 48 hours past, and [my baby] had a brain haemorrhage. The consultant that did the ultrasound thought that would be a grade 2, grade 3 brain haemorrhage, which potentially meant that, in the next week, we'd have to make a decision about his care. Again, totally shocked and overwhelmed with emotion, and definitely didn't want to be in that position to make the decision. Luckily, after a week, that subsided, and we carried on with the journey. (M9)

The mother described her emotions as *totally shocked and overwhelmed with emotion*. While the words used at the end of the quote appear to be "matter-of-fact" *luckily, after a week, that subsided, and we carried on with the journey*, this was not the impression given when combined with her voice tone. Her voice softened as she spoke of the situation improving and the need for decisions about his care not being necessary at that stage.

5.3 | Being separated

Being physically separated after birth from their newborn babies was extremely distressing for mothers. These delays were often due to the need to recover from their caesarean operation; their restricted movement and lack of hospital staff to transport them to the NICU were described by two mothers:

> What I found really hard was when I gave birth, when [baby] was born, I was not actually able to see him till I could stand up and I really had to push myself to get up so I can go see my son. That was pretty traumatic. I don't know whether it was the nurses that I got, upstairs, or I'm not sure why, but when I was down in the nursery, I realised that other mothers were getting wheeled down in their beds, but for some reason they wanted me to get out of bed and stand up before I could go and see him. (M2)

> So after [baby] was born I wasn't even able to see him for 6 hours later because they didn't have any porters or anyone to take me down to … I was in pain for the first few days and couldn't stand up to do any of his care. (M8)

Extended and seemingly unnecessary separations prior to their first visit to NICU were as Mother 2 stated *pretty traumatic*. Even if their partner or other family members provided pictures and descriptions of the infant and their condition, mothers felt an imperative to see their babies.

Leaving hospital without their infant was also extremely difficult for mothers, as it was not the joyous time they had anticipated during pregnancy. For one mother going home without her babies provided additional time to think about what had happened and possibly how changed and difficult her life was going to be.

> I knew they were in good care in the hospital, and then when I went home it was very weird feeling …

> I was quite upset having to leave them there and not bring them home. And I guess as well, I had a lot of realisations about what [would] … happen when I went home. (M3)

6 | FEELING A FAILURE AS A MOTHER

Meeting the standard of motherhood that many mothers aspire to can result in some in these circumstances regarding themselves as failures. The inability to carry an infant to full-term and to experience the sense of achievement of having a healthy infant causes mothers of extremely preterm babies to feel guilty and that they have failed motherhood. This feeling of failure was accentuated when they saw mothers around them with healthy full-term babies. A significant potential outcome for these women as a response to their experiences identified within this and the previous theme is maternal mental illness. This theme incorporates three subthemes: lost mummy moments; slipped through the cracks; and you can't leave them with anyone.

6.1 | Lost mummy moments

The experience of having lost lots of *mummy moments* was significant for study participants, and a clear source of sadness and distress, those quiet periods of exploration spent together learning about each other. These mummy moments initially can become insignificant due to the concerns about survival of their infant but later become a potential source of sadness, distress and guilt. This immediate lost time with their infant and a lack of information about what was happening or would happen was likely to compound their feelings of maternal failure. One mother stated:

> I feel like I failed as a human being able to keep this baby inside me. I had one job and I failed at that … We were never told what to expect by anyone. So I just felt like I lost a lot of those mummy moments. (M8)

Of note, the use of social media by new parents is now a well-used and accepted medium to communicate and celebrate with family, friends and even an unknown audience. For mothers of preterm babies, whether and how they participate in this practice has the potential to compound emotions, insecurities and confidence about their mothering abilities and their feelings of distress they were experiencing. One participant commented:

> There was a point where I had to remove myself from social media and group conversations, because it's very hard looking at people who are living very happy lives, worrying about the smallest things, when your day-to-day involves multiple heel pricks, watching your baby's heart rate drop, one cannula after the next, invasive eye checks. It's a very, very intense traumatic environment. It's very hard to look at everyone else making plans with their life, when you can't even make plans for the next day, really, because you don't know what the next day is going to hold. (M9)

Mother 9 reinforced the *very very intense traumatic environment* she experienced and provided a counterpoint of the normal, routine experiences she was missing with her infant compared to her peers. Hearing positive motherhood stories compounded her sense of failure and the lost happy and expected experiences of motherhood.

