# Reclaiming Maternal Power: Mothers' Experiences of Preterm Birth in Ireland

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## BACKGROUND

The experience of having a preterm infant and spending time in a Neonatal Intensive Care Unit (NICU) is a unique and uncommon one. According to the World Health Organisation (WHO), approximately 15 million babies are born prematurely on an annual basis, with pre-term birth defined as '…babies born alive before 37 weeks of pregnancy are completed' (WHO, 2018). There are generally three categories of preterm birth which are based on the gestational age of the baby: (1) extremely pre-term (>28 weeks' gestation); (2) very pre-term (28 - 32 weeks' gestation); and (3) moderate to late preterm (32-37 weeks' gestation). In Ireland, approximately 4500 babies are born preterm per annum which equates to one in 16 babies (Health Service Executive, 2021).

Preterm birth is an event which can often prove traumatic for both parents of the baby presenting what may seem at the time like challenges of an insurmountable nature (Baum et al., 2012; Fayiz Al Maghaireh et al., 2016; Goutaudier et al., 2011; Heinemann et al., 2013) [1-4]. The sudden arrival of the baby before term, the fact that the baby is immediately hospitalised, and the inevitable alteration of parental roles, are all factors which can lead to '…a rollercoaster of emotions' (Petty et al., 2019; Stacey et al., 2015) [5,6], emotions which can potentially '…invade all aspects' of parents lives (Ricciardelli, 2012) [7]. Given their role as primary caregivers, as well as the fact that they tend to spend more time in the NICU, mothers' experiences tend to differ from those of fathers (Baía et al., 2016) [8].

Mothers are significantly impacted psychologically by pre-term birth. They experience psychological trauma due to the unpredictability of the situation, the associated lack of control, as well as the sudden nature of the preterm birth (Aagaard & Hall, 2008) [9]. Being unprepared for the birth can lead to feelings of detachment from the situation as well as feelings of guilt due to the inability to sustain the pregnancy (Cockcroft, 2012; Lindberg & Ohrling, 2008) [10,11]. Where mothers cannot engage in breastfeeding or expressing breast milk, this serves



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to compound any feelings of failure that may exist (O'Donovan, et al., 2019) [12]. Indeed a recent IPA study into parental experiences of parenting a preterm infant highlighted the mismatch between the real and imagined experience of the birth with related feelings of powerlessness, shock, anger, fear, and lack of control (O'Donovan, et al., 2019) [12].

Mothers of premature babies are also more prone to psychological stress in the post-partum period than mothers of babies born at full term (Meyer, et al., 1995) [13]. Psychological stress"…refers to a relationship with the environment that the person appraises as significant for his or her well-being and in which the demands tax or exceed available coping resources" (Lazarus & Folkman, 1986, p. 63) [14]. Perceptions of stress during hospitalisation of a very preterm infant (>28 weeks) is higher among mothers than fathers (Baía et al., 2016) [8]. Holditch et al. (2003) [15] found that 15% of mothers who had their premature baby admitted to the NICU experienced postpartum post-traumatic stress disorder. Recent research has demonstrated that mothers of babies born very pre-term are at risk of prolonged psychological distress and may be in need of extensive support to promote optimal outcomes for the children (Yaari et al., 2019) [16].

Stress can impact mothers of preterm babies in a number of ways. For example, a meta-analysis of the experiences of mothers in the NICU found that common challenges associated with stress included: anxiety surrounding the mother's relationship with her premature baby; issues with the development of a sense of identity as a 'normal' mother; coping with the NICU environment itself; striving to gain some form of control over the caring role in the NICU and relationships and communication with health professionals in that setting (Aagaard & Hall, 2008) [9]. Mothers suffering from acute stress interact less with their infants in the NICU and are less likely to engage in skin-to-skin contact, despite the latter being proven to be beneficial for the wellbeing of the baby (Gonya & Nelin, 2013) [17].

Maternal bonding and attachment may also be disrupted by preterm birth. Bowlby (1969) [18] describes how physical contact is a prerequisite for attachment, while Heermanm, et al. (2005) [19] highlight its importance for the transition to parenthood. Yet, these mothers do not get to hold their baby after he or she is born as is the case with full term babies. When they do eventually get to meet their babies, the fragile appearance and vulnerability of the baby can exacerbate the shock experienced and can induce fear (Miles et al., 1992) [20]. O'Donovan, et al. (2019) [12] describe how parents move from feeling disconnected to connected over the course of their NICU journey, a connection which is facilitated by physical contact with their preterm babies. Positive feelings have also been experienced by parents in this chaotic NICU world. One IPA study concerning 14 young Australian mothers highlighted that while the birth of a preterm infant has its challenges during hospitalisation, the joy experienced on becoming a mother is not fully diminished (Sheeran et al., 2015) [21].

Maternal identity is also altered in a significant way. An integral aspect of maternal role attainment - maternal identity - involves the incorporation of motherhood into a woman's concept of herself (Mercer, 1995) [22]. The birth of a baby results in a radical transformation of identify for mothers where they must adapt to a new role and responsibilities connected with the care and protection of their baby. These mothers experience the loss and mourning of their dreams and expectations concerning both pregnancy and bonding with a healthy full-term baby after birth (Rossman et al., 2015) [23]. As Spinelli et al. (2016) [24] highlight, mothers experience parenting a preterm baby within the transitional process to motherhood which takes place within the institutional environment of the neonatal hospital. Ultimately, in the context of pre-term birth, the development of maternal identity is often delayed to a significant degree (Mercer, 1995; Reid, 2000) [22,25].

