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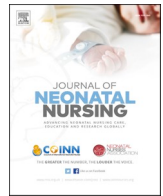
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Psychosocial needs of parents of infants admitted to neonatal care: A qualitative study

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ABSTRACT

This study aimed to explore the psychosocial needs of parents whose infants required neonatal care and to identify strategies to optimise parental psychosocial wellbeing. An exploratory qualitative study, comprising semi-structured interviews was undertaken with nineteen parents (mothers = 16, fathers = 3). The data were analysed thematically, and three themes and associated subthemes highlight interlinking issues in terms of parents' needs for stability during a time of uncertainty; their needs for connection with staff, other parents, and their infant; and a need for flexibility in the type, and timing of support. Social connectedness theory offers a lens for how psychosocial support can be provided during neonatal care. This requires opportunities for parents to socialise and receive information, instrumental and/or emotional forms of social support via staff and peers, and to create a sense of belonging and value as parents.

1. Introduction

Parents who have a premature (born <37 weeks gestation) or sick infant that requires admission to a neonatal unit often have higher levels of poor mental health such as elevated rates of depression, stress and anxiety when compared to parents of term infants (Flacking et al., 2012; Ionio et al., 2016) Poor parental mental health can disrupt the normative transition to parenthood (Watson, 2011) and has negative implications for parent-infant relationships and infant developmental outcomes (Grunberg et al., 2019). To date, most neonatal research focuses on improving parent-infant dyadic interactions, which can lead to parental psychological concerns being neglected (Nicolaou and Glazebrook, 2008; Thomson and Feeley, 2021). There are systematic reviews of qualitative studies to identify the needs of parents of premature infants (Govindaswamy et al., 2019; Merritt, 2021), however, these tend to report on generic (i.e. the need for a better NICU environment) rather than psychosocial needs. To date, one Swedish study focuses on the psychosocial needs of parents of extremely premature infants (Bry and Wigert, 2019). This study highlights issues such as the need for empathic treatment by staff and the need for different forms of emotional support. As Sweden generally has different care approaches to other settings (Flacking and Dykes, 2013) these insights may not be transferable. Our study aimed to explore parents' psychosocial needs in a UK context. We

also aimed to identify strategies to help improve parental, infant and family outcomes, particularly when no universal care pathways exist (Hall et al., 2015).

2. Methods

Design: An exploratory qualitative study was undertaken. This approach is suitable when exploring a topic with limited coverage and developing new knowledge (Hunter et al., 2019).

Participant recruitment: Parents aged 18+ years whose infant(s) required neonatal care within the last 2 years were recruited via online advertisements and forums.

Data collection: Interviews were conducted via Microsoft Teams or telephone. Consent was audio-recorded and stored separately from the interview recording. Interview questions explored parents' psychosocial needs, what support was offered, and what support they would have found helpful. Sixteen interviews took between 33-and 74 min to complete; one was stopped after 20 min due to participant distress. All interviews were transcribed verbatim for analysis purposes. Each participant was sent a £10 E-voucher in appreciation of their time.

Data analysis: Interview transcripts were uploaded to NVIVO qualitative software program. Braun and Clarke (2006) thematic approach was used comprising an iterative approach of reading and re-reading,

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identifying codes, synthesising codes into subthemes, and then over-arching themes. The initial coding framework was developed by MI and refined through ongoing discussions with GT and RN.

Ethics: Ethics approval was obtained from the HEALTH ethics sub-committee from the lead author's University (0116). Following the interview, participants were sent details of suitable organisations where help could be accessed.

Author reflexivity: All authors are female and have a medicine (n = 1) or psychology (n = 2) background. Two are parents, and none have clinical or personal experience in neonatal care. Two authors have no/limited research experience in this area. All authors were involved in data analysis which involved exploring for disconfirming cases and to capture all variations in the data set.

3. Results

Nineteen parents (mothers = 16, fathers = 3) took part in 17 interviews (with two interviews including both parents). As the interviews took place (January–May 2021) during the COVID-19 pandemic, 10 parents mentioned pandemic-related restrictions that impacted their experience. Collectively, the participants' infants received care from 10 different neonatal units; some parents reported experiences from more than one unit due to infant transfer. Participant and infant demographics are presented in Table 1.

Below we present three themes and associated subthemes that highlight interlinking issues. These themes describe parents' needs for stability during a time of uncertainty; their needs for connection with staff, other parents, and their infant; and a need for flexibility in the type, and timing of support.

Need for stability: Two sub-themes describe parents' psychosocial needs in preparing for neonatal care ('opportunities for preparation') and in 'managing uncertainties' of their infant's health.

