

Empirical Study: Parents of Premature Infants: Exploring Experiences & Parent-Infant Relations

A Thematic Analysis

Analysis Codebook

Theme: Emotional Impact			
Subtheme: Distress			
Code Label	Definition/ Description	Qualifications or Exclusions	Examples*
Difficulty leaving baby	Describing leaving the baby in the NICU and then when at home as hard and emotionally stressful.	Can include examples of where the parent describes how they felt leaving they baby in the NICU each night. Can also include experiences post NICU- how the parent felt leaving the baby once at home.	“... I think it’s really the separation... em not having your baby with you all the time and em I mean you’re allowed 24-hour admittance, you know you could be there 24/7 if you wanted, but you need to sleep at some point [...] I found it really hard being away from him going home in the evening ...” (Jess)
Feelings of guilt and self-blame	Expressing being at fault for what happened which can extend from the prematurity to parenting abilities	Includes parent apologizing to baby, not forgiving self, directly stating that they feel self-blame or guilt.	“...it doesn’t matter as long as he’s fed but there is there’s still an internal struggle of you know guilt and feeling terrible because it’s not me that he’s getting the milk from he’s getting it from somewhere else ...” (Jane)
Medical environment-intrusive or quick	Descriptions made about the NICU experience where parents felt that things happened very quickly (decisions, procedures) and also instances where parents felt the procedures or setting was intrusive to their bodies or time with their infant.	Can include examples of quick medical decisions made regarding the birth of the baby. Parents may use words such as ‘quick’, ‘sudden’, ‘chaotic’, ‘urgent’. Also instances where parents describe lots of changes happening regarding medical plans and relocation to different hospitals. With regards to the intrusive aspect of the environment, these will include times the parent describes procedures as being intrusive (e.g. lots of injections, treatments) or feeling that there are too many people in the environment.	“... there was always either another parent in the room, another baby in the room, a nurse in the room, or you know a doctor, or I was like, we were never ever alone. We never had space, no matter what time of day or night you went down there was always somebody else there ...” (Jane) “... there was my obstetrician there was midwives there was a couple of nurses there was like 17 people in the room and it all happened ...” (Eleanor)

Medical responses-dismissive, unhelpful	Expressing frustration at experiences where medical staff gave unhelpful advice/comments to the parent or did not believe them (where parent felt this)	Can include advice provided by staff as being unrealistic regarding parenting, unprofessional scenarios where the parent is not seen or followed up, staff making comments which show that they are not listening to parents' concerns.	"... and then also again maybe like a bit of a gap in the system was that I thought that babies who were born prematurely would be followed up very regularly by a paediatrician or something but over here em when we registered him with the GP and they referred him to the royal, it's a 28 week waiting list, so he hasn't been seeing by anyone yet and we are thinking 'not sure if that's good or not' so yeah ..." (Eleanor)
Sense of responsibility for health of baby	Expressing thoughts and emotions related to feeling responsible for the prematurity	Although this code is similar to 'guilt and self-blame' it mainly includes direct coded extracts where parents mention the word responsible and wonder what happened to make their baby premature. Examples include parents stating that they were not able to carry baby full-term and the mother's body failing the infant.	"... it took a while to realize that it wasn't my fault, that he was premature, there's a lot of guilt... and even though everyone tells you it's not your fault and you didn't do anything wrong [crying], you can't help but always think 'what if what if what if' ..." (Jess)
Suffering	Describing experiences of strong emotions felt by parent where the parent states they were in distress or found the situation difficult	Will exclude when parent directly states that they suffered from a mental health problem or when the situation is described as traumatic. Includes if parent mentions experiences where they felt helpless, awful and that the situations was hard/horrendous.	"... coming home without him and having the moses basket there and not having him to put in, that was pretty horrendous but that was just kind of one moment in kind of a lot of different moments you know that were pretty horrendous ..." (Jane)
Trauma and shock	Where parent describes situations where they felt it was traumatic or created a direct shock response (parent will use these words or use them indirectly through examples)	Can include parent receiving sudden news which shocked them, not believing what has happened, stating they were in a state of confusion or shock; can also include a strong emotion having an impact at a later point, may be linked to flashbacks of memory or a sensory part of the event, parent can describe having triggers to strong emotions from the past (at times these will be coded extracts where you directly see the trigger through the parent's distress), parent describes long lasting effect of the emotion (e.g. it won't ever leave me).	"... Looking back now I honestly think I was in shock em coz I think around 6 and 7 months I sort of started getting like flashbacks of his birth ..." (Lauren) "... And then saying goodbye, I don't think that is ever going to leave me just how hard it was to leave him in the hospital and then every single night [...] I just don't think you are ever going to get over that ... it's just awful" (Jill)

