

## **Katherine Sabin, Dr Fiona Challacombe - Written evidence (PRT0058)**

### **Background**

Parents of infants born sick or preterm requiring specialist treatment in a Neonatal Intensive Care Unit (NICU) are at increased risk of developing mental health difficulties. Parental psychological distress in the postnatal period may impact on parenting behaviour and is associated with poor cognitive and socio-emotional development in the infant. In the UK, neonatal standards of care do not include provision of psychological support for families after their infant is discharged home, and parents may access support through non-specialist settings. This research aims to understand the nature of parental psychological distress, service use and parents subjective experience of support and support need.

### **Methods**

This national online questionnaire recruited parents via the social media platforms of neonatal charities. Mothers and fathers who have had an infant who received treatment in a UK neonatal intensive care unit within the past 5-years were eligible; the final sample consisted of 296 parents, 249 (84%) of whom had an infant born preterm (<37 weeks gestation). The questionnaire explored parental experience across four time-points: the period of hospitalisation, discharge, 6-months post-discharge and 12-months post-discharge, to understand their experiences of psychological support, parent-infant bonding, non-specialised care needs and specialised, medical needs.

### **Results**

Parental symptomology, including symptoms of anxiety, depression and trauma showed no overall improvement from discharge to 12-months

post-discharge. The area of greatest unmet need was psychological support. Parents described the **enduring impact** that their infant's NICU admission had on them emotionally, and the difficulty of their perceived **lack of control**. Participants shared their experiences of support and proposed ways in which healthcare providers could better meet the needs of neonatal families; providing **psychologically informed care, encouraging connection**, and **bridging the gap** between hospital and community services.

## **Conclusions**

This study suggests the nature of parental psychological distress is complex and may persist for prolonged periods after an infant is discharged home from neonatal care. The data provides evidence for significant unmet need and suggests ways in which current clinical practices may be able to provide more effective, tailored interventions. The sample's lack of diversity may limit the generalisability of the findings.

## **1 Introduction**

It is well recognised that the postnatal period is a time of increased psychological vulnerability, whereby parents are at greater risk of developing mood and anxiety disorders (Dennis et al., 2017; Leiferman et al., 2021; Liu et al., 2022; Paulson & Baxemore, 2010). Mood and anxiety disorders in the postnatal period may affect parenting responsiveness, negatively impacting the developing bond between the parent and infant (Erickson et al., 2019). Consequently, a poor attachment relationship has been associated with delayed developmental milestones for the infant, including lower cognitive and socio-emotional competence (Hoffman et al., 2017).

Parents at even greater risk of developing mood and anxiety disorders are those with infants admitted to a Neonatal Intensive Care Unit (NICU) shortly after birth (Malouf et al., 2022; Tahirkheli et al., 2014). Approximately one in eight infants born in the UK will require treatment in a neonatal unit (Neonatal Data Analysis Unit, 2017). Neonatal intensive care is the highest level of specialist treatment that an infant may receive in a neonatal unit, often for infants born critically ill, or before 28 weeks gestation. The current study will specifically recruit parents who have had an infant that required treatment in neonatal intensive care.

It is well recognised across the literature that having an infant admitted to neonatal intensive care poses significant stress on parents. The often unexpected early or emergency delivery may prevent parents from being able to see or hold their baby after birth and medical intervention on the neonatal unit may act as a physical barrier further separating parents from their baby (O'Donovan & Nixon, 2014). When the infant is medically unstable and there is a perceived threat to their survival, parents may struggle to connect emotionally and form a bond with their infant (Fenwick et al., 2008). Physical contact between the parent and infant is an important milestone in establishing feelings of parenthood (Carton et al., 2020). Parents have reported feeling like an outsider, alienated from their own baby (Obeidat et al., 2009). They may feel uninvolved in decisions regarding their infant's care (Nystrom & Axelsson, 2002), and feel as though they must negotiate with staff or ask for permission to care for their own baby (O'Donovan & Nixon, 2014).

Discharge home from neonatal care is frequently perceived as the end of the neonatal journey, however infants are often discharged with special care needs or dependent on medical technology. Parents have reported feeling inadequately prepared to take their medically vulnerable infant home (Adama et al., 2016), perceiving themselves as unable to read their infant's cues or identify signs of illness (Dellenmark-Blom & Wigert, 2014). Garfield et al. (2014) described the difficult transition from the

safety net of the NICU which surrounds parents in reassurance that the baby is well, to home, whereby there are no monitors or medical staff offering constant reassurance. A review by Adama et al. (2016) highlighted the continual fear parents experience having taken their baby home, causing high levels of anxiety and sleep deprivation as they continually monitor their infant, through fear that their health may suddenly deteriorate. Support in the early post-discharge period can improve confidence in care (Adama et al., 2016) however, community healthcare providers are often perceived as inexperienced in providing care for neonatal infants (Garfield et al., 2014) and families may struggle to get appropriate referrals in place should their infant require developmentally supportive care post-discharge (Boykova et al., 2016).

Early intervention is essential for improving mental health outcomes for neonatal parents. If left untreated symptoms of mood and anxiety disorders may persist post-discharge. A US longitudinal study by Lotterman et al. (2019) found that mothers of moderate to late preterm born infants had markedly higher rates of anxiety, depression and PTSD both during their infant's hospitalisation and at the 6-month follow-up, compared to mothers of infants born full-term and healthy. Furthermore, there was no observed change in maternal symptomology over this 6-month period for the mothers of infants born preterm. Evidence within the literature also suggests that mothers of infants born preterm may experience delayed trauma processing. Mothers reported that during their infant's neonatal admission there was a sense of numbness, in which their sole focus was the infant's physical health and tending to their infant's needs. It was only as the intensity of the threat they perceived to their infant's survival decreased in the months following discharge that they began to process their own emotional response and trauma (Shulman et al., 2021). More recently research has therefore highlighted the continued vulnerability of neonatal parents' post-discharge. There is however limited research conducted within the UK among a more heterogenous sample of

neonatal parents, including fathers and parents of infants born full-term, yet critically ill.

Research by Bliss in 2015 found that 41% of UK neonatal units were not able to offer dedicated psychological support from a mental health professional. The latest national standards for neonatal care define psychology staffing standards, to ensure a psychological professional is embedded within each neonatal unit. It is therefore recognised that psychological provision in UK neonatal care has likely improved, however, more recent research is yet to be conducted. Furthermore, there are currently no standards for psychological provision post-discharge and neonatal parents often access untimely support through non-specialist settings which are not tailored to the unique needs of this parent population.

This questionnaire will address various factors which contribute to parental mental health, including understanding more about the nature of parental anxiety, depression and trauma post-discharge. The questionnaire will gather data to understand current service use as well as parents subjective experience of support. This research will investigate how well existing services are meeting the needs of neonatal parents and what changes should be implemented to better meet their needs. The findings will support the development of more targeted interventions, with the aim of alleviating psychological distress among the neonatal population.