6.2 | Slipped through the cracks

For most participants, being with mothers who had healthy full-term babies was confronting, as it heightened their awareness of what they were missing in the early months of motherhood. This was highlighted early for Mother 8 being in a postnatal ward after giving birth, surrounded by other mothers and their healthy babies. She described her emotional distress and the trauma she was experiencing as having *slipped through the cracks*.

> They put us in a ward … everyone had their babies. No one told us what it meant to have an extremely premature baby. In my mind my baby was going to die … It was hard for me to hear their babies cry … I should never have gone to the postnatal ward … I don't think anyone with an extremely premature baby should ever go there. It was cruel and awful and even in that time in NICU I think I was … our child was quite a healthy baby … I think we slipped through the cracks and a lot of things. (M8)

While this mother could visit her infant, being surrounded by mothers and their healthy babies was a constant reminder of her infant's critical situation, and the missed opportunities and joy of having a new, healthy baby. Lack of information resulted in additional distress, as she did not know what to expect; without this knowledge she thought *her baby was going to die*. Mother 8 continued talking about her experiences (by this time in the interview she had become tearful but did not want to stop until she had told her story).

> I think they needed to realise that even though it was … the first few weeks were really hard but even still like … we were still going through this as much as someone with a baby that might be really ill too. We saw babies die and stuff like that too. We were also going through stuff like they were. They [postnatal ward mothers] got a lot more support than we did. (M8)

Of note was the lack of support received, implying that midwives must recognise the need to provide mothers with their babies in the NICU emotional support during their stay in the postnatal ward.

6.3 | You can't leave them with anyone

A major issue for many participants was their necessary isolation once home, often resulting in a restricted lifestyle and a lack of social support that many mothers of term babies take for granted. During transition from hospital, mothers were excited to take their babies home even though they found leaving hospital difficult, as the isolation they experienced in hospital now continued at home.

> Being in [hospital] was a very isolating experience … then to come home and be so far from everyone, emotionally that was quite hard. (M4)

While social support is identified as a key element in reducing the onset of perinatal mental disorders, this important element was frequently missing from these mothers' lives, increasing their stress levels and distress:

> I probably would say the stress factor, it really continues. It's hard to manage the stress, or go to the gym and so on, because … you are very conscious of going, being around other people. Number one, taking your baby around other people, not taking them to a gym where there is germs and so on. You can't really leave them with anyone else because they are quite particular, they're all vulnerable babies. (M9)

Being unable to expose her infant to any health risks because of an immuno-compromised state, Mother 9 identified that many potential activities to reduce her stress were not possible. These everyday activities and the ability to leave the infant with others make caring for extremely preterm infants a relentless task. Mother 3 echoed this sense of isolation in an attempt to protect her babies.

> Yeah, I didn't take the girls out. I mean I took them on walks, but I didn't take them to anywhere public as such, until they were six weeks corrected. So that was nine weeks … of kind of isolation. Which I didn't mind, but yeah. I didn't do anything until they were six weeks corrected and had their immunizations. (M3)

While the mother was accepting of the need to be isolated, *I didn't mind*; this isolation posed a risk for the development of postnatal depression and other mental illnesses.

6.4 | Losing control

Mothers frequently described events where they lost control; commonly when they left hospital, as being in hospital with their infant provided some sense of control. Once mothers returned home the increased responsibility for their infant and their need to be hypervigilant compounded the level of emotional distress they experienced; as noted:

> The extreme difference from the hospital setting to home setting can … It really, I spiralled into massive anxieties, which I'm only just getting under control now, through seeing a psychologist, related to … I guess PTSD and all the rest. So, I think it's really important to make sure there's someone around that can point out that help. (M6)

Critically this mother was able to access support and treatment from a psychologist. She described strategies that need to be in place not only to get treatment for the mother, but also to provide assistance to identify that she requires professional help.

Mother 8 reflected on her work experiences in a *really high powered job* that may have been an underlying factor in her distress and the lack of control that she felt as a new mother of an extremely preterm infant.

> No … no I'm fine now I don't know if it was the initial shock. I did talk to the home nurse who came to visit she offered a group … I had a really high powered job and then I was stuck home with [baby] … As I said I'm fine now … I did have some things I had to work through … So I'm fine. (M8)

In the following quote, another mother talks about her loss of control at the moment of birth:

> [Baby] was taken away immediately by the neonatal team. Obviously, words can't actually explain what goes through your head at that time. It's just ridiculous in regards to the shock and the trauma and how upset you actually feel. (M9)

Her reference to a lack of words highlights the impossibility for many mothers to articulate and share their emotions and the trauma that is occurring with others. This in turn makes it difficult for others to understand the level of trauma the mother is experiencing.