Mothers are also impacted by the disruptive and stressful nature of the NICU environment. Disruption to routine, the lack of normality in the hospital environment, as well as insufficient information, contribute to the levels of stress experienced in practice (Heinemann et al., 2013) [4]. Moreover, the appearance and noises within the unit (caused by the alarmed machines which monitor the infant's heart rate, oxygen and respiratory levels) also exacerbate maternal stress levels (Preyde & Ardal, 2003) [26].

Similarly, experiencing a loss of control and barriers to contact with the baby is a very difficult, yet common, part of the NICU experience for mothers (Whittingham et al., 2014) [27]. Indeed, it is commonplace for mothers to have to seek permission from the NICU nursing staff to care for their own infants (O'Donovan, et al., 2019) [12]. Such is the intensity of the environment that it can result in mothers feeling overwhelmed and unable to cope (Lindberg & Ohrling, 2008) [11].

How mothers experience the NICU environment can also be impacted by their daily interactions with medical professionals. For example, Petty, et al. (2019) [5] found that the provision of inconsistent information by different medical professionals

was often a key source of distress. Similarly, an investigation into the effects of the environmental and structural features of two different NICUs in Italy identified the need for explicit information for mothers concerning their babies' condition and changing status in order to reduce the stress experienced (Trombini et al., 2008) [28]. Finally, practical challenges such as travel to and from the NICU, the visitation hours and rules, and the need to balance other aspects of family life, can also add to maternal stress in the NICU (Lee et al., 2012) [29].

In the context of preterm birth, every mother is unique and the manner in which they cope will differ from one mother to the next. The type of coping, such as problem-based or emotion-focused coping as per Lazarus, et al. (1984) [30], employed by mothers of preterm babies will depend on what stage of the stressful experience they are at (Lau & Morse, 2001) [31]. Given the mixed emotions mothers face at the outset of their experience, Lau and Morse suggest that emotion-focussed coping, taking action to regulate stressful emotions, is most effective at this stage; whereas at later stages, problem-focussed coping, identifying and taking action on the source of stress, may result in mothers seeking information concerning their babies condition (2001).

A variety of coping processes have been adopted by mothers during their infant's hospitalisation (Arnold et al., 2013; Gavey, 2007; Heidari et al., 2013; Heinemann et al., 2013; Russell G et al., 2014) [4,32-35]. For example, a qualitative research study by Smith, et al. (2012) [36] involving 29 parents of preterm babies, identified a variety of coping strategies employed by parents of preterm infants which included: participating in care of the baby, taking time away from the NICU, searching for information, drawing on support from family and friends and engaging with other NICU parents. Relationships with other parents within the NICU has been found to be a key determinant in parental coping since talking with other parents helped to normalise the experience (Stacey et al., 2015) [16].

Psycho-social support has been identified as a necessary protective factor for mothers of preterm babies (Singer et al., 1996; Williams et al., 2018) [37,38]. The latter has been defined as "…medical information; social information; support in coping with emotional reactions; support in the bonding process; and finally social support from the informal network (relatives, friends, and colleagues)" (Eriksson & Pehrrson, 2002) [39]. In the context of support in coping for example, reassurance, information, comfort, and support have all been identified as important types of social support for mothers of preterm infants (Wang et al., 2018) [40]. Information through early educational and emotional support for parents of premature babies has also been proven to decrease stress (Abdeyazdan et al., 2014) [41].

Effective communication of medical information is essential which helps reduce maternal stress in this context (Cockcroft, 2012) [10]. Regular communication promotes confidence and competence in caring for the premature baby which supports better mother-infant attachment (Ncube et al., 2016) [42]. Communication of an empathic nature from the medical professionals and the nursing staff has been shown to be particularly effective in reducing the levels of stress experienced by parents (Enke et al., 2017) [43]. The development of a collaborative and effective nurse/parent relationship as opposed to a hierarchical one is a critical factor which determines how parents feel about their NICU experience (Reis et al., 2010) [44].

Very little research has solely focused on maternal experiences of coping in the aftermath of preterm birth in the Irish context, with calls for more research in this area more generally (Fayiz Al Maghaireh et al., 2016, p. 2754) [2]. While a recent IPA study by O'Donovan, et al. (2019) [12] has explored the general experiences of mothers and fathers of parenting their preterm babies in Ireland, it fails to examine in detail the ways in which mothers cope with having a preterm baby and how they should be supported through the experience. Furthermore, little research examines how maternal identity is impacted by preterm birth and of those that do, these are outdated and fail to adopt an interpretative lens (Reid, 2000; Zabielske, 1994) [25,46]. Through adopting an interpretative lens via an IPA analysis, this study will explore how mothers in particular, navigate their way through the neonatal hospitalization of their pre-term baby in Ireland.

## METHOD

This was a qualitative study which used the data from semi-structured interviews as the basis for an interpretative phenomenological analysis.

## SAMPLE AND RECRUITMENT

A purposive sampling method was used to recruit four mothers over the age of 18 and who each had a pre-term baby. Criteria for inclusion were that mothers had to have had a pre-term baby (37 weeks' gestation); they had to have spent a period of time in an Irish neonatal hospital and they had to be a minimum of two years post-discharge. It was imperative that

no participant was experiencing any issues of a psychiatric nature at the time of the study or in the six months previous. Pseudonyms were used for the purposes of anonymising the participants and protecting their identity and confidentiality.