## **2 Methods**

### **2.1 Study design**

This study used an online questionnaire enquired about the psychological experience and support needs of parents who have had an infant that required treatment in a UK Neonatal Intensive Care unit. This study was

approved by the King's College London Research Ethics Committee (HR-21/22-26778) on 11/04/2022.

## **2.2 Recruitment**

Three neonatal charities and their stakeholders shared the recruitment poster across their social media platforms over a 3-month period from April 2022 to June 2022.

## **2.3 Participants**

Four-hundred and twenty-eight parents were deemed eligible to take part and provided informed consent, however, 132 participants were excluded due to high levels of incomplete data. The final sample consisted of 288 mothers and 8 fathers. Of the final sample, 249 parents had an infant who was born preterm (<37 weeks gestation; 84%).

## **2.4 Inclusion/ exclusion criteria**

Mothers or fathers over the age of 18, currently caring for an infant who was previously admitted to a neonatal intensive care unit in the UK, and who had been discharged from neonatal care within the previous 5 years were included. Parents were not eligible to take part if they; had an infant who was still receiving treatment in a neonatal unit at the time of recruitment, were unable to read English adequately to comprehend the questionnaire or were not currently caring for their infant (i.e. parents of a singleton that did not survive or parents of multiples in which all infants did not survive).

## **2.5 Procedure**

Participants read the information sheet and provided informed consent via the computer software Qualtrics, before proceeding to the online questionnaire. Participants took on average 48 minutes to complete the questionnaire and they were not provided with any compensation.

## **2.6 Questionnaire**

Using current research and the research teams clinical experience, a questionnaire was developed consisting of primarily multiple-choice questions, with additional open-ended questions included where relevant, so that the participant could elaborate or provide specific details should they wish to. The questionnaire first collected socio-demographic information and information regarding the infant and their neonatal admission. The following sections of the questionnaire were designed to explore the participants experience across five domains; a) Symptoms of distress and psychological support, b) Additional stressors, c) Non-specialised care for the infant, d) Bonding, e) Specialised/ medical care for the infant.

The psychological symptoms questions were designed to include the 31 items of the Perinatal Anxiety Screening Scale (PASS; Somerville et al., 2014) and the 2 items of the Patient Health Questionnaire 2 (PHQ-2; Kroenke et al., 2003). The response options were modified to understand whether each symptom was relevant to the participants at different time points. These standardised measures were therefore not used to screen for clinically significant symptoms of anxiety or low mood.

## **2.7 Data analysis**

The quantitative data was analysed using descriptive statistics. Categorical data is presented using frequencies and percentages.

The qualitative data was analysed using descriptive thematic analysis, following the principles described by Braun and Clarke (2006). The qualitative data was exported from Qualtrics and imported to the computer software NVivo, where the responses were read multiple times to familiarise with the data before preliminary codes were identified. The initial codes were used to generate themes which were refined and further developed, to reflect categories with broader patterns of meaning and shared attributes.

The type of answer and the detail provided in response to the free-text questions varied considerably across the sample. The quantitative and qualitative data were integrated at the interpretation stage of the analyses. Where relevant, the qualitative data is presented alongside the quantitative data.

### 3 Results

#### 3.1 Demographic overview of participants

Table 1 provides an overview of the demographic variables for the parents included in the final analyses and their infant.

**Table 1**

*Basic demographic data for the parents and their infants*

Variable	N= 296 <sup>a</sup>
	No. (%)
Parent	
Age	
18-24	11 (4)
25-29	48 (16)
30-34	115 (39)
35-39	86 (29)
40-44	30 (10)
45-49	6 (2)
50+	0 (0)
Prefer not to say	0 (0)



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Ethnicity

White	283 (96)
Black	2 (1)
Asian	4 (1)
Mixed/ Multiple	6 (2)
Other (Latinx)	1 (0)

UK country of residence

England	236 (80)
Wales	34 (11)
Scotland	19 (6)
Northern Ireland	7 (2)

Relationship to infant

Mother	288 (97)
Father	8 (3)

Co-parenting

Single parent	18 (6)
Co-parent	278 (94)

First-child

Yes	188 (64)
No	108 (36)

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Infant

Gestational age at birth

<24 weeks	16 (5)
25-28 weeks	72 (24)
29-32 weeks	102 (34)
33-36 weeks	59 (20)
>37 weeks	47 (16)

Birth weight

<1.5kg	148 (50)
1.5kg - 2.5kg	93 (31)
>2.5kg	55 (19)

Intensive care length of stay

< 1 week	75 (25)
1-4 weeks	120 (41)
4-8 weeks	43 (15)
2-4 months	49 (17)
4-6 months	8 (3)
> 6 months	1 (0)

Total neonatal length of stay

< 1 week	19 (6)
1-4 weeks	100 (34)
4-8 weeks	72 (24)

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2-4 months	81 (27)
4-6 months	19 (6)
> 6 months	5 (2)

Multiple pregnancy

Yes	41 (14)
No	255 (86)

<sup>a</sup> *Note:* Table may not equal 100% as a result of missing data or rounding.

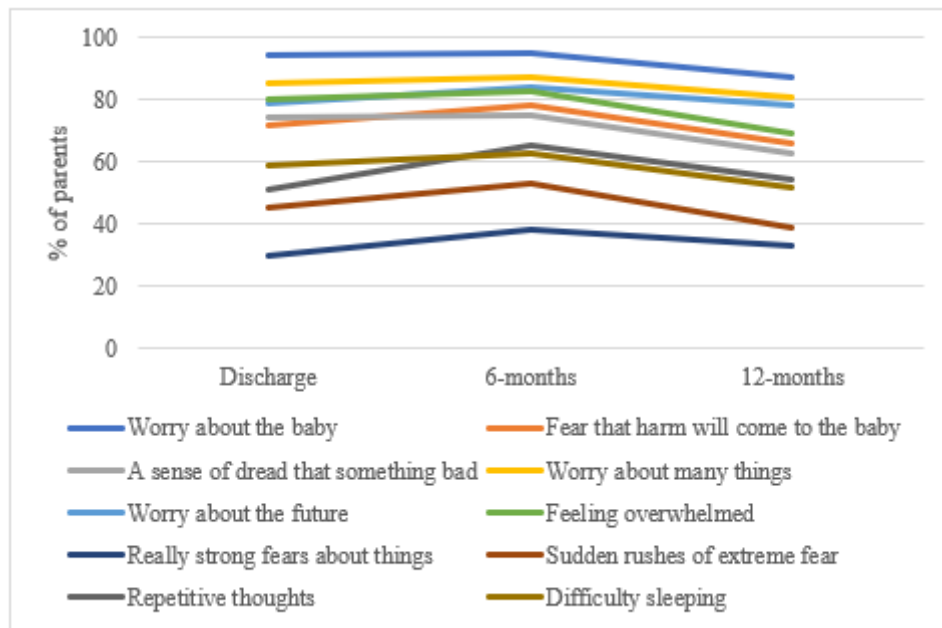
### 3.2 Psychological distress

The questionnaire presented participants with 33 different symptoms of psychological distress and asked them to indicate whether they had experienced each symptom at the time of discharge, 6-months post-discharge and 12-months post-discharge. A 'not applicable' response option was provided for participants whose infants were discharged less than 6 or 12 months prior. The percentage of participants who endorsed each symptom of psychological distress, excluding those who responded with 'not applicable' are presented in Figures 1-5.

