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Stressors and support system among parents of neonates hospitalised with systemic infections: qualitative study in South India

Shruti Murthy ,¹ Vasudeva Guddattu,¹ Leslie Lewis,² Narayanapillai Sreekumaran Nair,³ Hinke Haisma,⁴ Ajay Bailey^{5,6}

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¹Department of Data Science, Prasanna School of Public Health, Manipal Academy of Higher Education, Manipal, India

²Department of Paediatrics, Kasturba Medical College, Manipal, Karnataka, India

³Department of Medical Biometrics and Informatics (Biostatistics), Jawaharlal Institute of Postgraduate Medical Education and Research, Puducherry, Tamil Nadu, India

⁴Population Research Centre, Faculty of Spatial Sciences, University of Groningen, Groningen, The Netherlands

⁵Department of Human Geography and Spatial Planning, Faculty of Geosciences, Utrecht University, Utrecht, The Netherlands

⁶Transdisciplinary Centre for Qualitative Methods, Prasanna School of Public Health, Manipal Academy of Higher Education, Manipal, Karnataka, India

Correspondence to

Prof.dr.ir. Hinke Haisma, Population Research Centre, Faculty of Spatial Sciences, University of Groningen, Landleven 1, NL-9747AD, Groningen, The Netherlands; h.h.haisma@rug.nl
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ABSTRACT

Objective To explore stressors and support system for families with a neonate admitted with a systemic infection.

Design Qualitative study using in-depth interviews (IDIs), based on principles of grounded theory.

Setting A busy level III neonatal unit of a tertiary care teaching hospital in coastal Karnataka, India, between May 2018 and January 2019.

Participants Parents and accompanying attendants of neonates admitted to the neonatal unit with one or more systemic infections.

Methods Using purposive sampling, semi-structured IDIs were audio recorded, transcribed verbatim and a thematic analysis was performed.

Results Thirty-eight participants were interviewed, lasting between 30 and 59 min. Babies' hospitalisation with sepsis was an unprecedented, sudden and overwhelming event. Stressors related to uncertainties due to the information gap inherent to the nature of illness, cultural rituals, financial constraints, barriers to bonding and others. Parents reported experiencing insomnia, gastric disturbances and fatigue. Support (emotional and/or financial) was sought from families and friends, peers, staff and religion. Availability and preference of emotional support system differed for mothers and fathers. In our context, families, peers and religion were of particular importance for reinforcing the available support system. Participant responses were shaped by clinical, cultural, financial, religious and health service contexts.

Conclusion Designing a family-centred care in our context needs consideration of stressors that extend beyond the immediate neonatal intensive care unit environment and interactions. Understanding the influence of the nature of illness, financial, familial and cultural contexts helps identify the families who are particularly vulnerable to stress.

INTRODUCTION

Neonatal intensive care unit (NICU) hospitalisation is traumatic for neonates and their entire family. Families of hospitalised preterm/low-birthweight neonates experience stress, insecurity and alienation.^{1,2} However, sepsis in the baby—a time-critical, devastating bloodstream infection with an unpredictable clinical course—poses different challenges for a family compared with babies who are not seriously ill.^{3–6} It can range from a localised infection to life-threatening manifestations.^{3,4} Complications (eg, septic shock and cardiopulmonary arrest) can progress suddenly and rapidly leading to multiorgan dysfunction and death, despite corrective measures.³ This situation can be frightening

for parents, with stressors affecting different fronts of their lives.^{4–6} Families of infected/seriously ill babies are subject to health inequalities, face acute stressors, worry constantly about devastating consequences and continually have feelings of inadequacy.^{5,7,8} Moreover, neonates of stressed parents are at the greatest risk of cognitive and behavioural problems compared with healthy neonates.^{9–11}

Research on NICU experiences, particularly from high-income countries (HICs), has driven a paradigm shift in neonatal care design, giving rise to concepts such as 'family integrated care', 'family-centred care' (FCC) and 'neonatal intensive parenting unit'.^{12–15} These studies have informed innovative policy guidelines for incorporating mental health professionals, peer support and communication changes in neonatal care.^{16–18} However, research in India exploring families' psychosocial needs during NICU hospitalisation is largely quantitative^{19–22}; qualitative research is scarce,²³ with none focusing on sepsis. Numerically 'scoring' parents' experiences does little to capture in-depth experiences of familial needs and contexts. Understanding families' cultural contexts (eg, religious and daily life practices) and support systems is essential for understanding parental needs and effectively using their capabilities in designing and supporting FCC.^{24–26}

Despite policy recommendations on introducing FCC in Indian public healthcare, progress has been slow.^{22,27} Neonatal care continues to be technology-driven and provider-centred, with limited parent involvement.²² Considering that India bears the highest global burden of neonatal sepsis,²⁸ this exploratory study was conducted in coastal South India to understand the (1) stressors and (2) sources of support for parents and accompanying attendants having a baby admitted for the treatment of sepsis in a private tertiary care level III NICU.