## DATA COLLECTION

Semi-structured interviews were employed as the method of data collection for the current study as is common in IPA studies (Breakwell, et al, 2012) [47]. The semi-structured interviews in the current study were participant-led, whilst at the same time being guided by the researcher. Interview questions focussed on the mothers' experiences of having a preterm baby and the circumstances surrounding it, and their coping and resilience at this time. The interviews were recorded using a Dictaphone and lasted from between one hour and one hour thirty minutes. All four interviews were transcribed verbatim by the first researcher.

## DATA ANALYSIS – IPA

In the context of the relatively rare incidence of preterm birth, no two experiences are alike. Thus, in order to honour the specific meanings mothers attribute to their experiences, added to the fact that IPA is more frequently associated with smaller homogenous samples (Smith, Flowers, & Larkin, 2009) [48], this method of analysis was deemed most effective for the current study. Conducting an IPA analysis involves six distinct stages. While no single method is prescribed for working with the data; the approach detailed by Smith, et al (2009) [47] was adopted for the current study. The first step for all four participants required that the first researcher familiarise herself with the transcript data by reading and re-reading each transcript. With the first reading, the audio recording was listened to so that the voice of the participant could be imagined during subsequent readings. It was helpful to document some thoughts at this stage. Stage two involved an exploration of the semantic content as well as the language used. Descriptive comments were the first point of analysis – 'taking things at face value' (Smith, et al, 2009, p. 84) [47] where key words used by each participant were highlighted. Secondly, the language used by each participant was explored, particularly the way in which things were presented through metaphor or otherwise. Finally, the conceptual comments, which represented the interpretative aspect, took an interrogative format. The latter stage was one of the most time-consuming for the researcher, since it involved constant questioning, reflecting, making mistakes and the re-organisation of ideas. This stage also demanded input from the researcher's own personal and professional experiences and psychological knowledge. It is this aspect of the initial analysis that formed the bedrock of the more in-depth analysis that followed.

Stage three of the analysis involved the observation of emerging themes from within each transcript. The identification of themes involved identifying the main areas of significance for each participant throughout the interview. The themes were not only reflective of the words of the participant, but they also incorporated the researcher's interpretation of these. Stage four of the process involved considering whether there were any connections between the emergent themes. At this stage, some themes appeared more important than others, resulting in some being then eliminated. Having first listed all themes in chronological order, clusters of related themes were then produced. Step five involved repeating the process outlined above for the next participant and once all four transcripts were analysed in accordance with stages one to four as described above, step six involved looking for patterns across all cases with the identification of superordinate themes.

## REFLEXIVITY

Reflexive thinking was critical on an ongoing basis, given that the first researcher was also a mother of a preterm baby and had spent some time in the Neonatal hospital. This process included the first researcher keeping a reflective journal and ongoing reviewing with the other researcher, to check for potential influence.

## ETHICAL APPROVAL

In advance of data collection, ethical approval was obtained from the School of Applied Psychology's Ethics Committee in the University where both researchers are based. The Psychological Society of Ireland's Code of Ethics (PSI, 2019) served as an ethical guide for the study. Informed consent was obtained from all participants prior to the commencement of the interviews.

## RESULTS

The gestational age of the babies at birth ranged from 24 weeks to 30 weeks and the time spent by the mothers and babies in the neonatal hospital ranged from four weeks to 14 weeks. Each of the supra-ordinate themes, which represented different parts of the journey, informs the overarching theme to this study: gradual reclaiming of power. The sudden and unexpected preterm birth of their babies marked the

beginning of a journey for each of the four participants, Melanie, Julie, Mary and Anne, which began with their maternal identities being suddenly stolen from them. The repressive nature of the neonatal environment caused the mothers to feel disempowered because of the constraints placed on their maternal autonomy causing some of them to question themselves. In order to survive the journey through this environment, these mothers had to engage in strategies to protect themselves so that they were eventually able to regain any control that was lost to them. The reclaiming of this control involved drawing on both their own internal resilience, as well as external supportive alliances. Gaining control meant that these women were well-positioned to gradually reclaim their power as mothers through reconnecting with their babies in their home environments.

All the mothers experienced a loss of maternal identity in the sense of being robbed of, or taken from, what was perceived as a natural, or instinctive, path towards becoming, or being a mother. This loss occurred with the sudden and unexpected premature birth of their infant where they found themselves lost or overwhelmed in what they reported as an unnatural "neo-world". Also, lost or stolen from them were their hopes and expectations of what mothering should have involved. For two mothers, Anne and Julie, another impediment here was their pre-existing vulnerabilities that put them at more heightened risk to losing a sense of their own natural mothering.

Each mother talked implicitly about being dragged from a natural mothering path at home in terms of being caught up, or lost in, the unfamiliar world of the "Neo". As a consequence of being dragged or cut off from their familiar maternal paths, both Melanie and Julie felt the loss of a world that was known to them. Julie describes this as feeling cut off and stated her "whole life just stopped basically" (p.10), whereas Melanie felt disconnected from her old world and embroiled "in a bubble" in the Neo which led her to feeling a bit lost.