Opportunities for preparation: Parents often reflected on how ill-prepared they were for a neonatal admission. Some parents, particularly those with a high-risk pregnancy, wished they had known about this possibility during antenatal care, e.g., had a '*visit to the NICU [neonatal intensive care unit]as part of antenatal parent education*' (Mother_#1). Some mothers complained about being discharged or '*being booted out*' (Mother_#4) from the postnatal ward, with little warning. Other complaints concerned delays in finding out about practical-related support on the unit (e.g., parking passes, lockers, hire of breast pumps). Frequent requests were made for an 'induction' to help parents '*find your feet in this new environment*' (Mother_#9).

Table 1
Participant and infant demographics.

Demographics	M (SD)
Participant age	33.4 (SD = 4.2)
Ethnicity	**N (%)**
White British	11 (57.9%)
British Indian	3 (15.8%)
Chinese	2 (10.5%)
Black British African	1 (5.3%)
Hispanic	1 (5.3%)
British Arab	1 (5.3%)
Education Level	
GCSEs	1 (5.3%)
A-levels	2 (10.5%)
Undergraduate degree	9 (47.4%)
Postgraduate qualification	7 (36.8%)
Marital Status	
Married	15 (78.9%)
Engaged	1 (5.3%)
Cohabitation	3 (15.8%)
Infant characteristics (n = 18)[a]	**Range and mean**
Gestational age at birth.	Range 25w-35w6days (mean = 30w6days)
Infant age at time of interview	Range 1–24 months (mean = 11.72 months)

[a] One participant gave birth to twins, one of which died at 11 days.

Managing uncertainties: The variability in infant's progress, the '*peaks and troughs*' (Mother_#8) often created a sense of helplessness. On occasion, parents felt staff incited disappointment when they were not fully honest about their infant's progress: '*Everyone kept saying, "Oh, we're going to try and get him downstairs to you today. […]" But every time I saw him, he was still in an incubator*'. (Mother_#14). Parents spoke of how they had or would have valued explanations about their infant's clinical needs to prevent '*false hope*' (Mother_#1) while balancing the level of detail, whereby '*too much information*' (Mother_#14) could instil greater levels of fear.

Need for connection: Three sub-themes describe parents' psycho-social needs for connection with staff ('value of familiarity'), other parents ('shared realities'), or their infant ('feeling like a parent').

Value of familiarity: Parents reported a need for '*continuity of care*' (Mother_#9) from a familiar caregiver. This was felt to be important to mitigate concerns of their infant's receiving differing standards of care, e.g., from '*students and the bank staff that you'd never met before […]*' (Mother_#3), and that their infant was better supported and cared for, '*as you trust that your baby is safe*' (Mother_#1). Parents often expressed reticence in help-seeking due to fears of being perceived as '*not managing*' (Mother_#13) and staff being '*there for the baby*' (Mother_#15). Whereas trust-based parent-staff relationships were believed to encourage disclosures, in part due to the staff member's understanding of their situation: '*having the same person that knows what we went through and how that would still affect us now*' (Mother_#6). A positive parent-staff relationship also increased the likelihood of parents' needs being proactively recognised and supported, '*I really appreciated that they'd picked up on how bad I was*' (Mother_#1).

Shared realities: Parents frequently described the neonatal unit as '*isolating*' and '*incredibly lonely*' (Mother_#13), exacerbated by their family/friends often lacking understanding of what they had endured. A few participants who had connected with other parents, e.g., in the '*family room*' (Mother_#12) or unit-based (online or face-to-face) support groups, felt these parents offered a unique source of '*community*' and '*family*' (Mother_#4) due to their shared realities; hearing others '*success stories*' (Mother+#6) (e.g., about infant progress) could provide hope.

Overall, most parents interviewed described an unfulfilled need for parent-parent connections. While requests were made for unit-based social media groups, many preferred options for face-to-face contact. Most of these parents also wanted staff to facilitate these connections, such as through staff-led parent groups, due to self-generated introductions being considered '*awkward*' (Mother_#14). A further suggestion was for staff to initiate a buddy system with parents at different stages of their journey to prevent the '*same sharing of pain*' (Mother_#8).

Feeling like a parent: Parents described feeling helpless and '*disempowered*' (Mother_#9) when unable to provide infant care. They expressed the need for skill-development and '*enough*' medical knowledge (such as through '*baby boot camps*' (Mother_#6)) to keep their infant safe, particularly at the time of discharge. Some participants also referred to the benefits of staff providing proactive updates to facilitate parent-infant connections during periods of parental absence from the unit, such as via updates (text, photos, videos) on a dedicated website (e. g. VCreate www.vcreate.tv): '*I would wake up to a little update of what's happened […] I had the connection to my baby even when I wasn't at the hospital*' (Mother_#17).

Parents also described different methods used by staff to facilitate positive parent-infant relationships, such as bonding squares; a diary of the infant's journey; a flower made from the ECG leads; poems; and other means to recognise and validate parent involvement:

> They gave me a lovely keyring which you can attach a bead to for every seven days that you were pumping (Mother_#15).