Around the time of discharge, 1 in 2 parents on average reported any one symptom of psychological distress. This increased to 2 in 3 parents on average by 6-months post-discharge, however the average decreased to 1 in 2 parents by 12-months post-discharge. The percentage of parents endorsing each symptom of psychological distress was therefore highest at 6-months post-discharge and no overall improvement in parental symptomology was observed over the first year post-discharge.

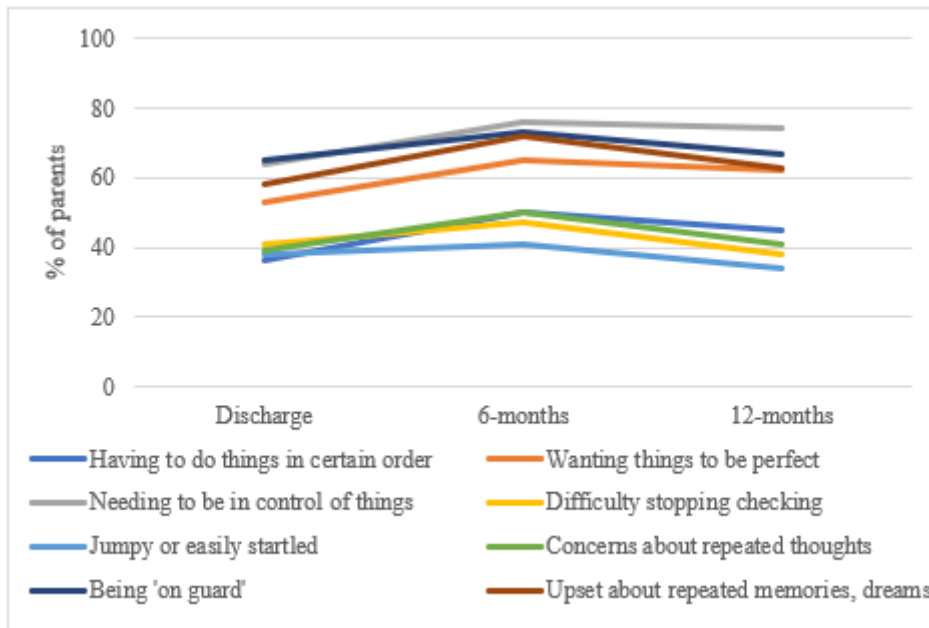
### Figure 1

Number of parents experiencing symptoms of the PASS; Excessive Worry and Specific Fears, across three time-points post-discharge. Almost all parents reported significant worry about their baby across the first year post-discharge.



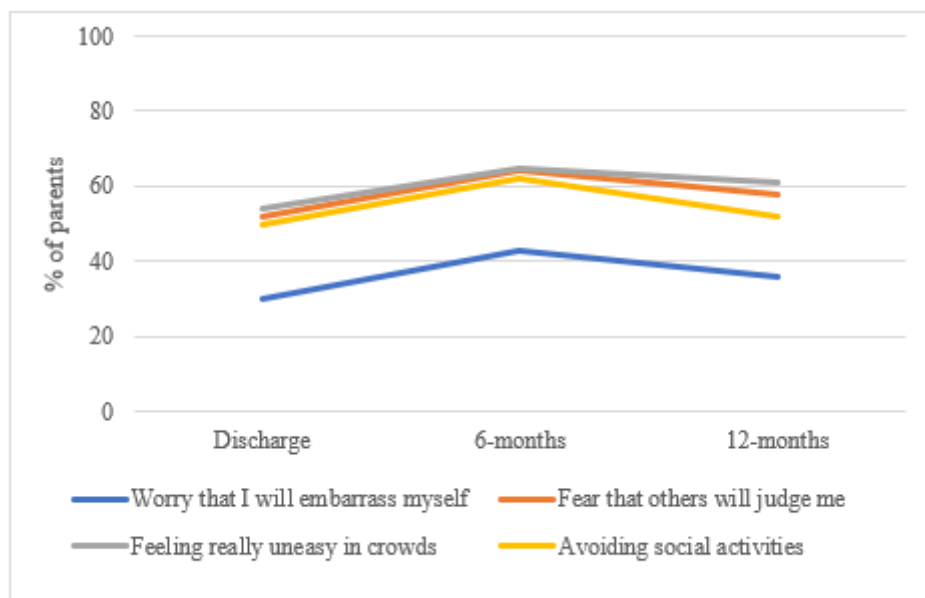
### Figure 2

Number of parents experiencing symptoms of the PASS; Perfectionism, Control and Trauma, across three time-points post-discharge. The majority of parents reported needing to be in control post-discharge which they may feel is needed due to the lack of control they experienced whilst their baby was receiving neonatal care.



**Figure 3**

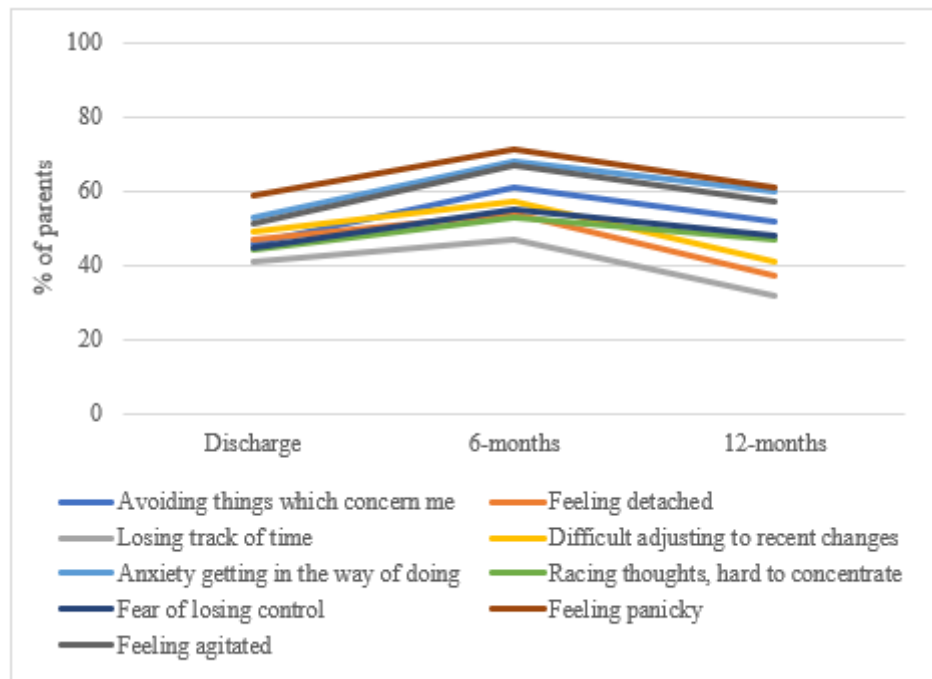
*Number of parents experiencing symptoms of the PASS; Social Anxiety, across three time-points post-discharge. Parents experienced significant social anxiety post-discharge which may be due to the difficulties in transitioning to becoming a parent of a child with additional needs.*