Subtheme: Feeling Different

Code Label	Definition/ Description	Qualifications or Exclusions	Examples
Feeling different	Parent describes experiences where there is a marked difference in what they thought their experience was going to be like and how it actually is; also where parents describes encounters with people where there is a difference in experience (full-term parents vs preterm parents)	Can include extracts of conversations with other parents where the difference between full-term and preterm is clear; different routines that preterm parents have to do at home that differ from the general population of parents; where parents describe experiencing things that others haven't. Excludes extracts which only focus on what the parent feels they have lost out on.	“... I did get into arguments with a lot of people like close to me, like my mum and my sister [...] just after he was born and it was because I think ‘you don’t understand’ and ‘you don’t understand what I’m going through, you don’t know what it’s like’. I know my sister has kids and I’m kind of like ‘but it’s not the same’ ...” (Jane)
Lost experiences	Expressing missing out on an experience of a full-term birth and what the prematurity meant for the parents’ identity and pre-formed ideals of what they would be doing as a parent of a new-born baby.	Includes comments where the parent states ‘I was meant to have’, ‘not what I imagined’, ‘I wish’, ‘should have been’... parents can give examples of what they missed out on during pregnancy, at birth, first contact with their baby upon birth, or during the first few weeks of the baby’s life. Can also include comments where parent compared their experience to another parent’s (of a full-term baby).	“... em, but people would tell me about their delivery and how hard it was or how hard something was and I’m just like ‘oh, really?!’ [laughs], so I’m sure some other people have it a lot worse than I do, I know that but it’s when people are like ‘yeah I was in labour for like 3 hours’ and I’m like ‘I wish I was in labour, I wish I had the whole natural birth ...” (Mia)
Seeking and desiring normality	Describing wanting their parenting experience and child’s health to be like other parents and children (normative)	Can include comparisons being made with other parents along with wishes to be like that (not enough for just a comparison to be included here). Includes parent making plans for the future and also fearing the negative impact of the premature birth and not wanting this to be in their life (e.g. such as future births, the child’s future experience and sense of self)	“... ‘why couldn’t I be like all the other mummies in the maternity ward and have their friends and family up to see the baby whenever they were just born?’ ...” (Mia) “... you were getting all this information and you were reading about it and you are kind of just willing them to go ‘come on crawl’ ...” (Jane)

Subtheme: Feeling Unprepared & Fearful

Code Label	Definition/ Description	Qualifications or Exclusions	Examples
Feelings of fear	Parent describes experiences in the NICU or post NICU of feeling scared in the moment or due to future possibilities	Includes times the parent mentions the following words: fear, terror, scared, frightened, scary, anxious. Parent ascribes these emotions to future possible events such as the infant dying or having health problems and also at times is linked to parent describing this emotion and linking it to hypervigilance.	“... and completely scared of what would happen and how long she would be in there for, how long she would be on the little breathing mask and if there would be any long term difficulties with ...” (Mia)
Feeling unprepared	Describing not being ready for the experience of becoming parent of a prematurely born infant and not knowing what to do	Can include where parent describes things they didn't do or had to look up, things they didn't physically have like a hospital bag ready, staff not knowing how to help them with care of baby, things not being explained to parent by staff members which led to parent feeling unprepared, or feeling alone after the NICU.	“...well I suppose that was just, at the start I remember looking at that machine thinking ‘what do all those numbers mean, what do all those letters mean, what does everything mean’ and it was really disempowering coz you were thinking, ‘my baby’s not well and I don’t know what is going on’...” (Kate)
Worries & fears with developmental milestones	Expressing fears for future regarding infant meeting developmental milestones and current fears of infant not meeting milestones presently	Can include if parent mentions their infant not being the right weight, not feeding well, being tiny, also if parent expresses worries about school and if child will be behind....	“... I suppose when Megan was growing up we were always worrying ‘would she meet this milestone, would she be developmentally okay, would she be developmentally delayed, would there be any disabilities or anything ...” (Kate)
Self-doubt with parenting	Expressing worries and doubts with thoughts of not meeting their child’s needs or not knowing what to do	Can include verbalizations were parent mentions ‘what if’s’ in relation to their parenting. Includes extracts where parent mentions wanting to give up due to feeling unable to do a task (e.g. pumping or breast feeding, or caring for baby while they are in NICU). Also includes instances where parent feels judged by staff.	“... but I think that for me was possibly one of the biggest things of going ‘oh we’re not in like a really clean clean clean environment any more, oh my goodness’, ‘what if something happens to him’ and again ‘what if I make him sick, what if I do something wrong?’ ...” (Maria)