Julie, was not totally dragged away, as she had conflicting priorities, but it led her to feeling torn between her natural mothering path and the Neo world: "I felt as if I had two kids but half the time it felt like I had none because if I was travelling to go and see Maggie, he [her son] was at home… oooh…It was a nightmare". (p.2) Anne, like Melanie and Julie, found herself suddenly taken from her natural mothering path and sucked into the overwhelm of the Neo world. For both Mary and Julie, feeling lost or displaced as a mother in the Neo world, effectively lead them further away from their natural mothering paths.

Not only were they dragged from the natural path of being a mother but added to this was the denial of any associated hopes and expectations they had concerning what should happen for a new mother. The hopes and expected rituals which ordinarily surround the birth of a full-term baby such as having a normal labour and birth, being able to celebrate the baby coming into the world with loved ones, and bringing your baby home soon after birth, were never to be for these women. As Melanie said: "…you just feel so hard done by… you feel like this experience that's… you have in your head is just ripped away from you…". (p.18) The hope a mother has for leaving the maternity hospital with a healthy full-term baby was dashed for Mary and Melanie, "…I just remember that feeling leaving the hospital, no longer being pregnant and without my baby. And I remember it was just a horrific feeling" (Mary, p.16). Yet, the denial of these rituals did not totally undermine the instinctual sense of excitement that was experienced following the birth, but it was short-lived. For Melanie, "…the elation maybe lasted a day or two I think, that was the excitement of the fact that the baby was born." (p.5) For Anne, the dashed expectations surrounded the absence of a normalised homecoming for her son:

"…there was no fanfare, there was nobody there celebrating it …I didn't have any help. When people came over, they wanted to see baby and they were waiting to see this normal, you know, big, huge fat baby and they wanted you to be there smiling and going, oh my god look what I produced?! When in actual fact, it was awful" (Anne, p.21).

The heightened vulnerability of some mothers, stemming from pre-existing traumatic experiences, led them to being more susceptible to outside influence, thus losing more of their own sense of a mothering role. When entering the unchartered territory of the Neo, all four mothers were vulnerable due to circumstances surrounding the preterm birth. Anne and Julie's previous traumatic experiences left them even more vulnerable. Anne felt completely consumed by overwhelm in this strange new environment. Her focus was sheer survival. This served to delay her return to her natural mothering path:

"Yes, I would say I suffered from postnatal depression. I would definitely say that, and I would say, it was impacted by the trauma of the birth - the way he came out into the world. But I would definitely say that it was connected to my own past … traumatic experience". (p.22)

Moreover, the health status of their preterm babies added further to their vulnerability. Julie's baby was born extremely pre-term and, as a result, needed a number of medical interventions. Furthermore, she had already experienced a preterm birth, and had lost several babies previously. This contributed to a heightened vulnerability which she reported left her feeling "Anxious. It never got easier leaving her behind, even though you know you're calling back." (p.18).

Disempowerment was palpable amongst all the mothers who internally felt restrained and inhibited or constrained by the strange Neo environment in which they found themselves. Consequently, they were left questioning or doubting themselves. Each mother felt inhibited and restrained in themselves as they were unable to carry out their maternal role to the extent that felt natural to them. Anne felt inhibited as she did not possess the medical expertise which would have enabled her to know what to do for her baby: "there was a huge knowledge barrier there… There was completely, I didn't know what was going on. Yeah. I felt completely and utterly out of the loop". (Anne, p.27) This lack of medical expertise led her to further question and doubts herself: "I remember sitting there and I just remember the most unnatural things like to ask my husband's permission – like 'Can I touch him?'" (Anne, p.6). Whereas, Julie was self-conscious and unable to relax due to the absence of clear and consistent information from the medical consultants concerning her baby's prognosis:

"… but you were just built up with all this anxiety of not knowing what's going to happen next. I think, that has left its mark on me the most… kind of like one minute you're told something, the next minute it's gone. But even though it's gone, it's kind of just left you in kind of a bubble of confusion" (p.11).

As well as feeling inhibited, some mothers felt restricted or restrained in the unnatural Neo environment. All mothers felt relegated from the position of primary carer to a largely observational role as a result of watching the nurses carry out the daily cares of their babies. For Mary, this meant she'd "peek in and see him" [her son] (p.2); whereas for Melanie, there was a feeling of resentment "you're watching other people mind your baby. Literally, you know, you're watching other people tell you what to do with your baby" (p.7). On the other hand, Anne who was completely overwhelmed was happy to be an observer, "…because they knew more than I did, they were minding him. I was just going in to have a look at him and I was happy then because they knew exactly what he needed" (p.5).

The freedom to be guided by instinct and simply do what they felt was appropriate was constrained by the environment in which these mothers found themselves. Constraints on personal autonomy manifested both implicitly and explicitly within the Neo. Being constrained resulted in the mothers' experiencing feelings of guilt, pressure, and an invasion of their rights. All mothers felt constrained from naturally engaging in roles which ordinarily would facilitate connection and bonding with their babies. "…there was always a physical barrier there which was the incubator. So, like, you couldn't cuddle your baby like you would if the baby was born naturally" (Mary, p.10). The explicit pressure to do certain things also served to heighten feelings of restricted autonomy:

"taking him out of the incubator… again that was something that, you know, we were encouraged to do because it's supposed to be good for the baby and, you know, but it was, it stressed me out, because I was worried about his monitors going off and his oxygen levels going down and the risk of infection and things like that" (Mary, p.12-13)