**Figure 4**

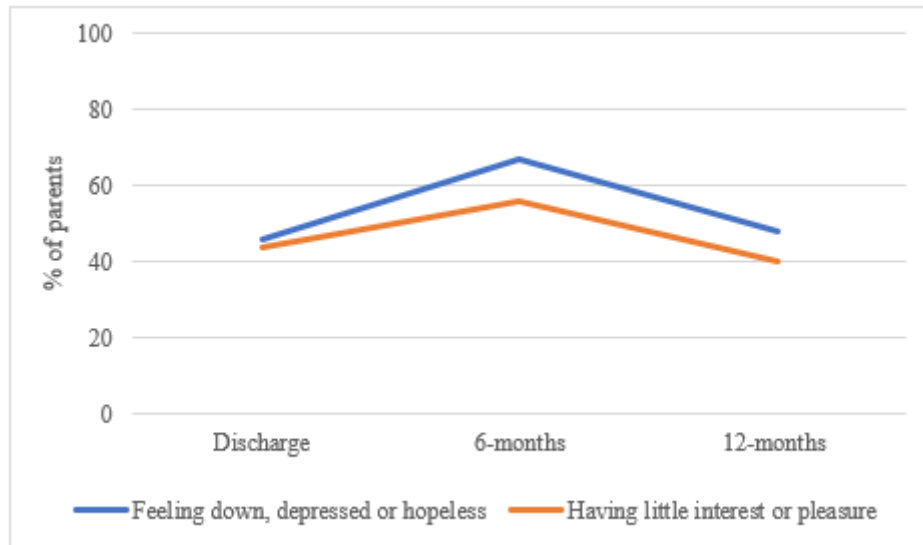
*Number of parents experiencing symptoms of the PASS; Acute Anxiety and Adjustment, across three time-points post-discharge. The majority of*

parents did not experience improvements in their anxiety in the first year post-discharge.



**Figure 5**

Number of parents experiencing symptoms of the PHQ-2; Depressed Mood and Anhedonia, across three time-points post-discharge. The symptom 'feeling down, depressed, or hopeless' increased the most in the first 6-months post-discharge which may be a result of parents' concerns for the future and the realisation that the infant's additional needs may have long-term implications.



The qualitative data described the complex emotional reactions parents experienced throughout their NICU journey. Many felt a constant fear that their infant may die, which one mother referred to as a *"life and death pendulum"*. Some parents described distressing intrusive thoughts. Others shared how they had developed compulsive behaviours they felt they must carry out in order to keep their baby safe.

*Mental images of my baby lying at the bottom of the stairs, as if I'd thrown him, but knowing I would never do it, but couldn't shake the image when it occurred. (Mother, infant born prematurely)*

Symptoms of trauma including nightmares or flashbacks were frequently reported. Participants described how sights or sounds relating to their NICU experience could trigger such symptoms, for example, seeing an ambulance or hearing a medical monitor.

Parents had developed avoidant behaviours; avoiding social interactions or crowded places in an attempt to protect their medically vulnerable infant from germs or illness. Participant responses referred to feelings of isolation or loneliness, which some parents recognised was not through lack of support but because others did not understand what they had been through.

A small number of parents disclosed having had suicidal thoughts. Some experienced panic attacks, whilst others described the feeling of being numb.

*I wasn't able to feel a full range of emotions any more. I just felt numb. I didn't really feel happy for months afterwards. (Mother, infant born prematurely)*

Participants experienced externalising symptoms including anger, rage or irritability. The qualitative responses also referred to internalising symptoms, including feelings of guilt and self-blame, as well as poor body image and a lack of self-confidence. Some parents reported feeling mistrust, suspicion or jealousy towards the medical staff caring for their baby. Jealousy towards other parents whose infants did not require treatment in a NICU, or grief at the loss of their anticipated birth and postnatal experience were also reported.

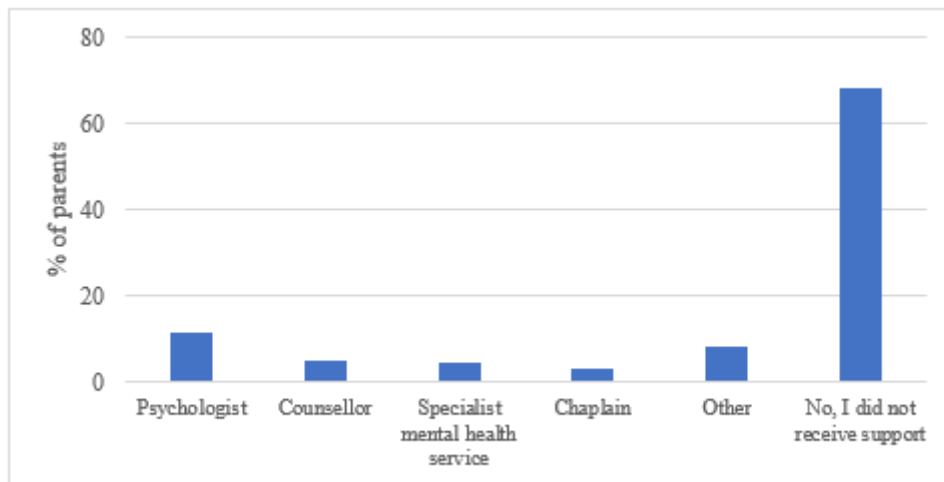
### **3.3 Lack of psychological support**

Thirty-two percent of parents reported having received emotional support during their infant's neonatal hospitalisation; Figure 6 illustrates the different services from which parents accessed this psychological support. The majority of those who did receive psychological support on the NICU were seen by a Psychologist (12%). Participants who selected 'other' shared how they had received support from neonatal charities or informal emotional support from healthcare professionals.