7 | DISCUSSION

The common factors experienced by mothers interviewed in this study were: experiencing emotional distress and not being provided with adequate care, not experiencing motherhood as expected, losing control of the situation, and becoming isolated. Participants commonly spoke of being traumatised by their personal and vicarious experiences in NICU and the life and death struggles they had been through and witnessed, including watching other babies die or observing many life-threatening situations that occur regularly within a NICU. For mothers the NICU can be a frightening place with technology, unfamiliar noises and words, providing limited care for their fragile infant, and coming from a different culture can further exacerbate the emotions (Ardal et al., 2011). NICU nurses also experience a sense of uncertainty and a concern about providing false hope (Green, Darbyshire, Adams, & Jackson, 2015). A trusting relationship between the nurse and mother is essential for acceptance of any professional support that is offered in the NICU (Green et al., 2015).

Women struggled with their disappointment at missing out on the expected normal, happy activities and experiences of motherhood. This is not uncommon for mothers when their babies are requiring a long-term NICU stay. As identified by Beck and Woynar (2017), claiming motherhood in a NICU is a difficult developmental process for women. Ensuring that mothers (parents) are included in decision-making and that they provide informed consent is an essential part of regaining control and evolving into a mothering role (Green et al., 2015).

In a study of mothers of low birthweight babies (<1,500 g) with PTSD, mothers with high levels of PTSD symptoms were more likely to be less sensitive and less effective at structuring interactions with their infant (Feeley et al., 2011). These outcomes have significant implications for an extremely preterm infant if their mother is not emotionally available to provide sensitive and timely interactions and physical care due to PTSD and other mental disorders; diminished quality of interactions between the mother and infant; and impacts on the developing relationship (Beck & Harrison, 2017).

Despite this cohort of mothers being at significant risk for mental disorders (Bergström, Wallin, Tomson, & Flacking, 2012), findings in this study identified that psychological care was not offered or was limited during their infant's NICU stay and when discharged home. This places mothers at high risk as the probability of developing postnatal depression increases by 60% if risk counselling is not received (Bergström et al., 2012). These findings confirm the importance of providing mothers who are vulnerable with early and ongoing mental health assessment, support and interventions (Austin et al., 2017). Well-tested referral pathways are therefore required in the NICU and community for these mothers (Hynan, Mounts, & Vanderbilt, 2013).

Participating in a psychosocial assessment during the antenatal period and the first year after birth is now identified as enabling early identification and intervention to minimise the onset of perinatal mental illness (Austin & Highet, 2017). Psychosocial risk factors include: lack of emotional and social support; history of mental health problems; recent significant stressors; low self-esteem and high anxiety levels; domestic violence; substance misuse; and adverse childhood experiences (NSW Department of Health, 2009). In Australia, the Edinburgh Postnatal Depression Scale (EPDS) is widely used in the postnatal period and in an adapted form for the antenatal period as an essential component of the psychosocial assessment process (Austin & Highet, 2017). The Antenatal Risk Questionnaire (ANRQ) can also be used in the postnatal period, and in conjunction with the EPDS (Austin & Highet, 2017).

In this study, when mothers received a psychosocial assessment it was mainly conducted during their infant's stay in NICU, not when they had been discharged home with their infant. If psychological care was offered it was limited. This is of significant concern as these women were clearly at high risk of developing mental disorders that will impact on their ability to provide the necessary physical and psychosocial care for their babies (Austin et al., 2017). This concurs with recent work that found that parental experience of being discharged home with a preterm infant can be emotionally challenging, necessitating a range of support mechanisms to assist parents to cope with this period of transition (Petty et al., 2018). Protocols therefore need to be developed to ensure that the recommended schedule of psychosocial screening for mothers occurs during pregnancy, while their babies are in NICU and ongoing during the first postnatal year.

Mothers also spoke about the lack of social support they received; social support provides a critical link to health and well-being (Feeney & Collins, 2015). Lack of support reduced their ability to accept offers for time out and to enable involvement in self-care strategies and services that are available to many mothers of full-term, healthy infants (Hall, Ryan, Beatty, & Grubbs, 2015).