METHODS

The study protocol (online supplemental file 1) supplements this section with additional details. A qualitative study using in-depth interviews (IDIs), guided by the principles of grounded theory,^{29,30} was conducted between May 2018 and January 2019 in a level III NICU of a tertiary care teaching hospital in a coastal South Indian district. We included parents and grandparents (1) having babies (0–28 days) admitted to the study site for treatment of a systemic infection and (2) providing written informed consent. A purposive sampling was used to recruit participants immediately or within the first few days after diagnosis to capture

Table 1 Coding scheme for a category under the theme 'stressors'

| Category | Subcategory | Code | M | F | GP | |
|---|-------------------------------------|---|-----------------------------|---|----|---|
| Uncertainties due to information gap Participants did not know or understand aspects related to sepsis or its hospitalisation, which led to uncertainties. | Unfamiliar disease | What has happened to baby | x | x | x | |
| | | Reason for infection unknown | x | x | x | |
| | | Why my baby | x | | x | |
| | | Why sudden admission | x | x | x | |
| | | Chances of survival unknown | x | x | x | |
| | | Discharge date unknown | x | x | x | |
| | | Why breast milk not given | | x | | |
| | | If treatment is working | | x | | |
| | | False assurance | x | x | x | |
| | | Scary terminologies | x | x | | |
| | | Will baby be disabled | x | x | x | |
| | | Why so many doctors around the baby | x | | x | |
| | | Sudden deterioration in baby's condition | Sudden vomiting | x | x | x |
| | | | Vomiting milk since morning | x | x | |
| | Weight loss | | x | x | x | |
| | Stopped drinking milk today | | x | x | x | |
| | Sudden stomach swelling | | x | x | x | |
| | Stomach swelling worse today | | x | | | |
| | Suddenly requires breathing support | | x | x | x | |
| | Requires ventilator today | | x | x | | |
| | Not active today | | x | x | x | |
| | Suddenly drowsy | | | x | x | |
| | Cost-related | Suddenly seems limp | | x | x | |
| | | Sudden shaking of hands | x | x | | |
| | | Cost estimate unknown | | x | x | |
| | | No transparency in cost increase | | x | x | |
| | | Reason for stalled financial scheme unknown | | x | x | |
| 'Who to ask for money?' | | | x | x | | |
| Unsure on financial scheme—availability | | x | x | x | | |
| Unsure on financial scheme—use | | x | x | x | | |
| Financial constraints 'Relates to participant's struggles in arranging money to pay for medical and non-medical costs related to baby's hospitalisation' | Inaccessible financial support | Baby not named | | x | x | |
| | | Insurance applies to either mother or baby | x | x | x | |
| | | Inadequate information | | x | x | |
| | Lack of adequate resources | Contrasting information | | x | x | |
| | | Stalled schemes | | x | x | |
| | | Limited or no savings | | x | x | |
| Barriers to bonding Pertains to barriers that hindered participant–baby bonding | | No income | | x | | |
| | | Inaccessible visiting hours | | x | x | |
| | | Postpartum movement restrictions | x | x | x | |
| | | Mother unwell | x | x | x | |
| Unfamiliar NICU environment Pertains to first-time experience with sights and sounds in NICU and the hospitalised baby | | Mother in a different hospital | | x | x | |
| | | Tubes and pricks—baby | x | | x | |
| | | Oxygen mask | x | | x | |
| | | Beeping sounds | x | | x | |
| | | Machine/incubator | x | x | x | |
| | | Inadequate breast milk | x | | x | |
| | | Sick baby | x | x | x | |
| | | Baby in ventilator/machine | x | x | x | |
| | | Pumping breast milk | x | x | x | |
| Baby's distress | x | x | x | | | |

Continued

Table 1 Continued

| Category | Subcategory | Code | M | F | GP | |
|---|-------------|---------------------|----------|---|----|---|
| Spouse/parent health Pertains to participants' stress regarding their spouse's health (father/mother) or parent's health (grandparent) | Physical | Insomnia | | x | x | |
| | | Disturbed sleep | x | x | x | |
| | | Insufficient sleep | x | x | x | |
| | | Gastritis | | x | | |
| | | Chest pain | | x | | |
| | | Back pain | x | | x | |
| | | Leg pain | x | | | |
| | | Weakness | x | | | |
| | | Dizziness | x | | | |
| | | Fatigue | x | x | | |
| | | Not eating | | | | x |
| | | Emotional | Stressed | x | x | x |
| | | | Crying | x | x | x |
| Not talking | | | | x | | |
| Mute spectator in distress Pertains to participants' inability to | | Reduce baby's pain | x | | x | |
| | | Empathise with pain | x | x | x | |

F, father; GP, grandparent; M, mother; NICU, neonatal intensive care unit.

and understand their experiences as soon as they knew of their baby's condition. Exclusions included (1) parent/spouse unavailable at the study site during the data collection period and (2) parents with babies who were in the midst of treatment.

