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Stuck inside a hall of mirrors: facets of mum guilt on the SCBU

This paper provides a parent perspective of guilt on the special care baby unit (SCBU) through the voice of a mother of a premature baby, Arthur, born at 29⁺¹ weeks' gestation. The focus of this piece is on the experience of having a 'healthy' preterm baby (defined by a stable condition and no complex medical or intervention needs) and what 'guilt' looks like from this view. There is an urgent need for future research to work more with fathers and the wider family to examine their roles better. The paper will incorporate evidence from previous literature to delineate facets of guilt and how an understanding of this can help clinicians to better support the individual needs of families. Recommendations will be made for how a knowledge of parent guilt could shape practice on the neonatal intensive care unit.

Rachel Collum

Lecturer in Psychology, Faculty of Health Sciences and Wellbeing, University of Sunderland School of Psychology

As a mother who spent over 10 weeks on the SCBU when our little boy was born unexpectedly at 29⁺¹ weeks, if you asked me to list the worst three emotional states I felt, they would be:

- fear
- powerlessness
- guilt.

A wealth of literature has explored the experience of fear and disempowerment on stress and anxiety on the neonatal unit^{1,2} and beyond³ and the role that clinical teams can play in mitigating the risks of this.^{4,5} However, a quick literature search on 'guilt and neonatal' comes up with very few papers that explicitly explore this emotion.

Only two studies identify guilt as a qualitative 'theme' in its own right^{6,7} and both of these had as their demographic mothers of extremely preterm babies (born at <28 weeks' gestation) who were very often in critical conditions. Fowler et al⁷ noted that mothers in their interviews, who had been home for six months post-discharge, spoke a lot about 'failure' as a mother, especially when comparing their babies to others who had been born healthy at full-term: "I had one job and I failed at that."

Ireland et al⁶ interviewed families as long as 3-7 years post-discharge and identified both physical and emotional guilt in mothers. An example of physical guilt was a perception that they should have challenged the medical team more and/or made different decisions about their

babies' care. Emotional guilt was encompassed by a feeling of lacking skills and not living up to the 'societal norm' of having a healthy, full-term baby. These studies both highlight the pervasiveness of guilt and how it can be driven by both practical and emotional aspects. Whether this is the same for parents who face less uncertainty about their babies' health is not clear.

During our time on the SCBU, we never once had any sense that our little boy could die. Our understanding was that he had been born very early and required oxygen to help him breathe and a feeding tube to provide him with the nutrients he required, but he ultimately just had to grow. During our time on the unit, we never saw him need resuscitating, he didn't require any surgeries and he had only a positive prognosis. We were not those parents who are escorted into the Quiet Room and the blinds closed. And yet my recollection of my time on the unit is one gripped by fear that something bad was going to happen. Every beep of the monitor, every episode of bradycardia, every desaturation, came with a paralysing terror. A move back into the incubator from the cot felt like the bricks were crumbling from the path to home; a call in the night to tell us our little one had been put back onto CPAP (continuous positive airway pressure) had only one take-home message: he's not getting better. So, for mothers like me with babies who are relatively stable and healthy

Keywords

very preterm; prematurity; neonatal; parent voice; family-integrated care (FiCare); NICU

Key points

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1. Mothers of 'healthy' premature babies have very different psychosocial needs to mothers of poorly or critically ill babies.
2. There are many different facets of guilt that a mother on the NICU can experience.
3. Guilt can underpin a conflict of identity in mothers – the 'theoretical mum'.
4. Good FiCare can enable mothers to identify and work through their feelings of guilt, supporting them to become 'really mum'.

compared to many on the unit, what does guilt look like?

The paper will focus on the impact of guilt for the mother and not the father due to a lack of literature and being based on the author's personal experience.

The hall of mirrors

For a few weeks after first arriving on the SCBU, I would buzz the Intercom to enter and state: "I'm here to see Arthur". Like a visitor coming for a job interview. Eventually I learned to say: "It's Arthur's mum" but even until the day I said it with the car seat in hand, I'm not sure I ever felt anything but fraudulent in announcing it. Because on the SCBU, I was a 'theoretical mum' (FIGURE 1).

I had given birth to this little boy but he wasn't 'mine'. I didn't get to make the decisions about his care; I didn't know what oxygen levels or drug combinations or nutrients would help him to grow and keep him alive; I even needed help for the first few days to change his nappy, navigating tubes and wires through a dimly lit incubator porthole. What kind of mother can't look after her own child? Here was the first smack of guilt. The mirror that's all blurry, with no real image of what it's meant to look like in this unnavigable maze. There are other mirrors too: the fragmented one you feel glad not to be; the tall, sturdy one you wish you were, and then the one in the distance that duplicates getting further and further away. All of them a representation of guilt.