Subtheme: Frailty of Life & Well-being

Code Label	Definition/ Description	Qualifications or Exclusions	Examples
Anticipating medical problems or death of baby (NICU)	Describing concerns held by the parent or medical staff about the outcome of the birth during pregnancy or health of baby once they were born. Upon birth some parents will state feeling close to the potential death of the baby	Can include symptoms the parent felt before birth that were ‘warning signs’ such as chest pain, preeclampsia, waters breaking, bleeds, sepsis, heart rate decreasing. Can include instances where the medical staff were concerned and did extra tests/ took precautions. Parents will at times also describe having initial concerns about the future health of the baby/ long term problems or will make comments related to having expected the baby to die.	<p>“... completely scared of what would happen and how long she would be in there for how long she would be on the little breathing mask and if there would be any long term difficulties with her like learning difficulties or anything like that type of thing, yeah...” (Mia)</p> <p>“... I suppose yes not fully believing them and also kind of in the back of my head was the well she is alive now but will she be in an hour or two hours or a day, you know that sort of, coz that we didn’t know if there were any other underlying issues...” (Eleanor)</p>
Anticipating medical problems post NICU	Describing times when the parent felt problems would arise post NICU for their baby due to the prematurity. These can be developmental, physical (infections), neurodevelopmental.	Can include if parent had future thoughts of baby having ASD, ADHD, Cerebral Palsy, learning disabilities. Can include instances where the parent was expecting a relapse/infection (and then engages in preventative measures to keep baby safe). There is a sense of the parent not knowing what would come of the prematurity in the future.	<p>“... that was always something I was very aware of like, you know could she have cerebral palsy because she's, could she have higher risk of autism because she's been premature, could she be at a higher risk of ADHD... so I suppose it is something I'm aware of that I hope she doesn't have to face ...” (Lauren)</p>
Medical problems of infant	Describing medical issues that the infant had upon birth, during the NICU, and after discharge. Gives a sense of the vulnerability of premature infants and their common relationship with illness and the medical system	Can include times where parent describes medical conditions such as bradycardia, breach, eczema, baby needing CPR, heart monitors, surgery. Also includes times where the baby relapsed while at home and had to go back to NICU.	<p>“... up until now Alfie is still sick all the time so this week from Monday to Thursday he cried all night long he got maybe three hours sleep max in like broken bits and he was just crying and crying and crying...”</p>

<p>Medical/psychological problems of parent</p>	<p>Descriptions provided of physical problems that the parent had either before, during, after the birth and also psychiatric problems the parent mentions having or believing to have had.</p>	<p>Can include physical problems such as organs failing, loosing blood, surgery due to complications post birth, parent staying in hospital due to their own physical problems, where parent mentions having PTSD, anxiety disorder, post-natal depression, or makes comments such as 'losing my mind'.</p>	<p>“... I think I probably have PTSD from his birth, self-diagnosed PTSD [laughs] but I think I probably do, em because it was so, so traumatic, it was very very very frightening... em and all my worst things that could happen... seemed to happen [laughs] you know? ...” (Maria)</p> <p>“... after that I had my own complications with the placenta, I had, I lost a lot of blood and I had to go to surgery myself...” (Eleanor)</p>
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*Participant names are pseudonymised