Need for flexibility: This theme comprises two sub-themes that describe parents' 'varying therapeutic needs', and 'flexibility in timing' when support should be provided.

Varying therapeutic needs: While not all parents felt they needed emotion-based support, most complained about how this support was lacking; '*in terms of emotional support for me, they did nothing*' (Mother_#3). Overall, there were mixed views on the types of therapeutic-based support that parents needed. Some wanted to talk to someone outside of their neonatal journey who could help distract them, e.g., '*to talk to, not necessarily about the baby and the situation*' (Mother_#6). Parents were divided on whether this should be a healthcare professional (e.g., nurse, therapist), a '*stranger*' (Mother_#7), or anyone '*medical or not*' (Mother_#4); what was important was for parents to express their perspectives, and for them '*just to listen*' (Mother_#8).

While parents equally expressed the need for formal therapeutic support, on these occasions, and in contrast to who should provide the listening-type support, parents spoke of wanting support from therapists who were '*specialised in the neonatal unit*' (Father_#6), and who understood their situation. One of the few parents who had accessed formal therapy expressed her disappointment in receiving support from a therapist with no understanding of neonatal care, '*being dismissive of the actual circumstances and what I was trying to say*' (Mother_#4). Many parents also referred to the need for '*signposting*' to raise awareness of the different types of therapeutic support available both within the unit and the community. A further suggestion was for an automatic referral system at discharge to assess parental needs; '*sort of like has your baby recently been discharged? Do you need an appointment?*' (Mother_#8), and to signpost accordingly.

Flexibility in timing: Flexible access to support was perceived to be important due to fluctuations in parents' psychosocial needs, such as '[you] *just have bad days and you just suddenly need someone*' (Mother_#5). Parents described the need for support during periods of heightened uncertainty such as at the beginning when '*you don't know if he's going to make it*' (Mother_#7), in the face of setbacks '*when we went back to high dependency, […] I needed to talk to someone*' (Mother_#8), and during transitional periods, e.g. when the mother was discharged from the post-natal ward or following infant discharge. With one mother providing an insightful metaphor of '*an army behind you at one moment*' to '*you're on your tod* [own] *very quickly*' (Mother_#2). One mother who had not needed support to date still recognised that this might not always be the case: '*But maybe I buried it all and in five years it'll all come out*' (Mother_#13).

4. Discussion

Here we report the findings from a qualitative study focused on psychosocial needs amongst parents of infants who required neonatal care. Three themes and associated subthemes detail key areas of psychosocial needs, together with strategies and methods to optimise parental psychosocial wellbeing. While some of the findings are similar to the Swedish study by Bry and Wigert (2019) different issues regarding antenatal preparation, the types of emotional support and flexibility in provision were identified. An overview of the strategies to optimise psychosocial wellbeing reported by parents and mapped to the three themes are summarised in Table 2.

Overall, our findings suggest that the *social connectedness* theory may be a useful framework to improve parental psychosocial wellbeing. Social connectedness is a subjective experience of belonging and relatedness that involves interactions, information, and appraisals and comprises three key components - *socialising*, *social support*, and a *sense of belonging* (Ministry of Social Development, 2018) *Socialising* concerns humans' inherent need to connect with others. In our study, this concerned parents' needs to build trust-based relationships with staff, with implications for enhanced parental confidence, to encourage disclosures of poor parental mental health, and to facilitate needs-led care, as reported by others (Bry and Wigert, 2019; Thomson et al., 2013). These findings also support the wider UK-based *Better Birth* continuity agenda (NHS England 2015, 2019) for parents to be allocated to named nursing

Table 2
Strategies to improve parental psychosocial wellbeing.

Creating Stability

- Antenatal classes/education should be provided for parents with high-risk pregnancies to help prepare for a (potential) neonatal admission, including a visit to the neonatal unit where possible.
- Early conversations should be provided to help prepare women/parents for discharge from the postnatal ward and for infant separation.
- All parents should receive an in-depth induction (i.e., verbal, written and/or digital) to the neonatal unit that includes insights into neonatal unit processes, and available resources and support (e.g., car parking, lockers, equipment hire, Facebook groups, etc).
- Staff should provide frequent updates on the infant's progress (during ward rounds, regular discussions with staff), with information tempered to offer 'honest' insights while not instilling fear.

Creating connections

- Parents should be assigned named caregivers to provide continuity and to help build trust-based relationships.
- Staff should help facilitate parent-to-parent connections, e.g., via staff-led parent groups and/or a buddying system.
- Ongoing opportunities (such as via targeted education sessions) should be provided for parents to develop knowledge, skills, and capacities to provide direct care for their infants.
- Secure web-based messaging services (e.g., VCreate) should be used to offer updates (text, videos, photos) during periods of parental absence.
- Creative means should be used to facilitate parent-infant connections and to validate parental involvement (e.g., bonding squares, diaries, photos of infants).