Participants were asked to describe their NICU experiences in terms of stressors and support system. A pilot study conducted on five participants refined the semistructured IDI guide (online supplemental file 2) to fit our research inquiry. Audio-recorded interviews were conducted in a participant-preferred language, location and time.

A thematic analysis was performed (Atlas.ti). Interviews were transcribed and anonymised, and field notes were typed following each interview. Coding and subsequent categorisation were done in two cycles,²⁹ and data were organised to list the participant-reported stressors and support systems. We inductively derived our categories conceptually^{29 30} under the two themes of 'stressors' (table 1) and 'support system' (table 2) to address our two research objectives. Exploration of concepts in subsequent interviews guided data saturation and identification of disconfirming sources.³⁰⁻³²

Stressors were coded by identifying factors that the participant described as making them feel strained, tensed or something which they did not prefer to encounter (table 3). Support was described in terms of what/who supported them emotionally and financially/reduced their stressful emotions (table 3). Physical health associated with the themes was also coded. We ensured trustworthiness by instituting measures for credibility, confirmability, dependability, transferability and positionality (table 4).^{33 34}

RESULTS

Thirty eight of 47 participants took part in the study (19 mothers, 15 fathers, 4 grandparents; online supplemental file 3 and table 5). Three parents were interviewed as a couple. Three grandparents accompanied the mother and one grandfather accompanied a father. IDIs lasted between 30 and 59 min. Nine repeat interviews were conducted. The interview was handwritten for one father and mother as they denied permission for audio-recording. The experiences have been described under the two themes of 'stressors' and 'support system' to address our research objectives. Mothers and grandmothers frequently cried and could not vocalise their despair. Mothers hesitated

to express themselves in front of their husbands. Participants reported their baby's hospitalisation to be an emotionally and financially shocking and unprecedented event (box 1, quotes 1 and 2) for them and their families.

Theme: sources of stress during baby's hospitalisation due to sepsis

Stressors were described by participants as sources that caused anxiety, tension, strain and anguish (table 3) when dealing with their baby's hospitalisation. Participants typically reported more than one emotion for each stressor. Stressors related to uncertainties (due to nature of illness and finance), cultural practices, financial constraints, barriers to bonding and others. Grandmothers typically mentioned that 'no one should have to face a situation like this' and they questioned why 'God was showing them such a day'.

1. **Uncertainty due to information gaps:** parents were disturbed and anxious when faced with uncertainties regarding their baby's well-being or NICU-related costs.
 - Baby's survival and well-being.
 - Sudden bouts of deterioration in baby's condition (box 1, quotes 3 and 4): participants were frightened when they did not understand suddenly why the baby deteriorated when the baby seemed to be recovering (eg, abdominal distention, vomiting, weight loss and drowsiness; table 1). This led to feelings of shock, confusion, misunderstanding, guilt and sadness among all participants.
 - Baby's condition, treatment and outcome (box 2): mothers repeatedly blamed themselves for their baby's condition (quote 1). Additionally, they expressed an unmet need of understanding why it happened to their baby, if other babies faced such illnesses (quote 2), what it meant for their baby to have an infection and why no guarantee was given for the baby's survival or discharge date (quotes 3 and 4), why they were separated from their babies and why certain treatment decisions were made by the staff (quote 5). The anxiety and fear resulted in some fathers perceiving a loss of trust in the staff (quote 6). However, participants typically hesitated to ask for more information from the staff (quote 7).

Table 2 Coding scheme for a category under the theme 'support system'

| Category | Subcategory | Code | M | F | GP | |
|--------------------|-------------------------------------|---|-----------|---|----|--|
| Family and friends | Emotional | 'Don't worry, baby will be fine' | x | x | | |
| | | Expressing feelings | x | | x | |
| | | Crying | x | | x | |
| | Financial | Savings from father, in-laws and paternal uncle | | | x | |
| | | Lease on assets from father | | | x | |
| | | Income and savings from brother | | | x | |
| | | Interest-free loan from friends | | x | | |
| Peers | Sepsis-related experiences | Familial background information | x | | | |
| | | Breastfeeding problems | x | | | |
| | | Baby's condition | x | | | |
| | | Feelings of guilt and shame | x | | | |
| | General hospitalisation experiences | Postpartum recovery | x | x | x | |
| | | Fatigue | x | | | |
| | | Husband's/parent's background | x | | x | |
| | | Selective information sharing | | x | | |
| | | Financial support | | x | x | |
| | | Own background | x | x | x | |
| | | Hospital facilities | x | x | x | |
| Staff | Doing their job | Trusting staff | x | x | x | |
| | | Observing staff do their duty | | x | | |
| | | Caring despite being busy | | x | | |
| | | Running around without rest | | x | | |
| | Trouble shooting | Breastfeeding challenges | x | | | |
| | | Kangaroo mother care | x | | x | |
| | | Pumping breast milk | x | | x | |
| | Knowledge and competency | Understand baby's condition | x | | | |
| | | Understanding machine | x | | | |
| | | Understanding sights and sounds | x | | | |
| | | Learning to operate machine | x | | | |
| | | Postpartum health and nutrition | x | x | | |
| | | | Baby care | x | | |
| Religion | | Undertaking 'Harke' (vows) | | x | x | |
| | | Placing faith in God | x | x | x | |
| | | Donating to religious cause | | x | x | |
| | | Praying to God | x | x | x | |

F, father; GP, grandparent; M, mother.