The intangible expectations and pressure which these women succumbed to, not only served to implicitly restrict their rights to operate freely as mothers within the Neo, but also impacted them in their outside worlds. For example, Melanie felt somewhat morally restrained in that she needed to conform to the rules and practices within the Neo: "But what, what more could I do? You know, like, you know, you don't know what's right; you don't know what's wrong. You feel like you're doing nothing" (Melanie, p. 10). Whereas Mary had internalized the implicit expectations of the Neo to the extent that it continued to impact her emotionally while on the outside: "Guilty was probably one of the biggest things, …I should be up there when I wasn't up there… there was an expectation that you'd be there all the time…, even if you were doing nothing but sitting there…" (p.12)

All the mothers felt disempowered by the insensitivity, or what they perceived as a non-caring ethos of the healthcare professionals in the Neo. Mary felt disempowered in what she described as a threatening and challenging environment: "…a nurse asked me to get the child blessed, I had another occasion where a nurse said to me, that our child was costing 1000 euro a day. Em…And they are things that stick with me." (p.8) Melanie felt undermined as a mother by what she perceived as an ethos of the nursing staff which was "you know I'm kind of in charge of your baby - I'll tell you when to change him, when to, you know, it's, it's a bit condescending or something or it's just, it's so fake yeah." (p.35)

Indeed, Melanie, Mary and Julie, all felt their maternal autonomy was eroded by the nurses being in charge: "…like I had a baby but was she wasn't really mine. I had to have permission to hold her, or to touch her. I… I felt like I lost a bit of myself "(Julie, p.3). Anne felt her autonomy violated having decided when pregnant that she did not wish to breastfeed her baby but felt very pressured to do so:

"I didn't like the manner. I did not like it. I did it because I had to do it. And I was trying to do the right thing. But she was literally, I felt invaded. I felt my space invaded; I felt my privacy invaded. I felt pushed into something I wasn't ready for. And they didn't care" (p.46)

Being constrained or restrained by the surrounding environment resulted in the mothers questioning themselves at various stages of the journey. At the outset of the journey, and being in unfamiliar territory, meant that Melanie engaged in a moral questioning of her rights as a mother: "it didn't make sense to me I was always waiting for a nurse or a midwife to kind of come in and offer to bring me down to the Neo." (p.6). Whereas Melanie, Julie and Mary, were left questioning and doubting themselves as mothers due to being unable to carry their babies to term and engage with their babies as normal:

"…. because I couldn't do any of the things that a mom, should be able to do for Ben because I couldn't carry him to term, for whatever reason, I couldn't breastfeed him when he WAS born. Like I couldn't hold him, I couldn't do the things that, you know, parents, expect to be able to do." (Mary, p13).

Over time, the mothers developed a more protective mode in order to help them survive the arduous journey through the Neonatal hospital. This involved a cognitive reframing of the experience on a conscious level or a more instinctive (self-preservation/survival) mode. Protection, via automatic unconscious defence mechanisms, emerged when the mothers felt severely threatened or overwhelmed and unable to act.

Both Melanie and Mary cognitively reframed their experience to adopt a positive future focus to get them through. Part of this involved focussing on the success of their babies in reaching the milestones within the neonatal.

All mothers employed the strategy of focussing on functional tasks to avoid processing things emotionally. For Anne, completely emotionally disconnecting from her baby and maintaining a more functional caring role is what got her through: "it felt to me like my baby had died and I was given this baby to mind, [I: okay], and I have to do my job…" (p.22). Whereas, Julie relied on her pre-existing maternal instinct and strength to survive within the Neo world:

"I think the mama bear is in you as well – you just keep going… you just have no choice – you just have to keep going. I think your kids make you do a lot of things… you just do anything for them to be honest" (pp. 23-24).

When they felt severely under threat within the Neo, various defense mechanisms were employed by the mothers such as fight or flight, escape and detachment. Indeed, such was the stress and overwhelm that Anne experienced on occasion, that her fight or flight response kicked in when she felt threatened. When her son momentarily stopped breathing while in the Neo, she fled "but for me that time I went 'I can't do this' 'I'm gone' 'I'm gone like' I'm, 'I'm packing my bags' this is it, I'm done" (p.32).

When feeling particularly vulnerable, escape provided a mode of defense for both Anne and Julie. For Julie, the 40-50 minute drive to and from the Neo twice a day represented a mental break. Whereas for Anne, leaving her son in the neonatal each night represented an escape for her psychologically: "I do remember feeling definitely a measure of relief. The responsibility was off my shoulders and the weight was lifted for a minute – relief" (p.33). While they were in the Neo, the mothers did detach somewhat emotionally from the outside world to help protect them from unwanted anxiety, drama, or stress. For Anne, while grandparents were permitted to visit her son, in her vigilant state she emotionally detached from them as she perceived them as a threat: "…my mother would have been very dramatic, and I really didn't like that – I couldn't deal with that. And my mother-in-law. Em… She was very nice, but she's super practical and I didn't like that either" (p.14). Similarly, Melanie and Mary, emotionally detached from 'well-meaning' friends on the outside since they really didn't understand what was going on for them "… anything would have set me off. Nobody could say the right thing" (Melanie, pp. 14-15).

Finally, emotional detachment from their babies and the situation in which they found themselves served a protective function for all four mothers and the process of dealing with the emotional trauma didn't happen until sometime afterwards: "I felt like the Neo time was just survival mode, and that the emotions crop up down the line" (Melanie, p.37). For Anne, the emotional detachment continued even after

she came home: "I was at home all day with him … but the connection was not there. And there's no point in saying it was, it just wasn't." (pp.23-24). As time passed, each of the mothers began to reclaim their power by finding different ways within themselves of gaining control. They also reached out and formed positive supportive alliances which provided much needed reassurance which helped them navigate through the experience. The rediscovery of their identities as mothers was empowering, but not an easy transition, and began when they were discharged from the Neo.