#### **Figure 6**

*Percentage of parents accessing emotional support from different services, whilst on the NICU. The majority of parents accessed no emotional support.*





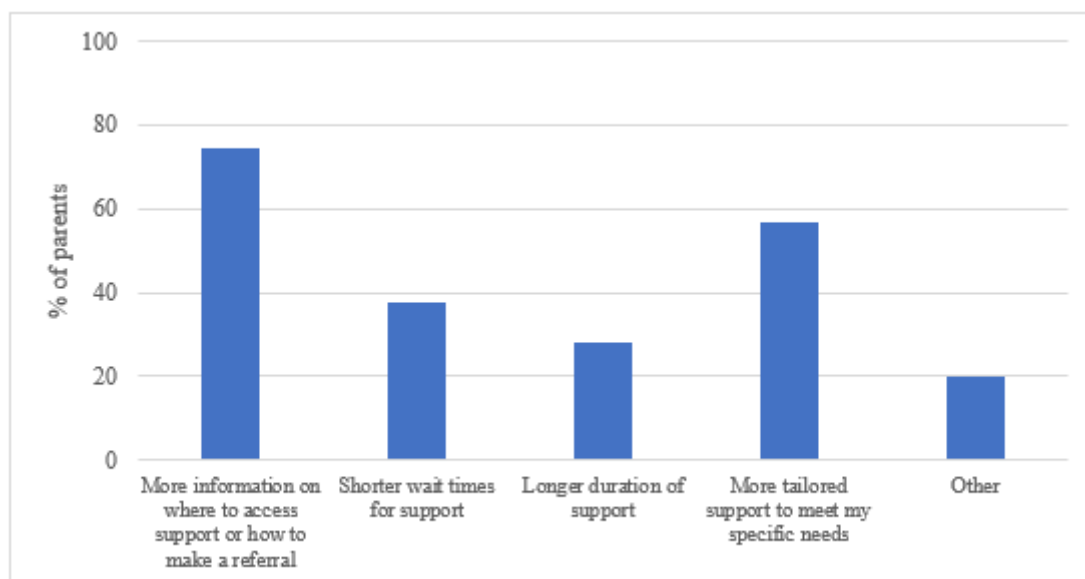
A higher percentage of parents received psychological support post-discharge (49%). Most commonly, emotional support was provided by a Health Visitor (28%). It was less common for parents to report receiving support from a psychological professional.

Parents appeared to delay seeking emotional support until 2-6 months after discharge (32%) or more than 6-months after discharged (31%). It was less common for participants to seek emotional support immediately after discharge (18%) or within the first month (20%). Twelve percent of participants shared that despite seeking support, they did not receive any.

Over half of the participants (61%) reported that they did not feel well supported emotionally throughout their neonatal journey. Figure 7 illustrates how services could ensure that participant's felt better support emotionally.

### **Figure 7**

*'How could services ensure you feel better supported emotionally?'*



Of those who did not feel well supported emotionally, most would have liked additional support during their infant's neonatal admission (80%), or immediately after discharge (72%). Fewer parents would have liked to receive more emotional support 6-months after discharge (62%) or 12-months after discharge (40%).

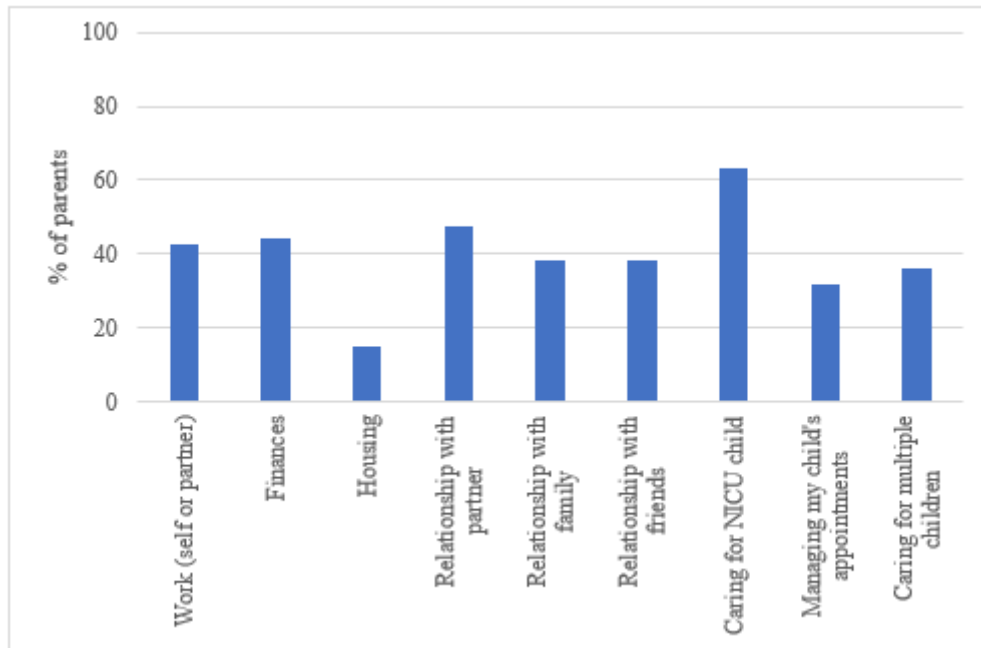
### 3.4 The wider impact of caring for a NICU baby

The questionnaire asked whether participants had experienced stress from several different factors, illustrated by Figure 8, during their neonatal journey.

Participants were able to share alternative sources of stress or elaborate on their responses in a subsequent open-ended question. Alternative sources of parental distress included the mother's own postnatal recovery, breastfeeding, parents' lack of self-care, travel expenses and access to the neonatal unit, having family members with ill-health and the exacerbated challenges as a result of the Coronavirus pandemic.

#### Figure 8

*'Throughout your neonatal journey, did you experience stress from any of the following...?'*