- Financial uncertainty (box 3, quotes 1–3): many outborn admissions were referred 'urgently' to the study site because (1) baby did not improve clinically despite treatment or (2) infrastructural problems (also confirmed from NICU staff and medical records). Participants reported receiving no information, from referral facilities regarding the type of setting they would encounter financially. Fathers and grandparents, particularly of outborn babies, felt unprepared and helpless when their need for 'timely, transparent and accurate cost-related information' was unmet. Unemployed mothers were unaware of the treatment costs and mentioned their husbands handling financial decisions.

2. **Financial constraints** (box 3, quotes 4–6): families who lacked health insurance and faced inaccessible financial support had to bear all costs. With limited money at hand, fathers and grandparents struggled to source money 'by hook or crook'. A manual labourer recalled preventing his recently delivered sick wife from seeking medical help as the insurance covered only the baby's costs. Fathers faced conflicting choices of having to remain on site at the NICU, go offsite to earn money or avail financial assistance.
3. **Cultural rituals** (box 3, quote 7): some mothers mentioned feeling stressed about cultural practices which they believed were responsible for their baby's infection that ultimately required hospitalisation. Participants also voiced their worry if hospitalisation meant a delay in observing cultural rituals/ceremonies for their baby.
4. **Barriers to bonding** (box 4, quotes 1–4): some mothers and babies were hospitalised in separate hospitals postdelivery (eg, outborn early-onset sepsis). Such mothers experienced 'uncontrollable rage' as they felt insecure and desolate, being unable to look after their babies immediately after birth. Fathers were frustrated at inflexible workplace and NICU visiting policies, which prevented them from visiting the baby for days. Grandmothers reported mothers getting hysterical when they could not see their baby for a week. In contrast, a couple recalled how their antenatal provider referred them to our study site before delivery (as opposed to just the baby after delivery), in order to prevent separation of mother and baby (quote 4).
5. **Others**: this included having inadequate breast milk, being a spectator during baby's distress, struggling to manage additional roles without support, individual or spouse's disturbances in health (table 1).

Theme: emotional and financial support during baby's hospitalisation due to sepsis

Support was in the form of reassurance regarding the baby's well-being and/or finances (box 5). Participants reported various mechanisms of support that helped them become calm, happy, confident and hopeful during their baby's hospitalisation (table 3). Mothers typically sought emotional support; fathers sought financial support; and grandparents sought both.

Families and friends (quotes 1–3)

Mothers and grandmothers typically sought emotional support, while fathers (breadwinner) sought financial support. Mothers typically confided in their husbands but hesitated when they perceived husbands to be stressed. When husbands were inaccessible because of work, they spoke and frequently cried to their mothers, peers or nurses. Fathers did not actively seek emotional support claiming 'men had strong minds', but felt a sense of calm when their friends or family mentioned that 'all will be well'. Online supplemental file 4 lists the strategies that fathers reported for arranging money.

Table 3 Emotions and feelings attributed to a stressor and support

| Stressor | Support system |
|--|---|
| Aatanka (terror), bhaya (fear), hedarike (scared or frightened), sankata (problem), vikopa, kopa (rage or anger), dukkha (sadness), manasige navvu (hurting/painful to the mind), bejaru (feeling bad), sakkath chinte (worry), torture, anxiety, tension, stress, distress, helplessness, disappointment, hopelessness, frustration, hurtful, painful | Khushi (happiness or joy), cheerful, confidence, hopeful, chennagi ansodu (feeling good), feeling positive, don't feel bad anymore, not worried, shanti (relieved, calm or at peace). |

Table 4 List of measures taken to ensure rigour in our study

| Criteria | Measures taken in our study |
|--------------------------------|--|
| Credibility and confirmability | <ul style="list-style-type: none"> ▶ Triangulation of data from multiple sources of data collection. ▶ Audio-recording of interviews to retain information. ▶ Participant verification of handwritten interviews. ▶ Continuous and active immersion in data. ▶ Multidisciplinary team (experts in subject and methods) for <ul style="list-style-type: none"> – Interpretation of data (SM, AB, HH and LL). – External review of findings. ▶ Minimising subjective interpretations by adequate researcher (SM) training and experience in qualitative research methods and analysis. ▶ Checking coding cycles by a second qualitative expert (HH). |
| Dependability | <ul style="list-style-type: none"> ▶ Detailed report of research plan, implementation and challenges. ▶ Thick description of results written before preparation of manuscript. ▶ Provision of explicit reporting of analysis plan, participants quotations and emotions. |
| Transferability | <ul style="list-style-type: none"> ▶ Detailed protocol (online supplemental file 1) to report study design and context. ▶ Study limitations reported for further understanding of study settings. |
| Positionality | <p>About the interviewer (SM)</p> <ul style="list-style-type: none"> ▶ Is an unmarried female PhD student. ▶ Was in the third year at the time of interviewing. ▶ Is external to NICU and not a member of clinical NICU team. ▶ Is qualified in Bachelor of Dental Surgery and Master of Public Health. ▶ Has research experience since 2011. ▶ Has adequate training and experience in qualitative research methods and analysis. |

NICU, neonatal intensive care unit.