"At least you get to sleep"

Lasiuk et al⁸ concluded from their analysis of parent interviews, that it is the sense of agency and disruptions to systems of meaning rather than the status of the baby on the neonatal intensive care unit (NICU) that determines how negative the experience can be. Parents articulated feeling forced to rely on "...strangers to safeguard the survival of their tiny infants" and a sense of guilt that they weren't able to 'do' things for their baby. The perceptions of others about what it's like to be on the NICU can really exacerbate this sense of incompetence. I will never forget the time when I told a friend how empty the nights without my baby felt and his response was: "At least you get to sleep; most new mums wouldn't." Another time I had to decline attending a friend's wedding because our baby had only been on the SCBU a few weeks and she suggested: "But you could

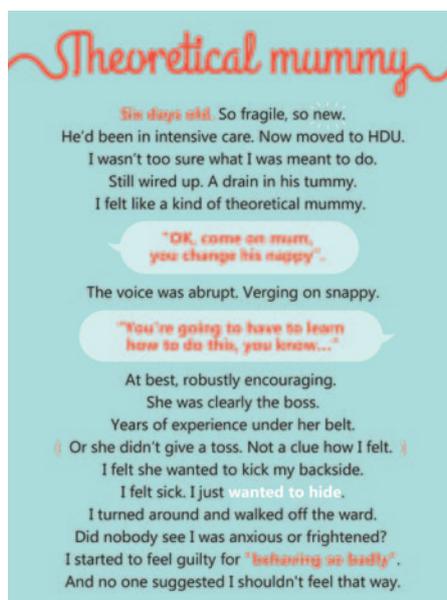


FIGURE 1 A parent perspective of guilt on the SCBU. Poem written by Gill Phillips (@WhoseShoes) and inspired by Helen Calvert (@yourclearday).

still come to the evening party, at least." In her view, our baby was safe in the care of someone else so why wouldn't we? When the people around you mirror back at you that you're not really a mum, that you somehow get 'bonus time' that a 'real mum' wouldn't, even that this is somehow an advantage, how can you feel anything but inadequate? As Lasiuk et al⁸ point out, it is the loss of *agency* that promotes the guilt.

In fact, being a NICU mum is a journey that is full of the most amazing achievements, and this is where the teams on neonatal units can help parents to identify and celebrate the fantastic parenting they're doing. Give the blurry mirror a wipe and there's a bright reflection right there. When I was on the neonatal unit, I felt a sense of guilt and injustice that I couldn't do all the things a new mum 'should'. I had to express milk into a machine instead of breastfeeding; I didn't get to have the babymoon period of sleep deprivation and cuddles; I had to wipe away blood from where needles had been inserted instead of baby sick from my shoulder. At the time, these things felt like failures.

Petty, Jarvis and Thomas⁹ suggest that practitioners can help parents to highlight their achievements by proactively deciphering the language that they use. They analysed the narratives of 23 parents asked to 'tell your story' and found parents use a very high volume of metaphors, especially to describe negative experiences where metaphor provides some safe

distance. This could go some way to explaining why guilt often goes unrecognised, because it is masked within phrases such as: "I felt like I was a million miles away". By paying attention to the language parents use, practitioners can identify where they may be struggling to connect with their babies and can empower them by acknowledging the many aspects of being 'real parents' they perform every day.

"I'm sorry I left you"

The biggest wrench and source of guilt for us on the SCBU was having to walk away at the end of each day. Leaving my tiny little baby alone for the night in the care of nurses I might never have met sat so at odds with anything I ever thought parenthood would be. No matter how many times nurses told us that we needed to look after ourselves too, it still felt like nothing but abandonment.

Both Treherne¹⁰ and Makela et al¹¹ explored parents' experiences of closeness and separation in populations in Canada and Finland, respectively. Using a smartphone app, parents of 'stable' babies were asked to log every time they experienced closeness or separation on the NICU and then record a narrative about their feelings. Very similar themes emerged from both studies in which closeness was determined by parental involvement in decision-making and being able to directly care for their babies. The biggest source of separation for all parents was having to leave the babies in the NICU, even for short periods of time, with several parents feeling that they needed to provide 'justifications' for leaving. Interestingly, perceptions of how nurse involvement mediated feelings of separation were mixed between the studies. The authors of the Canadian study¹⁰ noted that: "When nurses stepped in to help it was a reminder that their {the parents'} infants were in the NICU," whereas Makela et al¹¹ observed that support from nursing staff was generally viewed as positive and didn't interfere with the parents' relationships with their babies. This may point to differences in *how* the support is offered. This was not examined in either of these studies but is worth consideration as part of a good family-integrated care (FiCare) package to ensure that nursing intervention complements rather than conflicts with what care parents want to be offered to their baby in their absence.

I will always remember a wonderful nurse who would read our little boy stories when he woke up in the night. To us, this was so reassuring because it meant he had someone with him who cared. Another parent I spoke to about this was horrified, however, and said she would have hated someone else doing 'her job'. This highlights the importance of staff working with parents to explore what works for *them*. Saying goodbye to a baby in the NICU every night is always going to be a wrench for parents. Perhaps the most helpful thing a nurse ever said to us was: "Your night is our day; call anytime." This enabled us to feel connected to the unit and assuaged any guilt about disturbing the staff. Working together on the goodbye routine and how to minimise the feeling of distance during absence is a crucial part of FiCare that can buffer against the goodbye guilt.