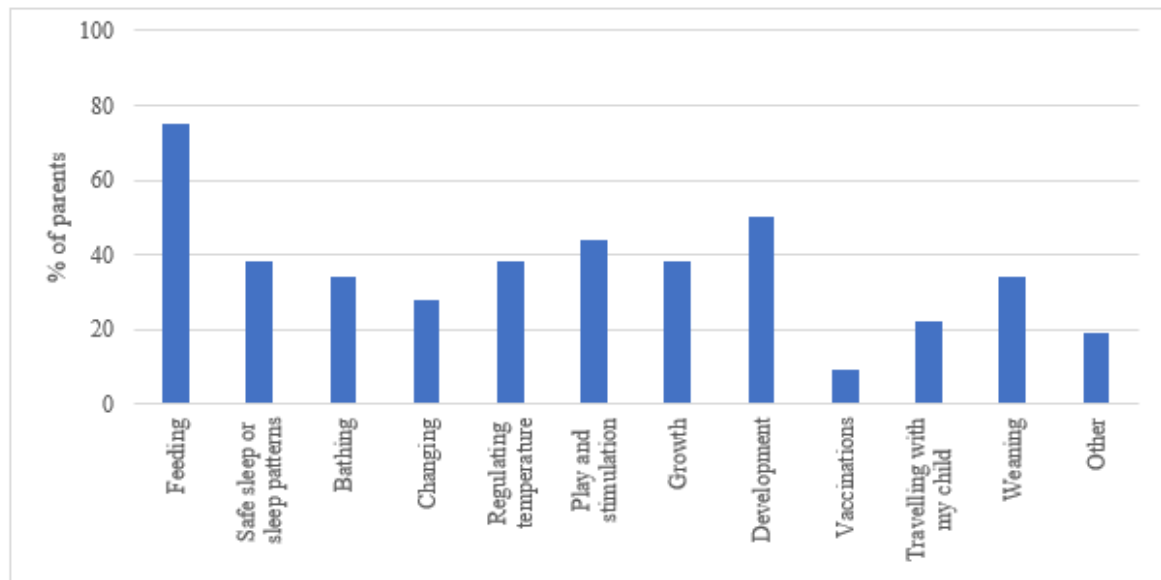
### 3.5 Non-specialised care

Non-specialised care referred to infant cares which were not medical (e.g. changing, breast or bottle feeding). A small percentage of parents (5%) were not given support during their infant's NICU admission to help them manage their non-specialised care. A larger percentage of parents (11%) felt that they were not well supported with their infant's non-specialised care (i.e. the support did not meet their needs). Figure 9 shows what aspects of their infant's non-specialised care they would have liked more support with or information about. Most frequently reported was feeding (75%).

During the infant's NICU admission (84%) or immediately after discharge (53%) were the most frequently reported times in which parents would have found additional support with their infant's non-specialised care helpful. Fewer parents reported needing more support with non-specialised care 6-months after discharge (34%) or 12-months after discharge (16%).

**Figure 9**

*'What part of your child's non-specialised care would you have liked additional support with or information about?'*



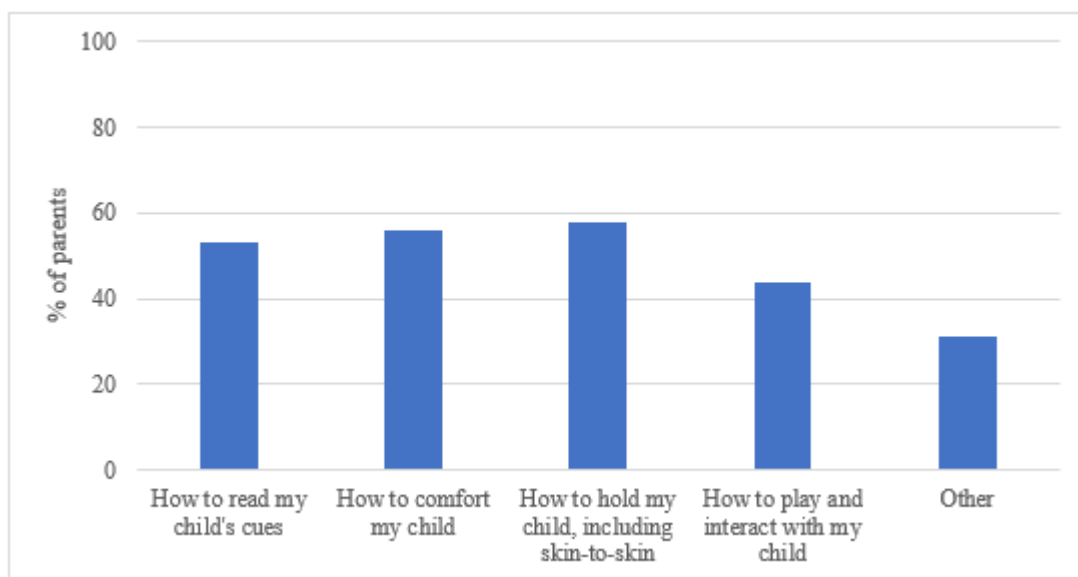
### **3.6 Bonding**

Fourteen percent of parents felt they were not supported when bonding with their infant. A larger percentage of parents (22%) felt they did not have the support they needed when bonding with their baby (i.e. the support did not meet their needs). Figure 10 shows how services could ensure that parents feel better supported when bonding with their baby. Better support around skin-to-skin was most frequently reported (58%).

The majority of participants who did not feel well supported with bonding would have found additional support helpful during their infant's NICU admission (95%). Fewer parents would have found additional support with bonding helpful immediately after discharge (45%), 6-months after discharge (28%) or 12-months after discharge (11%).

**Figure 10**

*'When bonding with your child, what would you have liked more support with?'*



### 3.7 Specialised care

Specialised care referred to the additional support that some infants required to manage their ongoing medical needs following their discharge from the neonatal unit. More than half (55%) of the sample reported that their infant had ongoing needs, which they perceived as either mild (50%), moderate (34%), or severe (16%).