Theme: Searching for Parenthood

Subtheme: Not feeling like a parent

Code Label	Definition/ Description	Qualifications or Exclusions	Examples*
Basic care needs (not feeling like a parent)	Describes memories where the parent feels they were not able to engage in the typical physical basic care needs of their child (e.g. changing nappy, feeding, availability to meet needs)	Includes specific examples of not being the main person responsible for providing basic care needs such as feeding, soothing, giving the baby a bath, or having the baby in the womb until full-term). Can also include instances where the parent does not know how to meet their baby's basic care needs due to prematurity (NICU and post NICU).	"... you know, but you're looking at this tiny tiny baby, I mean Daisy was 1 pound 14 at birth, you know, she's the size of your hand, you're looking at this tiny baby and you're thinking 'how on earth do you change that baby's nappy? ...'" (Helen)
Emotional needs/bond (not feeling like a parent)	Describes memories where the parent feels they were not able to engage in the typical emotional care needs of their child (being present, looking at baby, holding them) or bond with them.	These experiences are typically in the NICU environment. Parent may specifically state that they did not feel like a parent (mum) and that the initial bonding was not the same as it could have been had the baby being born full-term.	"... I was in one ward and Layla was in the other all I could hear was reports of her or one picture of her and it was just, it felt like I wasn't really a mummy, this baby was inside me and then it was taken out and I couldn't see the baby so it was like, yeah it was really difficult, it was very very difficult very hard ..." (Mia)

Subtheme: Regaining parenting role

Code Label	Definition/ Description	Qualifications or Exclusions	Examples
Parent role recuperation (basic care needs)	Describing ways that the parent started to feel more like a parent in engaging in the physical basic care parenting tasks	Includes learning to do tasks with support from the medical team, regaining independence as a parent such as when the infant is moved to a cot, doing washes, feeds, nappy changes.	"... you sort of felt 'right well I've changed the nappy', I've just [done] those practical normal sort of aspects, as well I've held him and just those little bits and pieces where they've all come together and you think 'I feel like a mummy now' ..." (Maria)
Parent role recuperation (emotional needs)	Describing ways that the parent started to feel more like a parent in engaging in the emotional care of their	Includes seeking ways to stay longer with their baby in the NICU or to see them; parent stating that they were making up for lost time (e.g. holding more when they	"... holding her I just thought I didn't get to hold this baby for six weeks so I'm going to make up for all these cuddles because before

	baby and finding ways to connect with their baby	could), and instances where the parent directly identifies themselves as the baby's parent.	you know it she'll be walking and I'll not be able to hold her all the time ..." (Kate)
Returning to normality	Parent describes milestones or feelings where they feel that things are returning to how they were meant to be and back to a 'normative' parent/family experience	Can include the parent mentioning phrases such as 'new beginnings' and 'normal'. Examples can be coming home, reaching the baby's actual due date, losing dependence on medical equipment, finally being along with the baby (family unit without hospital staff).	"... we were in the car as a three. Danny.. I think I was sitting in the back with Nancy because I didn't want to be too far away so she was in the car seat and so he, Danny was driving the car and we hadn't set off yet but we got into the car and he turned round and went this is our family and then he started to cry ..." (Lauren)
Seeking closeness/connection with baby	Expressing a need and sense of importance of parent-infant contact for both parent and the infant. The contact has a sense of wanting closeness and connection with the baby	Can be instances where the parent seeks contact with their infant due to not having that at the start of the relationship, singing to infant to establish connection, playing with infant, wanting to be close to them, spending lots of time with them.... Can be both ways- sought by infant or parent	"... he got home in the 21st of July and I don't think we brought him anywhere for the first wee while, we just sort of stayed, coz I think we just craved that intimate time of 'no I just want to sit here and hold him' ..." (Maria)
Tuning in to baby's signs	Describing experiences where parent has learnt to read baby's signs and communications or that show the importance of going with the baby's cues	Can include soothing behaviours, excerpts showing that parent understands baby better (moods, vocalisations), actions where parent listens/helps the baby	"... I feel I've become a better mummy as I understand, he sort of teaches me, do you know what I mean?, if I'm doing something wrong he'll cry and let me know so he teaches me and I feel like we've got a closer bond for that ..." (Ava)
Subtheme: Different kind of parenting			
Code Label	Definition/ Description	Qualifications or Exclusions	Examples
Actions by parent- meeting developmental milestones	Describing actions that the parent has taken to help their child meet developmental milestones	Can include examples where parent state taking their child to hospital appointments or extra appointments to check developmental needs, changing the children routines in feeding, studying the milestones of the baby in reputable resources to monitor progress, engaging with the baby in more play/ sensory activities due to prematurity. Can also include parent stating	"... again this goes back to the milestones and stuff in that red book, the baby book and the other one the big green one they give you and it's kind of like what babies should be doing at what ages, em and I was kind of reading those kind of going okay he's 10 weeks now he should be doing this, he should be looking at his hands or something em the other ..." (Jane)