"We're lucky, he just had to grow"

To this day, this is my automated response whenever anyone asks me about our experience of having a premature child. I don't talk about the day where I held our son's tiny little fingers and watched him wince in pain over and over again, his eyes seemingly pleading: "Why are you letting them do this to me Mummy?" Tears streaming down my own face as multiple consultants repeatedly tried and failed to cannulate him. I don't speak of the nights I spent sobbing with empty arms as an industrial-strength machine drew milk for me to refrigerate and feed him via a tube instead of feeling his warm breath on me. I don't mention the time a nurse reached down my top and plucked my little boy away from our daily cuddle squealing in protest because he'd "Had long enough out." I don't tell them about how utterly hopeless I felt when I was told our baby would need to come home on oxygen (in the end he didn't, but perhaps that's another story). I just say, "We were lucky, he just had to grow". Lucky. If you described these experiences to me as a pregnant mother and asked me to label them, 'lucky' would not be a word that would roll off the tongue. But once you have been on the neonatal unit, when you see parents being taken into the Quiet Room, when you live for weeks in an environment where baby loss is far more common than any of the pregnancy books dare to mention, you do feel lucky that your baby isn't one of them. And then you

feel the abject guilt that you've thought that way. That you looked into the fragmented mirror with the pieces missing and were glad that wasn't the image of you.

Arnold et al¹² examined parents' first moments with their very preterm babies and identified five themes with some aspects of guilt contained within them. One was around 'causing' pain to their babies and the other was in 'taking up staff time'. When your baby isn't 'as sick', these are powerful comprehensions of what you 'deserve'. Any time I felt distraught over a desaturation that terminated a cuddle or frustrated by an increase in oxygen, I would think of those babies who might never make it home and tell myself not to be so ungrateful. What did I have to feel sad about? Our baby was going to be okay.

This mentality of comparison and the impact it has is something that has been unexplored in the literature but, from my own experiences, is the driving force behind adjustment when you come home. In her parent perspective paper on her baby's bereavement, Spencer¹³ states: "As we celebrate those who do leave the unit, I feel we should just as openly be able to honour those who don't." This is a beautiful recommendation but one that perhaps belies the fact that, as parents leaving the SCBU, we didn't feel celebratory. We had seen other parents leave; we had felt the burning jealousy. So we wanted to slip away without fuss, to downplay the sense of guilt that we were going home with our baby where others would not.

Borghini et al¹⁴ conducted a study comparing the mothers of full-term, low, and high-risk premature babies, established using the Perinatal Inventory Score at discharge. The researchers conducted the Working Model of Child Interview¹⁵ with parents to establish their perceptions of attachment to their children at six and 18 months post-discharge. They found that parents of the low-risk babies reported higher frequencies of disengagement whereas parents of high-risk babies tended to report stronger, closer bonds. There is a lot to pull apart within this study and certainly the literature on attachment theories has since become contentious. However, Makela et al¹¹ have also noted that: "Being physically near their infants did not always make them {parents} feel close," and there may be something worthy of further exploration in the idea that parents of relatively 'healthy' babies struggle to bond as well during a

NICU stay. In my own experience, the sense of guilt at our baby not being 'as sick' left me in a kind of limbo where no mirror truly reflected me: I wasn't able to be a 'real' mum but I wasn't 'deserving' of the title of 'NICU warrior mum' either. Strangely, this changed after the day of multiple cannulation attempts because then I *had* experienced the worst side of fear for our little boy; I somehow felt like I'd found the centre of the hall of mirrors.

Conclusion

We are only at the beginning of understanding the experience and impact of parent guilt on the NICU. If clinical teams do not fully understand perceptions of individuals as 'mum' and have no concept of what they see when they stand in the hall of mirrors, then we cannot help them to navigate their way back to the one mirror that just reflects them. This is why FiCare is needed: to work with families to understand their experiences of the NICU and support them to reframe their sense of parenthood.

During the COVID-19 pandemic, a poem circulated on social media highlighting how we are all in the same storm, but inequalities mean that people are facing it in different boats. I would argue that on the NICU, perhaps what matters most is the storm. For any parent, looking to see how big, how sturdy, how close to home the boats of other people are really doesn't help make your own journey any smoother. It's the storm that carries us. And this is what staff on the unit need to be aware of and supporting parents to understand. Guilt is the thing that stops us throwing the anchor overboard, feeling that we shouldn't ask for help because somebody else needs it more. But excellent FiCare will ensure every boat has an anchor; one that's the right size for the weight of it.

Practice points

- Staff on the neonatal unit can empower parents by acknowledging and celebrating all their achievements: turning them from being 'I shouldn't be doing this' to 'look at what you can do'.
- Staff need to be attuned to the language that parents use; training on deciphering meaning from metaphors may help.
- Positive 'goodbye' routines can enable parents to feel connected to their babies even when they're absent.
- Staff need to ensure that parents

understand every NICU journey is difficult, regardless of the babies' individual situations. Everyone's emotions are valid and justified.

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