A first step towards gaining control as mothers saw all four women finding simple ways of centring self, adapting to the environment, and adopting ritualised or habitual routines. Julie and Mary grounded themselves by keeping it in the day to prevent them from becoming overwhelmed. Mary also focussed on normalising her experience, through appreciating the congratulatory gestures made by those in the outside world. Whereas Melanie had a much ritualised routine in place to keep her focussed and grounded:

… my typical day was getting up in the morning, getting into the hospital, and sitting next to the incubator, waiting for the doctors to do their medical rounds. They do them. They'd,… just, just bring me up to speed on where they were with Jack, and like I said every three hours I was in the pumping room, expressing milk - back to baby …might pop up and get a cup of coffee - back to baby – expressing, lunch…back to baby… then I'd go home in the evening, have a bit of dinner, Tom would be finished work at that stage and back up then in the evening (p.4).

Mary and Anne calmed themselves by engaging in downward comparisons between their babies and other babies in the Neo. Anne reassured herself by comparing her boy with another Neo baby "…mine's [baby] gonna be okay because like you know he's got four weeks on her like" (p.5). Both Julie and Mary gained helpful information and reassurance – Julie, by asking for and receiving CPR training for babies, and for Mary, this information came in the form of a book on 'Premmies' provided by her partner.

Another strategy was the need to take back some control whilst also understanding and accepting a temporary loss of control. A growing sense of their own maternal role and responsibilities as the babies grew bigger and stronger helped these mothers retain some of their caring duties as less intensive nursing care was needed:

"And you want to be there with your baby … to do the things that you are allowed do, you want to be there to change the nappies, to dress them, you want to hold their hands, you want to think they're getting your sense of smell". (Melanie,p.14)

All mothers maintained a devoted bond to their babies by being with them every day and by doing what they could for them.

Over time, these mothers instinctively formed, and drew on, informal alliances with other Neo parents which served to reassure the mothers. This reassurance was vital given the lack of effective formal supports and helped bolster these women and get them through. Melanie, Julie and Anne treated the expressing room as their "…own little counselling room" (Julie, p.32), characterised as "the milking parlour, … that was where you really got to know people" (Anne, p.12). Melanie said "…you made very good friends in the Neo, my neo-buddies… they they're your biggest support really while you're going through it because they're a cohort of people that can completely and utterly relate to what you're going through" (p.21) Despite the loss of access to the pumping room for Mary, she still took back power through engaging in informal conversations outside of that space. However, at times Mary had to persevere to draw on informal connections as "unfortunately, that wasn't really encouraged…you weren't really able to talk" (p.20). While Anne's baby was in the Neo, these informal supports, while transient, were crucial; "you make friends with people that, you know, you'll never see again… And it's kind of better" (p.13). On the other hand, for Julie, losing the latter support "was the hardest part of coming home" (p.27). Significantly, in the absence of professional support, all of the mothers were more heavily reliant on informal alliances and supports.

Upon discharge from the Neo, all the mothers were, for the first time, solely responsible for their babies: "it's like D-day - like you're just doing it… it's such a weird experience" (Melanie, p.22). Taking on responsibility and gaining control as a primary carer was not easy and took time given that they were discharged from an environment which, although repressive at times, also provided safety and reassurance. Coming home facilitated Julie and Anne finally reconnecting with their babies. For Anne, this took time until she got support around her pre-existing trauma; while for Julie, it was a more natural transition in a relaxing space where she "found that coming home you kind of looked at the child more rather than at the machines because you do get obsessed with the noise and the beeps…" (p.24).

To help them to gain control as mothers, they adopted rituals or routines that had previously worked to protect their vulnerable babies in the Neo environment. All the mothers were hypervigilant about the risk of infection. Mary and Julie did this by requiring visitors to wash and sanitise their hands before they met their babies. Over time, as their maternal confidence grew, the mothers began to flex and adapt and develop new routines. As Melanie recalls "I remember them saying to me that all these babies are in a routine when they get home after being in the Neo, you know, not true!" (p.35).

## DISCUSSION

The current study adds significantly to existing Irish literature by examining an area which has remained largely unexplored to date - that of the unique lived journey of mothers who have had to persevere to reclaim the maternal power lost to them because of preterm birth. This adds further insight into how mothers empower themselves in what has been found by O'Donovan, et al.(2019) [12], as supported by a 2016 systematic review by Fayiz Al Maghaireh, et al. [2] to be a traumatic experience common to both the mothers and fathers of preterm infants.

Moreover, while existing studies have explored maternal identity in the context of motherhood more generally (Mercer, 1995; Smith, 1999) [22,48], the current study focusses on how maternal power is gradually reclaimed following preterm birth. Much focus in the existing literature has centred on maternal identity including an exploration of its key features (Zabielske, 1994) [45] and the delayed development of maternal identity (Reid, 2000) due to preterm birth. The current study brings added complexity to this area by providing insight into how that maternal identity is delayed through a journey of maternal disempowerment to gradual reclaiming of power. Moreover, the current study provides a deeper understanding into how these mothers become disempowered from the various challenges and threats associated with preterm birth. It also explores the ways in which they successfully regain their power over time.