		that they were active in thinking how they could help baby meet more milestones.	
Flexible parenting	Speaking of being different with their baby in terms of setting boundaries and limits. Different type of parent who in a way is more flexible	Can include parent describing themselves as soft, making allowances, and spoiling their baby. Can also give a sense of the parent compensating for what the infant went through early on, therefore wanting to not put that strain in their life post NICU.	“... whereas Megan slept in my chest all the through the days and things like that, em all the things that you shouldn’t do, I held her whenever she was sleeping and I sat and watched TV, I was just so happy to have her ...” (Kate)
Heightened precautions post NICU	Describing behaviours and thoughts related to needing to keep the baby safe from the likes of germs or feeling anxious because of this (anxiety tends to drive these behaviours). These behaviours will differ from the normative parent population as they tend to be directly linked to the baby being premature and the kind of care they received in the NICU.	Can include behaviours were parent does not go outdoors with baby in order to protect them from infection or does not interact with others/invite them to the home. Can include parent seeking only expert opinion about their baby’s development and what they need to do.	“... I was meant to be close to my friends and they all wanted to come and see me I was very much saying ‘Don’t’ em you know so that was so I suppose I isolated myself more than I probably needed to em because I believed I was protecting her ...” (Evelyn) “... I think em you know everything is completely different whenever you have a baby who is preemie, em I think you are very conscious of germs and people passing him around ...” (Jill)
Medical environment-clinical features and protocols	Descriptions made about the NICU experience where parents speak about the guidelines adhered to in the hospital and the specific features in the NICU that are noticeable to them such as public nature of it, sounds, areas for parents etc.	Includes examples where parent describes instances where they needed to ask permission to do things with baby, the busyness of the ward, the ward being noisy/public. Some coding extracts may also mention being regimented and controlling and there being lots of medical equipment around the care of the baby. There will also be extracts where parents speak of protocols in the hospital that did not allow for flexibility of care. Excludes specific examples around the routines that baby’s had in the NICU- this would go under the code of ‘medical routine in NICU’.	“... there’s lots of machines and lots of beeping and lots of things going on but it’s so quiet and it’s almost like there’s a fear you know even though all the parents are there and it’s all their children but there seems to be almost this fear and you just sit and you stare and it’s very strange...” (Jane) “...and when I see other mummies and I’m like, they are not as obsessed with sterilizing and cleaning, I suppose I had been in that sort of institutionalized environment I was so into sterilizing, infection control, all the things I suppose other preemie mummies were...” (Kate)