Table 5 Participant characteristics (N=38)

| Characteristic | Category | Mother n=19 | Father n=15 | Grandparent n=4 | Total N=38 |
|--|----------------------------------|----------------|----------------|--------------------|---------------|
| Age range (in completed years) | 21–30 | 14 | 7 | – | 21 |
| | 31–40 | 5 | 8 | – | 13 |
| | 41–50 | – | – | 2 | 2 |
| | 51–60 | – | – | 1 | 1 |
| | 61–70 | – | – | 1 | 1 |
| Occupation type | Homemaker/unemployed | 17 | 1 | 1 | 19 |
| | Business | – | 5 | 1 | 6 |
| | Fixed-term employees | 1 | 5 | – | 6 |
| | Daily wage labour | 1 | 2 | 1 | 4 |
| | Agriculture/fishery | – | 1 | 1 | 2 |
| Type of family | Permanent employees | – | 1 | – | 1 |
| | Joint | 11 | 4 | – | 16 |
| Residence in the same town of study site | Nuclear | 15 | 7 | – | 22 |
| | | 4 | 3 | – | 7 |
| Admission | Outborn | – | – | – | 20 |
| Type of pregnancy | Lower segment caesarean section | 18 | 8 | – | 26 |
| | First pregnancy | 14 | 5 | – | 19 |
| | Abortions—1 | 2 | 1 | – | 3 |
| | Abortions—2 | 2 | 2 | – | 4 |
| | Abortions—3 | – | 1 | – | 1 |
| | Neonatal death | – | 1 | – | 1 |
| | Live child at home | – | – | – | 5 |
| Type of systemic infection | Neonatal meningitis | 4 | 1 | – | 5 |
| | Neonatal sepsis | 19 | 8 | – | 27 |
| | Neonatal pneumonia | 2 | 3 | – | 5 |
| | Septic arthritis | 1 | – | – | 1 |
| | More than one systemic infection | 1 | 1 | – | 2 |
| Sex of neonate | Male | 15 | 10 | 4 | 29 |
| Previous experience with sepsis (families and friends) | Requiring admission | – | – | – | 0 |
| | Not requiring admission | – | – | – | 0 |
| Previous intensive care experience | | – | – | – | 0 |

Box 1 Unprecedented situation and sudden deterioration in baby's condition

Unprecedented situation

Quote 1: So after the birth of the baby, we will be expecting a healthy baby. We will not be knowing something that is related to all this [infection]... [we] would not be knowing if it would not have happened to us or our parents. We have a belief that [baby care] will happen easily and it will be economical. But when such a thing happens, it becomes a headache, a big problem and heavy burden for people like us, because [we will] not be having any information. (Father, 37 years, neonatal sepsis)

Quote 2: We had not heard of anything like this. And never have we seen a small baby having such a condition to be kept in the machine. It was not like this in our times. We have played with many babies and all babies were healthy. We have not seen all of this at all. All our children grew well, we did not have a sight of all this. God should not give anyone this this trouble. (Grandmother, 44 years, neonatal meningitis)

Sudden deterioration in baby's condition

Quote 3: At one time they say, "[The baby] is getting better, let's see". At another time, they say, "There is danger". Why? What happened suddenly? I am is so frightened. (Mother, 33 years, neonatal meningitis)

Quote 4: They [doctors] are saying now that the intestines are not working...and it's started vomiting now. Something has happened. They are not telling us, something has suddenly happened. (Grandfather, 57 years, sepsis with necrotising enterocolitis)

Peers (quotes 4 and 5)

All participants exchanged views with peers on their baby's condition and unfamiliar NICU environment. Mothers typically connected on their 'sepsis' experiences with similar mothers in the NICU (eg, during breast feeding or kangaroo mother care)/dormitory or veteran parents in wards. While fathers sat next to other fathers in the lobby, they exchanged general views about hospitalisation.

Staff (quote 6)

Some mothers recalled how nurses, when reached out to, would help in troubleshooting daily problems, and gaining knowledge and competencies. Other mothers reported feeling shy to ask questions to nurses. For some participants, simply observing care coordination, and staff tirelessly 'do their best despite being busy' for the baby gave them hope and reassurance.