Creating flexibility in types and timing of support

- Parents should be provided with different opportunities for support dependent on need, such as listening visits to offload, and more formal therapeutic support to ameliorate adverse emotional responses.
- Therapeutic support should be provided by professionals with a background or understanding of neonatal care.
- Parents should have flexible access to psychosocial support so it is available when needed (such as during times of uncertainty, setbacks, or key transitional periods).
- Parents should receive information (verbally, written, digitally) on different types of support available to them (both during the neonatal stay and after discharge). This could also involve an automatic referral at the point of discharge to assess parental needs and to signpost as appropriate.

staff to facilitate parent-staff connections. A further issue concerning socialisation is parents wanting to socialise with other parents to help normalise and validate their experiences (Rossman et al., 2011), particularly when engaging with their existing personal networks could be problematic (Flacking et al., 2007) A unique finding in our study was that parents often wanted this contact to be stimulated by staff, such as through staff-led parent groups.

Social support relates to the type of support provided or perceived to be available (namely, informational, instrumental, or emotional). In our study, informational needs concerned antenatal information to help parents prepare for the neonatal experience (Janvier et al., 2012) and ongoing, and balanced information about their infant's health where the focus is on providing realistic insights while preventing harm (Thomson and Balaam, 2021). Instrumental support concerns skill development to enhance and develop parental capabilities; with practical support being a cornerstone feature of Family Centred Care (FCC) interventions which are designed to situate parents and families at the centre of infant care and decision-making (Gooding et al., 2011). Regarding emotional support, our study highlighted strategies that staff used to promote parent-infant attachment, e.g., bonding squares, and diaries, though evidence of the impacts of these methods is needed. While our study concurs with others about a lack of therapeutic support for parents (Bliss, 2018), we also found that parents' needs were not uniform. Parents expressed different times at which support would be preferred (Hynan and Hall, 2015), and at key transitional points, particularly infant discharge (Purdy et al., 2015). Our findings also emphasised the need for clear and comprehensive signposting within neonatal care and the community. A further area of emotional support, currently unreported, concerns parents varying needs for therapeutic-based support. While formal therapeutic support was required from those who

understood the reality of their situation (Bry and Wigert, 2019), opportunities to vent and offload with others (professional or otherwise) unconnected to neonatal care were also reported. This latter request aligns with a listening visits type intervention that focuses on empathic listening and collaborative problem-solving. To date, only one resource-intensive feasibility trial of listening visits by nurses has been undertaken in neonatal care with positive outcomes on maternal wellbeing (Segre, Chuffo-Siewert, Brock and O'Hara, 2013). Further research that modifies who and how much 'listening' support is provided could be beneficial.

Finally, a *sense of belonging* is to feel loved, cared for, valued, and connected. While the importance of enabling the parenting role is discussed by others (e.g., Craig et al., 2015), our study suggests this is achieved when suitable socialisation and social support systems are in place. Opportunities to maximise parent-staff and parent-parent contacts and support could help parents to feel confident and valued as a parent, and to feel emotionally connected to their infants and within the social milieu of neonatal care. Creating systems of care that enable and promote socialisation and the provision of suitable social support needs to be a priority (Hynan and Hall, 2015).

Regarding study strengths, we specifically asked parents about psychosocial needs and strategies, rather than inferring their needs from parents' general experiences. However, this did rely on parents being able to articulate hypothetical, rather than evidence-based solutions. Our study included parents from different sociodemographic backgrounds who had infants at different gestational ages, and who were exposed to different levels of neonatal care. While similar insights emerged across the data set, as only three fathers were included, further dedicated research is needed. As the study was conducted during COVID-19 with some neonatal units imposing restricted visitation policies, the findings may not be wholly representative of general care. Furthermore, as we did not screen parents for any mental illness, it may be that parents' needs may have differed depending on their mental health issues. Further research to confirm or refute these insights is needed.

5. Conclusion

This qualitative study focused on eliciting psychosocial needs and strategies to optimise psychosocial wellbeing for parents whose infants required neonatal care. Three themes highlight interlinking issues in terms of parents' needs for stability, to enable and facilitate connections to be formed with staff, other parents, and their infant, and for varied and flexible support options to be available. While a small-scale study, it identified similar needs and views amongst a heterogeneous group of parents and highlighted areas that require further evidence, such as the impact of different forms of emotional support on parents' psychosocial health. Social connectedness theory offers an important lens for psychosocial provision in neonatal care. This requires parents to be enabled to socialise and receive different forms of social support via staff and peers, to enable parents to feel confident in caretaking, valued as a parent, and to feel emotionally connected to their infants.

Declaration of competing interest

None of the authors have any conflicts of interest.

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