Having to be hypervigilant and restricting contact with family and friends for many weeks to protect their babies from infection clearly compromises a mother's mental health. Being hypervigilant was not an unrealistic maternal attribute for these women as the majority of their babies were readmitted to hospital with infections within weeks of discharge, reinforcing their fears for their infant's health status. This hypervigilant behaviour is not unexpected and is also a common symptom of PTSD (Holditch-Davis, Bartlett, Blackman, & Miles, 2003; Jubinville et al., 2012).

Mothers' isolation from social support was further compromised as they had difficulty socialising with other new mothers of healthy babies. They spoke about their experiences being very different from mothers of healthy babies. Using social media, they read stories and saw pictures of healthy babies compounding their feelings of distress and loss of the rituals and experiences of being a mother of a healthy infant. These encounters with mothers of healthy babies reinforced their missing experiences as mothers and the expected joy they would experience and the guilt of having an extremely preterm infant.

Along this journey from NICU to home, NICU and community nurses are well placed to provide additional, essential support for mothers with extremely preterm infants. An increase in nurses' awareness of mothers' experiences as noted from these findings, including in some situations their deteriorating mental health status resulting from their lack of control and impotence relating to the care of their infants, is required (Beck & Woynar, 2017). To provide this support, development, implementation and evaluation of continuing education about perinatal mental health and the developmental stages and behaviours of extremely preterm infants is recommended.

While these findings are specific to Australia, they have potential application to the wider global community. Extremely preterm babies are a vulnerable group, and the outcome of these babies varies depending on the degree of residual damage resulting from their time in the NICU. This exploratory study demonstrated that Australian midwives, nurses and other health professionals require increased awareness of the psychosocial needs of mothers with extremely preterm infants. We propose that similar health professional gaps in knowledge are likely to exist in many countries. Improved health professional education therefore needs to be provided that focuses specifically on this group of mothers so that support is tailored to their particular needs. Supporting the mental health of the mothers of extremely preterm babies not only will improve maternal well-being, but there are positives for the infant who has a caregiver who is emotionally available and responsive to the infant's unique needs.

A significant and common theme that emerged from these study findings was the need identified by parents for tailored education for health professionals within the community setting. This highlights the need for increased awareness in these professionals relating to the psychosocial needs of mothers with extremely preterm infants. In turn, this will lead to further national and international research that will explore education needs of health professionals so that their knowledge and awareness extend to this group of mothers. This will ensure that the support they receive is specifically tailored to their psychosocial needs.

7.1 | Limitations

Conducting telephone interviews precluded observation of nonverbal communication patterns, specifically monitoring participants' facial expressions and body movements. Parental dyad or partners' experiences were not explored, and therefore, additional important issues or themes may not have been identified. Each woman gave birth in a different hospital that may have different practices and transition support processes. These findings may not be applicable in other countries as health services for pregnant women and new mothers may differ.

8 | CONCLUSIONS

The birth of an extremely preterm infant is a traumatic event for mothers as they navigate the emotions of anxiety for the survival of their infant, sorrow and feelings of guilt and failure as a mother. These mothers are at high risk of developing PTSD and/or other perinatal mental illnesses due to the continuing lack of emotional and physical support; recent significant stressors; low self-esteem and high anxiety levels. Regular psychosocial assessment, while recommended in this healthcare system, was less than optimal from the viewpoint of these participants. It is therefore crucial that these assessments are systematic and consistent, particularly for this cohort of new mothers, to enable early identification and interventions to reduce their risk of psychological sequelae. As part of the interventions, mothers require significant professional and community social support to enable them to maintain their mental health and maternal role. There is a need to provide education to midwives and community health professionals.

9 | RELEVANCE TO CLINICAL PRACTICE

Understanding a mother's experience is important to enable informed, high-quality support and improve infant outcomes. This study highlights the need for nurses and other health professionals to focus not only on the health of the extremely preterm infant but also on the mother's psychosocial needs. Nurses are well positioned to work with mothers to support the design and implementation of interventions that have the potential to both improve maternal well-being and enable mothers to be emotionally available and responsive to their extremely preterm infant.

ACKNOWLEDGEMENTS

We would like to acknowledge the support provided by the Miracle Babies Foundation who assisted us with recruitment; and the University of Technology, University of Hertfordshire and Tresillian Family Care Centres for the support and encouragement they provided for this study.

CONFLICT OF INTEREST

No conflicts of interest have been declared by the authors.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

How to cite this article: Fowler C, Green J, Elliott D, Petty J, Whiting L. The forgotten mothers of extremely preterm babies: A qualitative study. *J Clin Nurs*. 2019;00:1–11. https://doi.org/10.1111/jocn.14820