Religion (quotes 7 and 8)

Fathers and grandparents also reported feeling relieved to 'place their faith and burden on God' helping them to 'accept their fate when they cannot do anything' in this situation. Participants, despite financial constraints, reported offering daily prayers and religious donations (despite financial constraints), and undertaking rituals and sacred vows as directed by priests. Hindu parents reported feeling at ease when priests agreed and encouraged them to delay all rituals until the baby is discharged from the hospital.

DISCUSSION

We found that dealing with their baby's sepsis was an unprecedented and shocking emotional and financial experience for families. Our findings corroborate the international qualitative evidence on NICU hospitalisation (including preterm and low

Box 2 Baby's condition, treatment and outcome

Quote 1: All I feel is tension. I have lost all my happiness. My baby...not sure what may happen. There is panic regarding what may happen to my baby. What is this condition I do not understand...What a horrible mother I must be to have given it to my baby in the womb. No one should go through this. Why is God showing us such a day? [weeping]. (Mother, 28 years, neonatal sepsis)

Quote 2:

GF: Madam, do you know if such babies are admitted here? Does this happen to other babies or is our baby the only one here like this? I want to understand if there are other babies like ours in this hospital...

F: Yes, we are very worried, we want to know if this has happened to other babies before.

(Father (F), 28 years, and grandfather (GF), 57 years, neonatal sepsis with necrotising enterocolitis)

Quote 3: I am waiting when I can go back. But I am not getting any information on when my baby will get better. They have been trying for quite a while. They say that there is problem in the... what do you call that? (points to the throat). They don't seem to know. They did some procedures, they even got a surgeon here to assess. But they are not sure what it is. They are trying different things. I want to be certain about my baby...(Father, 43 years, neonatal sepsis with congenital malformations)

Quote 4: Even when I met the doctor the second time, the day before yesterday, I requested, "Sir, will you confirm again that there will be no problem for the baby later? Can you confirm and tell me if there are any other related organs that will be affected afterwards? Please confirm that there will be no problem". But the doctor told that it cannot be reassured right now and that we may know as the baby keeps growing. But he said that, "95% she is OK, absolutely OK"...But that once concern will persist in the mind that if there is some problem tomorrow...It is very painful. (Father, 37 years, neonatal sepsis)

Quote 5: When our baby was on ventilator, and regardless of the critical issues, (doctors) should at least initiate mother's milk. Mother's milk, everyone knows, is next to amrut [immortality potion]. It is God's gift. There is no replacement for mother's milk, even if you give a NASA scientist-prepared milk. (Father, 34 years, neonatal sepsis)

Quote 6: The doctor or sisters did not inform anything. They just took the baby. How should we understand what is happening inside for so long, and why? I am not telling that I doubt the treatment given or anything. They must be treating properly. But they should tell us something. There is no communication at all. What was wrong with the baby? What are they giving the baby? We just sat there outside waiting anxiously. Some lepsis, what is that? (Father, 33 years, neonatal sepsis)

Quote 7: We say 'Vaidyo Narayano Hari' (in Sanskrit), meaning 'Doctor is God'. We have to have faith in them and show our trust. So, we should not question them. Questioning them would be like doubting them, which is incorrect (Father, 37 years, neonatal sepsis)

birth weight), such as communication gaps, separation from the baby, unexpected changes in parental role, inability to breast-feed, baby's distress and financial distress.^{7 8 35-39} We add to this by highlighting experiences shaped by the nature of illness, financial, cultural, religious and health service factors relevant to neonatal sepsis.

Box 3 Finances and culture

Financial uncertainty

Quote 1: No one told us that it would cost so much in this hospital. The previous hospital told us, "If you want the baby to live, go there immediately." Here every night, I lose my sleep with the tension of by how much will the cost increase if they do additional tests tomorrow. Why don't people take into consideration that people cannot pay? Had I known this; I would not have agreed to come here. (Grandmother, 47 years, neonatal sepsis, outborn admission)

Quote 2: ...It would have [been] very good if transparency was present...they should tell us in advance how much it may cost. If we get an idea about [how much] we have to pay...otherwise where to arrange all of this in time?...On asking, they said, "No, we give you the bill at the last. You pay an advance [money] now". We wanted to know why we are asked to pay so much and that too within a day? (Father, 28 years, neonatal sepsis with necrotising enterocolitis, outborn admission)

Quote 3: I am not getting correct information. Where is this insurance office and who has to sign? I went outside and looked around everywhere. One person tells me this [Child Insurance X] is applicable only for surgery, not for treatment. But my friend last year claimed it fully for his baby, just for treatment. Not for surgery. I do not know what to do now, this is very confusing. (Father, 30 years, neonatal sepsis, outborn admission)

Financial constraints

Quote 4: I could neither attend my father-in-law's funeral nor travel to avail financial aid, despite being eligible. My wife is unwell. [Nurses] told me I have to be available for my baby. (Father, 33 years, neonatal sepsis, outborn admission)

Quote 5: The other financial assistance is not ready to sanction assistance because the baby's name is not there on the card. How can we insert the baby's name when we have not named it? Both doctor and the guruji have advised us to postpone naming ceremony until baby gets OK. We cannot name it till then. (Grandmother, 42 years, neonatal meningitis, outborn admission)