Medical routine in NICU	Describing practical medical tasks that the infant needed on a regular basis in hospital such as specific feeds, checking blood levels etc, also includes the routine that the parent implemented in their life to accommodate for their baby being in the NICU	Can include parent mentioning their new routine and pattern of visiting the NICU, medical tasks that the baby needed on a regular basis in the NICU (e.g. sterile environment, certain medicines). Excludes if the parent is focusing more on the routines that they continued once home. This would go under the code 'medical routine once home'.	<p>“...It was constantly timetabling, constantly getting ready to go or to comeback, you know, so it was constant movement. Does that make, you know, rather than being still with the baby in the house...” (Lauren)</p> <p>“... I went up to the neonatal from about 9 o'clock and so was leaving here about half eight or quarter past eight, and we sat there for about 9 hours every day...” (Kate)</p>
Medical routine once home	Describing practical things that parents needed to do for the baby relating to the hospital such as attendance at hospital appointments, routine at home that came from hospital.	Can include routines that were established in the hospital and were adopted in the house; but at times parent might not mention this directly and may say things like 'it was very clinical... we did this'.	“... There were a lot more appointments, there was a lot more check-ups, and she came home on medication [...] so there were things that had to be done there and for the first 6 months of her life she had to go back once a month for an injection for her chest, so there was a lot more that I had to do ...” (Evelyn)
Parent(ing) expectations	Describing experiences where parent had certain expectations of things they would have done (knowing about other people's baby's etc.); also experiences where others use their own ideas/expectations of parenting a full-term baby and give the parent advice	Excludes instances where the parent describes what they were deprived of or didn't experience due to the prematurity (these would go under lost experiences). Includes instances where parent described needing to learn themselves as the expectations of what they needed to do are different due to prematurity; also includes parent being more overwhelmed at tasks due to baby being premature (linked to what they had expected it would be like); parents thinking about the infants age and where they should be in terms of development	“... like when I was feeding on demand you know it was actually quite often it was maybe every hour and a half, or two hours, and em my mum did breast feed me and [partner's] mum didn't and she would constantly be like 'why is he still hungry? maybe you're not giving him enough milk, why don't you just give him a big bottle at night and let him sleep through the night' and then all the time I was like 'you know he needs to be fed on demand because he was premature and the most important thing is building weight and so if he wants to eat, I'm going to feed him' ...” (Eleanor)

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Theme: Moving Beyond Adversity

Subtheme: Hopeful Moments

Code Label	Definition/ Description	Qualifications or Exclusions	Examples*
Baby's strength of character	Parent describe their baby's as resilient and having overcome difficulties at a young age. These comments portray a sense of the baby fighting to live and thrive	Can include instances where the parent uses words such as 'fighter', 'strong', 'resilient'. Excepts can also be based on examples of the things that the baby has overcome such as surgery or other medical problems.	"... yeah I think that's something because he had spent time in hospital and em like even in those 5 weeks he had to deal with a lot of things that maybe full term babies or babies that hadn't spent any time in the hospital would deal with ..." (Eleanor)
Milestones during NICU	Describing experiences within NICU where there was a sense of moving forwards and hope at baby achieving new milestones. These experiences show a sense of hope.	Can be instances where the parent described the baby's feeding routine changing, moving to a cot, being discharged, making motor movements or vocalizations...	"... and then em like his feeds when they were increasing, so it was only like, they would have increased like 3mls and it would have been such a big step so I would have been so focused on going into the hospital, it's the first thing I looked at ..." (Lisa)
Milestones outside of NICU	Describing experiences outside of NICU where there was a sense of moving forwards at reaching new milestones. These experiences show a sense of hope.	Can include instances post NICU or before NICU when the baby was still in Utero. These can be such as meeting the first year anniversary, baby staying in utero longer, scans in utero going fine.	"... the woman came up from tiny life [to] track his progress and all and he was always like on track of the months of his age, his actual age, he was always following his actual age ..." (Ava)
Thankfulness at baby being alive	Expressing feelings and thoughts of being lucky with how a difficult situation wasn't worse (i.e. death of baby) and that there baby is thriving and alive	Can include words/phrases ascribed to the baby such as 'miracle', 'survived', feeling 'lucky', things could have been worse. Some parents may also describe their thankfulness in an experience such as hearing their baby breathe and being in disbelief.	"... I also know that we were very lucky in an unlucky situation coz I sort of knew that David was okay like David came out crying so for me I was like 'right, dead on he's fine' he came out and he just cried and he was breathing on his own so I was kind of like 'right okay that's like that's a big hurdle' ..." (Jill)