The first supra-ordinate theme focussed on how maternal identity is stolen from these mothers who experience preterm birth. All the mothers experienced being suddenly dragged away from what they considered to be their natural path of motherhood and were redirected to the unchartered territory of the neonatal hospital. The current study gives more in-depth insight into how mothers of preterm infants become what Baum, et al, (2012, p.603) [1] term 'in suspension' whereby identity as mother is delayed and leaves mothers feeling 'neither here nor there'. This present study also found that pre-existing trauma served to heighten maternal vulnerability to the loss of their natural or familiar mothering path. Moreover, the hopes and expectations these mothers had for the pregnancy and the birth were also abruptly removed from them, a finding consistent with previous research which highlights the mismatch between the real and imagined experiences of mothers in this context (Lee, et al, 2012; O'Donovan, et al., 2019) [12,29]. Furthermore, while the current study found that the maternal sense of happiness and excitement at the birth of their babies was not completely diminished by the traumatic nature of the experience, it was short-lived. Thus, this acknowledges that the joys of becoming a mother can be overshadowed to some extent by the nature of preterm birth, a finding which adds nuance to the findings of a previous study involving Australian mothers of preterm babies (Sheeran et al., 2015) [21].

The second supra-ordinate theme focussed on the overall sense of disempowerment these mothers felt through being repressed, and having their autonomy constrained which resulted in a tendency to question self. Building on previous research by Williams et al. (2018) [38] where mothers described the Neo environment as a stressor, the current study found that the environment caused these women to feel restrained and inhibited in themselves, unable to carry out their maternal role to the extent that felt natural to them. This was in part owing to the feelings of helplessness and the sense of disconnection they felt from their babies due to the enforced observational role the women had to adopt, feelings confirmed by another Irish study in this area (O'Donovan, et al., 2019) [12]. The requirement to obtain the permission of the medical staff to interact with their babies served to further relegate them from their primary carer roles which was taken over by the nursing professionals, a finding consistent with Spinelli et al.'s research (2016) [24]. Furthermore, the inhibitive nature of the physical environment prevented these mothers freely engaging with their babies on a regular basis, and the lack of confidence they felt in that space was heightened by the perceived insensitivity of the healthcare staff. Feelings of failure left some of the mothers questioning themselves in terms of their maternal role and responsibilities. While such feelings of failure are reportedly common amongst mothers in such circumstances (O'Donovan, et al., 2019) [12], the current study provides further insight into how this feeling of failure arises.

An integral aspect of renegotiating identity for these mothers was the need to self-protect in order to survive the journey. The third supra-ordinate theme centred on how these women instinctively sought to self-protect and the variety of strategies they employed to do so. The way in which each of these mothers perceived the Neo environment and the circumstances surrounding the birth of their babies was the main determinant of how distressed they felt (Biggs et al., 2017) [49]. The current study saw the use of maternal instinct to cope and survive as a form of self-preservation. Maintaining a positive focus elsewhere, such as on the Neo milestones, served as a form of emotion-focussed coping since it helped these women to protect themselves from the emotional impact of what was going on around them (Lazarus & Folkman, 1984) [50]. By focussing on positive developments, they could also emotionally detach or disconnect and didn't have to emotionally process, and deal with, the trauma in their lives. This is in line with existing research which identifies detachment and disconnection as common methods of coping amongst parents of premature babies (Beck & Harrison, 2017; Ionio et al., 2016; Lindberg & Ohrling, 2008; O'Donovan, et al., 2019; Trombini et al., 2008) [11,12,28,51,52]. Similarly, through focussing on functional and practical tasks such as expressing milk, this also helped the women to avoid emotionally processing what was happening.

In circumstances where these women felt particularly threatened, they engaged their defense mechanisms as a form of self – protection. The current study has shown that when mothers felt overwhelmed or under threat, unconscious and instinctive defense mechanisms were adaptive for these mothers, helping them navigate a painful experience. This finding agrees with prior research by Feldman Reichman et al. (2000) [53]. Threat resulted in the fight or flight response kicking in, while protection was also found in escape from the Neo environment as a helpful mechanism of emotional protection, the latter being well supported by previous research (Feldman Reichman et al., 2000) [53]. Finally, some mothers emotionally detached from their babies and their situation as a way of surviving their time in the Neo, a well evidenced survival mechanism for parents of preterm babies (Arnold et al., 2013; Lindberg & Ohrling, 2008) [11,32]. The current study adds to existing knowledge in that these women indicated that they only started processing what happened after they left the Neo which potentially informs the most appropriate time for interventions.

The fourth supra-ordinate theme captured the ways in which mothers sought to reclaim the power that had been taken from them as part of renegotiating their maternal identity. Over time, the mothers engaged in what Lazarus and Folkman (1984) [50] refer to as emotion-focussed coping which supported them in gradually reclaiming their maternal power. Through the adoption of emotion-focussed coping strategies (Lazarus, 1966) [54], all the participants demonstrated that they could positively adapt to regain or maintain psychological wellbeing despite experiencing adversity which, according to Hermann et al. (2011) [19], refers to resilience. By grounding themselves, by keeping what was happening in the day for example, these women demonstrated resilience and began to take back some of the power lost to them. Furthermore, engaging in downward comparisons with other babies in the Neo was another way to psychologically support them. The employment of self-help strategies before transitioning to home proved an effective way of regaining control for some of the mothers. This confirms Lao and Morse's theory that problem-focussed coping for mothers of preterm babies emerges towards the latter stages of the neonatal journey (Lau & Morse, 2001) [31]. Maintaining the limited control they already had as mothers, through having some input into their baby's care on a daily basis, was regarded as critical for these women not only in their quest to reclaim power, but also in terms of supporting their growing confidence as mothers, consistent with previous research (Jones et al., 2007; Williams et al., 2018) [55]. Keeping informed about the baby's progress, also supported these women in regaining their maternal power. Baía et al. (2016) [8] found that regular communication with the mothers of preterm infants concerning the baby's progress engenders a sense of control for them. It was clear from the current study that the absence of clear and consistent information from the health professionals served to undermine any sense of control these women had, a finding consistent the research of Enke et al. (2017) [43].