Quote 6: We are paying whatever they ask, whenever they have asked. Health insurance card is there. But it seems it is not applicable for the babies. One more scheme has stopped. He [son in law] does not earn much at all. We sold all our property, we borrowed, we have sold our gold, we have given away our cooking vessels also. From where do we get more now? (Grandmother, 48 years, outborn admission)

Cultural rituals

Quote 7: So many relatives and elders came to see my baby...I did not let [them] touch him or put ghee on his tongue. But I couldn't stop them from crowding and burning incense around [baby]. Someone surely gave it [infection] to my baby (tears swelling). (Mother, 27 years, nurse, neonatal sepsis, outborn admission)

Our findings reflect those of studies in low-income and middle-income countries (LMICs), where families played a 'non-participant visitor' role,⁴⁰ seldom actively seeking information despite their unmet need, except for seeking a guarantee of recovery. Similar to a study on caregivers in Indian intensive care,⁴¹ these were influenced by an immense faith in doctors, a fear of disturbing staff or being judged for seeking information. Further research should explore if limited parent-staff interactions could additionally be influenced by staff-parent 'power balance' in busy LMIC settings.^{40 42} This makes it challenging for

Box 4 Barriers to bonding

Quote 1: When they brought [me] here, all mothers were with their babies [tears in eyes]. I was the only one staying without my baby here...so painful... [wipes tears] Many mothers without breast milk were keeping their babies [with them]. I had breast milk, but I was unable to keep and feed [my] baby...I felt an uncontrollable rage from within. Many times, I imagined going to the doctor's room, screaming at [the doctor], secretly taking my baby and running away. [starts crying] (Mother, 21 years, non-local resident)

Quote 2: She has been hysterical...not sleeping, not eating, just crying when she sees others with their babies...She said today "It has been continuously 1 week from that morning [when they took the baby], and I still have not got the baby in my hands. Just give me the baby in my hands, and I will go away where I want to go". It is such a such a dilemma...We may have to forego the baby or the mother...It is just too painful...She knows baby may not survive if we take it from here. She says that she will take responsibility for whatever happens to the baby. It will not be possible [for us] to stay further. (Grandmother, 48 years, non-local resident)

Quote 3: I could not come here immediately when this happened. I cannot just leave everything and come suddenly. I have to make lot of adjustments at work...I have to work till evening and then I come with home food for my wife. I stay the night and leave in the morning for work. It has been 3 days I have not seen the baby, because visiting hours are closed by the time I can come. Maybe Sunday I can see (Father, 28 years, local resident)

Quote 4:

F: We went to [charity hospital] in the evening as she [wife] was very tired. Doctor said "All water has gone. But the baby's (foetal) heartbeat is present. It will be difficult to save [the baby] if [the baby] is remains here [at this facility]." The doctor [wife interrupts]

M: There is no facility there, at that place. There is no NICU like this...That is the reason they sent us here saying that (study site) has all the facilities.

F: The doctor checked and said, "Probably water must have leaked. Everything is safe. I will do the C-section in 20 minutes. But it will not be possible to save the baby immediately because it has been a long time since the baby has got infection. To save it" [wife interrupts]

M: [Doctor said] "It will be a 2 hour travel. You will be here and the baby will be there. That will not be correct." So we came here itself. We came here around 8 o'clock night...delivered around midnight.

(Father (M), 33 years, and Mother (M), 27 years, non-local residents)

Non-local residents were those who stayed in a different town (far away) from that of the study site

families to be eligible to share decision-making with doctors in an unfamiliar and stressful environment.

Nature of illness

The 'sudden' worsening of the apparently healthy baby—a hallmark of sepsis⁶—was a universally present stressor in our study. This was pronounced for babies experiencing severe infections and associated complications, which meant more uncertainty, prolonged stay and increasing costs (eg, due to meningitis, septic shock and comorbidities). Similar to two Scandinavian studies among guardians of critically ill babies, our participants

Box 5 Support

Quote 1: When I would cry, many doctors and sisters have consoled me saying that nothing would happen [to the baby]. I have seen my husband cry when he is alone. I do not want to stress him more by getting emotional in front of him. (Mother, 21 years, local resident, neonatal meningitis).

Quote 2: I have very good friends, Madam. They keep enquiring about the baby and the situation here. They say- Don't worry, everything will be ok. Despite their financial problems, they give it to me. I told them I will repay it back once...uh...once I get out of here. So I am not much worried now. (Father, 34 years, non-local resident, neonatal sepsis)

Quote 3: Our minds are not weak like women. We do not need to share what we feel, we do not need to cry. Our duty is to give courage to others, and we have to be strong. If I just sit alone for sometime, I will be OK. (Father, 30 years, local resident, neonatal sepsis)

Peers

Quote 4: M: We [mothers] talk. I then understood that many of them have the same problem. In fact, some of the other mothers have more serious problems...Some or the other problem...There are two babies, two months, three months. They have all been admitted.