**Figure 11**

***'Does your child have ongoing medical needs?'***

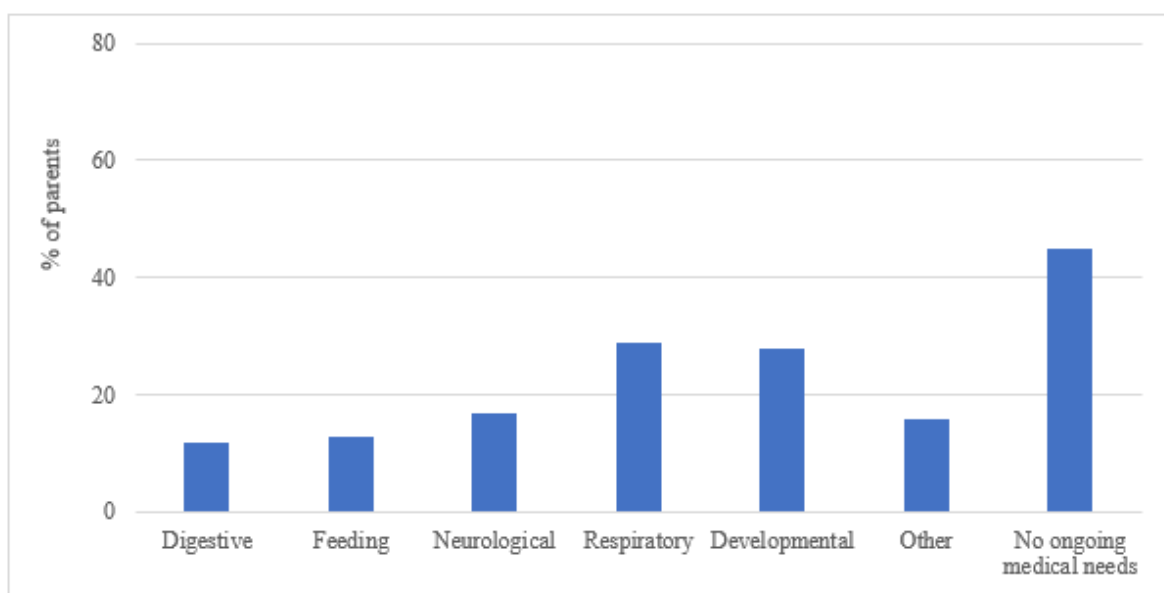


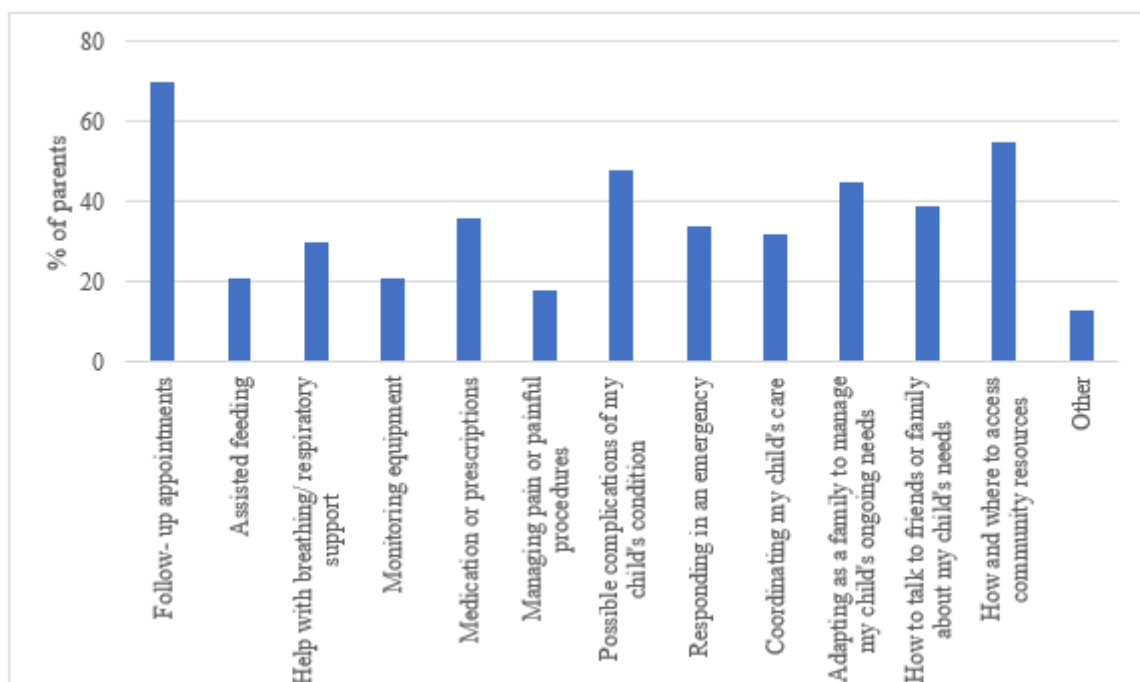
Figure 11 illustrates the different specialised care needs of infants in the sample. The 'other' option was endorsed by 16% of parents who described other areas of need for example auditory or visual, cardiac, renal, immune health and allergies.

Thirty-nine percent of parents shared that their infant had been readmitted to hospital once or twice (39%), or multiple times (25%), since they were discharged from the neonatal unit.

Twenty-nine percent of parents did not receive support with their infant's specialised care needs. Thirty-six percent of parents did not feel that they were well supported with their infant's specialised care needs (i.e. the support did not meet their needs). Figure 12 shows what aspects of their infant's specialised care needs parents would have liked more support with or information about. Most frequently reported was more support with follow-up appointments (70%).

**Figure 12**

***'When managing your child's ongoing needs, what would you have liked more support with, or information about?'***



In contrast to other areas of support, parents would have found additional support with their infant's specialised care needs most helpful immediately after discharge (57%) or 12-months after discharge (55%). It was less common for parents to want more support during their infant's NICU admission (34%) or 6-months after discharge (38%).

### **3.8 Qualitative analysis**

**3.8.1 An enduring impact.** Many parents described how their NICU experience had impacted their psychological wellbeing long-term. Others described feeling as though the experience had had an irreparable impact on their mental health.

*Worst experience of my life and after 4 years I still have ptsd.*  
(Father, infant born prematurely)

*I genuinely feel broken. I don't think I will ever be the same again.*  
(Mother, infant born prematurely)

Often parents did not recognise the emotional impact that their neonatal journey had had on them for months, or even years after their infant's discharge home. They noticed increased anxiety when their infant was no longer on a monitor or when home visits stopped and they no longer had the reassurance of medical staff. Several parents also shared how particular events post-discharge, for example the infant's first birthday, hospital readmissions or the return to work were especially challenging for their mental health.

*I found that I felt euphoric when my baby came home and it seemed that after a couple of months the emotional damage started to show. Nightmares and flashbacks etc.* (Mother, infants born prematurely)

For some the enduring anxiety impacted their parenting behaviour, as they recognised that they were more protective over their neonatal child.

For others, the heightened anxiety impacted their decision to have another child or their feelings towards future pregnancies.

**3.8.2 Psychologically informed staff.** This theme describes the need for both hospital and community healthcare providers to be more empathic. Several participants felt that the healthcare providers they encountered dismissed their distress entirely, and made them feel as though their emotions were not warranted. They wanted care providers to communicate in a less "*condescending or patronizing*" manner and to better recognise parental psychological distress and responses to trauma.

*The midwives understanding the potential impact of a traumatic birth and not shouting at me to stop crying all the time. (Mother, infant born prematurely)*

Parents wanted to be educated on the possible psychological symptoms that they may experience after taking their infant home, how to recognise trauma and how to seek help should it occur. They also wanted practitioners to recognise that parents are unlikely to go seeking support themselves during this time and therefore to proactively offer emotional support.

Many participants sought support but their practitioner failed to signpost them on.

*The GP and health visitor were completely useless and uninformed about what happened and how to help me. I reached out to both for support and got nothing. (Mother, infant born prematurely)*

Others were offered support, however the participants felt that the practitioner did not understand their specific needs or how to provide appropriate psychological support.

*There wasn't any support in NICU at all besides a nurse saying to me do you want me to get you antidepressants. (Mother, infant born prematurely)*



Further suggestions included charities having a greater presence on the neonatal unit, offering psychological support tailored to the needs of fathers and ensuring specialist trauma therapy, including birth trauma therapy that is more accessible both on the neonatal unit and after discharge.

**3.8.3 Fostering connection.** Parents described how distressing it was to be separated from their baby during their infant's neonatal admission, as a result of medical interventions or living long distances from the hospital. They described wanting to hold their baby on the neonatal unit but not feeling as though they were allowed to because the medical team did not encourage skin-to-skin, or they suggested that it may be harmful to the infant.