Subtheme: Self-Care and Growth

Code Label	Definition/ Description	Qualifications or Exclusions	Examples
Advocating for needs	Describing parts of their experience where changes can be made to better meet the needs of future parents in similar situations. This then in turn helps parents to better parent their babies.	Can include suggestions of staff interactions with parents in the NICU such as giving them more information about the medical process, being more sensitive to the emotional experiences of the parent, and ensuring that parents fully understand the medical jargon and are involved in decisions. Parents may also make suggestions about additional services needed in the NICU.	“... a big thing I think is they should have a psychologist or somebody on that ward who can actually get the mummy more prepared for having to leave the hospital coz obviously on day three isn’t that the day when the baby blues hit as well? ...” (Jill)
Maintaining mental health	Describing actions that parent took to look after their mental health during the process	Can include things that were done but not things that the parent wished they had done in hindsight (this is covered in code ‘mental health advice to parents’). Examples are talking to others, accepting each day, accepting help.	“... you were researching stuff whenever you went home and you were reading the books, so it was like knowledge is power kind of thing, the more you find out and the more you spoke to the staff and the more you spoke to other parents, the more sort of equipped you were to deal with all the things that you were facing ...” (Kate)
Mental health advice to parents	Expressing thoughts on what they would advise others to do or what they would have done in hindsight to cope with the experience-expressing what they learnt later which may have been helpful earlier on	Can include advice to parents such as asking more questions about their infant’s care and being more confident, reminding oneself more of the medical expertise of staff, taking each day as it comes, being in the present, not blaming self.	“... Not use the word should, I think that word is so powerful in someone’s head and it’s so part of our life you know, ‘you should just relax’, ‘you should be at the hospital’, ‘you should be doing a pump’, ‘you should’. I would try and take that out and just go with my instinct ...” (Lauren)
Reinterpretation of difficult experience	Parent thinks about their whole experience in a learning mode; what they learnt and gained, and speak about feeling lucky that the situation was not worse.	Can include instances where the parent states that they have gained from the experience such as parenting skills, connections with others, being with their baby longer, having a stronger bond, strength of their own character. Can also include where parents reflect on	“... Eh I wouldn’t want to do it again but I’m glad, I’m just happy that I learned so much from a bad experience ...” (Ava)

		comparisons with other parents who were not as lucky.	
Self-compassion, acceptance	Describing finding peace in the whole situation and accepting self and situation. Parent relays a sense that the situation couldn't have changed and that they learnt to forgive themselves and move on	Can include direct examples where parent states they now accept the situation and that it has become easier to deal with. At times parents may state that they realise they weren't at fault for what happened.	"... I just think over time finding peace with what's happened. Like I said to you a year ago I couldn't have talked really about it but just finding an inner peace with it [...] and just coping with everything and dealing with and processing everything and giving my time you know to have that ..." (Helen)
Subtheme: Interpersonal Support			
Code Label	Definition/ Description	Qualifications or Exclusions	Examples
Medical staff supportive and responsive	Describing experiences where staff actions have made the parent feel supported and understood. They will be specific examples of care by individuals or the neonatal unit provided	Can include examples of staff including the parent in the care of the baby, normalising emotions, showing kindness, responding to emotions, and being proactive in helping the parent (e.g. anticipating their needs without parent asking). Also can include staff listening to concerns and acting on them rather than dismissing these.	"... so and they walked us down, two of the nurses walked us down literally to the front door, you know it was just, you know other people, if their baby is healthy and fine they just go up and go home, but it was just, they all wanted to say goodbye and they were so encouraging ..." (Maria)
Support from others outside of medical staff	Describing relationships outside of the medical profession that have helped the parent to cope with the experience and which have been helpful to the parent's emotional well-being	Can include examples of this through receiving advice from others, the helpfulness of talking to others, friendships based on shared experience (having a premature baby), and sharing learnings with others parents. Can also include instances where parents receive practical support from others (e.g. with driving, food).	"... whenever I went up to the hospital with pain and [my partner] was working quite far away so he had to drive quite a bit to get home [...] so my sister was the first person I called then to say, 'can you come and wait with me?' so she stayed there until he got there, so she was in the delivery suite and all with me ..." (Jess)

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