In addition to adopting strategies from within, these women also reached out for support which assisted them in regaining power as mothers. This support took the form of informal powerful alliances which were largely formed in the expressing room within Neo environment. While this space was not available to all mothers, those who did use it, benefited from the alliances that were formed there where they could share experiences and empathise. Alliances were also formed outside this space, but these were often disbanded by some of the nursing staff. The formation of beneficial supportive networks with other mothers within the Neonatal environment is a common finding in other research studies (Smith et al., 2012;

Williams et al., 2018) [36,38]. Furthermore, the relationships formed with other NICU parents were regarded as being a key determinant in parental coping (Stacey et al., 2015) [6]. The current study identified such alliances as supportive for women, and while these relationships could be transient in nature for some mothers, that didn't detract from them supporting mothers in regaining power. The loss of these alliances was one of the hardest aspects to going home for some. In recognising the need for professional support for mothers in a similar situation to theirs, it was clear that this was something that the mothers would have valued and benefited from. The latter is in line with the findings of previous research in this area (Levick, Quinn, & Vennema, 2014; Preyde & Ardal, 2003; Roman et al., 1995) [26,56,57].

The final supra-ordinate theme focused on the rediscovery of maternal identity at home. The mothers first had to deal with the sudden and cautious transition to full-time motherhood which was challenging and led to feelings of insecurity, ambivalence, and unsteadiness, a finding consistent with the research of O'Donovan, et al.(2019) [12] and Petty, et al. (2019) [5]. As Feldman Reichman, et al. (2000) [53] point out, the more parents are involved with their babies during hospitalisation, the easier the transition to home will be. The mothers in the current study felt largely unprepared resulting in a more challenging transition. Learning to take control at home was an important aspect of recouping their lost maternal identities. This involved bringing home some of the rituals or routines that had previously worked in the Neo to protect their vulnerable babies. O'Donovan, et al.(2019) [12] had similar findings, noting that such tendencies tend to decrease over time post-discharge.

Thus, the foregoing discussion elucidates how the traumatic event of preterm birth can result in mothers having something instinctive to them – their maternal identity, suddenly taken from them without warning. While the removal was sudden, the journey to recover it takes time. The journey involves mothers feeling disempowered because of not only feeling relegated from their role as primary carer, but also due to the repressed nature of the environment in which they find themselves. While seeking to self-protect, these mothers all demonstrate a common resilience to surviving the challenging environment in which they found themselves. Signs of resilience from within, as well as reaching outside themselves for support, ensure that these women recover the power lost to them. This ensures that they are ready for the final transition to home and the rediscovery of the identity stolen from them at the outset of the journey.

While the current study provides an in-depth understanding of how mothers renegotiated their identity in the face of preterm birth, it was a small sample size and so further research is needed in the area. While the results of this qualitative study are not generalisable to the wider population as is the case in quantitative studies, the results are transferable across individuals with similar situations.

It is clear from the current study that preterm birth also affects fathers. The ways in which preterm birth affects the identities of fathers warrants further exploration in the Irish context specifically. A more detailed investigation into how pre-existing trauma affects mothers of preterm babies in terms of identity formation warrants further investigation. Finally, the most effective ways of ensuring neonatal parents can support each other through the Neo journey through the provision of suitable spaces and supports warrant further exploration in the Irish context. The latter assumes all the more importance given the visiting restrictions that have been or may be applied during the various waves of the current COVID-19 pandemic.

Some of the experiences of the women in the study point to the need to educate medical professionals on how to effectively collaborate with, and empower, parents while they are in the Neo. To ensure a smooth transition home, it is vital that mothers regain their sense of control, power, and confidence from early on. This will ensure that when they do go home, they are well-positioned to assume full care of their babies. Given the inherent vulnerabilities of the mothers of preterm babies, informal beneficial alliances assume even more importance for these mothers, particularly in the absence of formal professional supports. Thus, such alliances should be supported, not discouraged. Moreover, it should be noted that all of the mothers in this study identified the need for both personalised one-to-one support for parents of preterm babies as well as professionally organised group supports within the Neo itself.

The current study is the first of its kind in Ireland to exclusively and interpretively explore the lived experiences of mothers who, in the aftermath of preterm birth, must renegotiate their maternal identity in a challenging and, at times, threatening Neo world. The exploration of their individual journeys sheds light on the challenges these mothers face and how in the absence of appropriate supports, they cope with their experiences. The findings make clear that with right support from medical staff within the Neonatal environment, these

mothers can be empowered to regain the pieces of maternal identity that were stolen from them when their babies arrived early into the world. The latter suggests that education for neonatal medical staff on maternal experiences of preterm birth would be most beneficial in the long-term.

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