*My child couldn't be held as he was cooled and I felt useless I didn't know what I could do I felt like a stranger to my child. (Mother, infant born with HIE).*

Parents wanted staff to be more positive about the developmental benefits of skin-to-skin and to support early parent-infant bonding, as opposed to inducing feelings of guilt or fear.

*I mainly worried about having to give my daughter back she didn't feel like mine having to ask for a cuddle with her etc. (Mother, infant born prematurely)*

Participants also wanted staff to be more encouraging of peer-support and to help facilitate parents forming connections with other parents. The benefits of peer support resonated with many participants as they felt comfort knowing someone understood what they had been through.

**3.8.4 Bridging the gap.** A key theme across participant responses was the need for continuity between hospital and community care. Community teams were perceived as lacking the specialist knowledge needed to

provide tailored neonatal support. Parents suggested that the NICU outreach service offer a longer duration of support, or that support post-discharge be provided by more experienced practitioners who have been specially trained to support neonatal families.

*There is a big disconnect between the support provided by NICU vs the support available when discharged to a community paediatrician. We do not feel supported at all as my child has got older and their difficulties have become more severe. It would be helpful if NICU "looked after" children until the age of 5, rather than age 2. (Mother, Infant born prematurely)*

Parents suggested that the neonatal Psychologist should offer follow-up post-discharge as they perceived community staff as having little concern for their mental health and they wanted to be able to access specialist trauma support. Similarly, it was suggested that community healthcare teams offer the mother a health check post-discharge, because there was a lack of concern for the mother's physical recovery from birth.

**3.8.5 A lack of control.** A number of parents reported feeling as though important decisions regarding their infant's care plan had been made without them. Few parents expressed feeling angry and disagreeing with the consultant as they tried to advocate for changes to their infant's care. This was described as "*deeply traumatising*", reducing a sense of empowerment. They shared how they did not know what part of their infant's care they were able to be a part of, and how they had missed important milestones in their baby's care because neonatal staff had not involved them.

*I didn't know what I was allowed to do, things were often done for me without conversation and I didn't feel like a mother. (Mother, infant with suspected infection due to PPRM)*

## **4 Discussion**

It is well evidenced across the literature that neonatal parents experience high levels of psychological distress during their infant's hospitalisation. This study provides some evidence to suggest that high levels of parental psychological distress may persist post-discharge. No change in overall symptomology was observed between the point of discharge and 12-months post-discharge, a finding previously reported in longitudinal research (Kersting et al., 2004; Lotterman et al., 2019). The enduring psychological impact was also evident across the qualitative data; participants described experiencing a delayed trauma response, only recognising their distress in the months following NICU discharge, a finding previously observed among mothers of preterm infants (Shulman et al., 2021). Others described challenges post-discharge which led to a worsening in their mental health, or the persistent anxiety and concern they had for their infant's development, similarly found among parents of preterm infants (Baraldi et al., 2020; Shulman et al., 2021).

Sixty-one percent of the sample did not feel well supported emotionally and psychological support was the area of greatest unmet need. Consistent with the quantitative data, the qualitative data signified the importance of healthcare providers validating parents' emotional responses and expressing a greater awareness of parental distress, as communication from staff was sometimes perceived as lacking empathy or compassion, consistent with previous literature (Bruns & Klein, 2005). The need for staff to show emotional intelligence, and deliver care in a kind, sensitive and empathic way was highlighted in a review by Adama et al. (2022). Participants discussed the need for there to be a greater awareness of trauma, what symptoms they should be mindful of and where they should seek help should they occur. The effectiveness of interventions which educate parents on posttraumatic-stress disorder have been shown in a review by Laccetta et al. (2023). Neonatal discharge planning should therefore consider educating parents on the

impact of trauma and how to manage it. This study further highlighted the importance of healthcare providers encouraging parents to be mindful of their own mental health and proactively offering them psychological support, given that they may not seek support themselves due to the overwhelming nature of their experience and their focus on the parental role.

Almost one in four parents (22%) did not feel they had the support they needed to bond with their infant. Often parents described a lack of encouragement from nurses as they felt judged asking to hold their own baby or scared of harming them because they were not educated on the developmental benefits of skin-to-skin. Some parents described feeling as though their baby was not theirs because of communication from staff, therefore it is important that staff recognise the importance of their role in promoting positive parent-infant interactions, educating parents to understand their baby's cues and encouraging them to become confident primary caregivers (Guillaume et al., 2013; Medina et al., 2018; Tan et al., 2020).

It is not uncommon for infants who have been treated in neonatal intensive care to be discharged home with additional care needs, as was the case for 55% of parents in this sample; 36% of whom reported not having had the support they needed to manage their infant's ongoing needs. Many parents reported little continuity between the medical care provided in hospital and the medical care provided post-discharge. Health Visitors or General Practice Doctors were perceived as lacking the specialist knowledge needed to provide appropriate care for neonatal infants and they had little knowledge of the infants' history or individual needs. The importance of providing continuity in care was recognised in a review by Adama et al. (2022). The current findings also highlight the need for there to be continuity in maternity care. Mothers described the lack of concern for their own recovery from birth, following their discharge from the postnatal ward. Medical care was focussed towards the infant

and the mother's own physical health was often overlooked. It is important that mothers recover safely and are given appropriate follow-up care so that they can provide optimal care for their infant.

There is a paucity of mixed-methods research within the field (Adama et al., 2022; Malouf et al., 2022; Roque et al., 2017). The integration of both quantitative and qualitative data strengthened the research findings, by providing a more comprehensive understanding of parental psychological distress and support needs. This study provides novel insight into the service use and subjective experiences of support for parents who have had an infant admitted to neonatal intensive care in the UK.

Limitations of this study include the sample's lack of diversity. The findings are not representative of families from minoritised ethnic groups, despite their overrepresentation in neonatal care (Schaaf et al., 2012). Similarly, there was a disproportionate representation of fathers within the sample, a challenge found in previous literature (Lorié et al., 2021; Turner et al., 2013). It is important that future research considers the needs of a more diverse community of neonatal parents. The retrospective nature of the data and the use of convenience sample may further limit the findings because of the inherent risk of recall and self-selection bias.

#### **4.1 Conclusions**

Several important considerations for current care practices are suggested. Both hospital and community care providers should be trained to recognise symptoms of parental psychological distress, and to communicate with empathy, creating a sense of safety for families. Neonatal parents should be informed of the likelihood of a trauma response post-discharge, enabling them to recognise symptoms and seek intervention earlier. Better pathways for accessing specialist psychological

support are also needed. Neonatal staff should emphasize the developmental benefits of parent-infant interaction and encourage regular skin-to-skin contact. Furthermore, post-discharge follow-up care should ensure that infants with ongoing care needs receive appropriate developmentally supportive care.

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