GM: By seeing them, our pain would reduce. All will be talking only about that. All would be having that same pain. It feels like we are all one. (Mother (M), 21 years and grandmother (GM), 47 years, non-local resident, neonatal sepsis)

Quote 5: They share everything with me... I only share with them what is necessary to be shared... because their mental uh...I mean, capacity is different and our way of thinking is different. There should not be friction. But I welcome if they want to share because [I] will listen if they want to share their pain. Then I will also share [with them]. So I avoid them getting affected because of what I share [with them]. (Father, 34 years, non-local resident, neonatal sepsis)

Staff

Quote 6: The sister taught me about the sounds on my baby's machine [incubator]. I learned to switch it off when it beeps. I feel good and understand it indicates the baby's temperature. (Mother, 27 years, neonatal sepsis)

Religion

Quote 7: [God] is one who saves everybody. One should have that confidence...In times of tension, just pray, meditate. That is our Dharma [duty], Sanatan Dharma [absolute or eternal duty]. Keep doing all your duties, and leave it to God. My Guru tells this to me that God takes care of everyone. We have to keep doing our duty towards living. He [God] is gracing us. We have to surrender to God. (Father, 34 years, neonatal sepsis)

Quote 8: In our side, what we do is something called as "harke" (vow). I did that, saying to God that I would go back and fulfil my vow if the baby becomes well. My mother-in-law had given around 1000 to donate to some place...and additional 200 to give for a puja (prayer). All this has to be done so we don't leave any stone unturned. (Father, 34 years, neonatal sepsis)

Non-local residents were those who stayed in a different town (far away) from that of the study site

'oscillated between hope and hopelessness',³⁶ and experienced constant fear and stress,⁷ making this group 'extra vulnerable'. This very sudden, unpredictable and life-threatening nature of sepsis is seen as an emotional burden on staff too.⁶ Additionally, similar to our findings, a Swedish study found that this nature of such complex conditions can strain nurse-parent trust.⁴³ As

recommended by a UK-based study,⁴⁴ 'tailored' and 'multifaceted' safety netting information should be explored in the Indian context for acute illnesses like child sepsis (eg, use of technology, involving prenatal care for early-onset sepsis, peer support in the absence of family support).

Financial inclusion

Our study findings reflect those from existing literature on the role of financial constraints.³⁸ Families struggled to arrange money at short notice for unpredictable, rising daily expenses. This shock was pronounced for families of cases who were referred without adequate information, were socioeconomically disadvantaged and lacked the resources to avail support. In India, where two-thirds of the population are socioeconomically disadvantaged,⁴⁵ and private level III NICUs offer the costliest neonatal care,⁴⁶ a lack of NICU insurance plans worsens families' predicament.⁴⁷ Additionally, an American study found that a lack of health insurance for neonatal sepsis can increase mortality and health resource use.⁴⁸ Financing schemes should account for cultural context and financial distress caused by poor referral practices and public healthcare infrastructure.⁴⁶

Health service barriers

Addressing parent–neonate separation is a core component in FCC. In our study, visiting hours for fathers could be made more flexible. Additionally, hospitalisation of mothers in separate hospitals from their babies hindered bonding for several days. This can be addressed by better planning the continuum of care for mother–baby dyads. Antenatal care providers can minimise mother–baby separation by appropriate childbirth referral practices.^{46 49} Additionally, letting parents periodically see the baby via video connection is a tested approach which can be explored for sepsis.⁵⁰ This can help parents meet their information needs and understand the technology surrounding their fragile baby.

Cultural practices

Mothers felt powerless to change cultural rituals that may have caused sepsis and which were likely to be repeated again once discharged (eg, prelacteal feeds, burning coal in baby's proximity).^{51 52} Such practices are frequent in the Indian context, and parents' decision to avoid them is often superseded by family elders who insist on these practices being conducted.⁵¹ Strategies to involve and sensitise grandparents and other elders to the dangers of such practices should be explored (eg, video counselling, involving community health centres).⁵¹

Support

Familial and religious support was a universal finding in our study. Immediate and extended families provided assistance as needed. Along with religious leaders, families provided emotional support to participants by encouraging faith-based coping, for example, reinforcing faith in God and offering prayers. We could not ascertain if participants questioned their faith or experienced negative religious coping while continuing to observe religious practices.⁵³ However, our findings support two studies from HICs,^{35 54} where religion played a positive role among religious parents by providing hope for their baby's well-being and survival in the wake of uncertainties.

Similar to findings from two studies from HICs, mothers and grandparents bonded over shared experiences with their peers, especially with 'veteran' parents who provided emotional support. In realising that there were other babies with sepsis, participants felt less lonely in their NICU experiences and became

more hopeful of their baby's recovery.^{55–57} Additional literature on religious, spiritual and peer support in the Indian context is required (eg, religious spending despite financial constraints).

All our participants were first-time NICU parents and grandparents. Many participants had premature and low-birthweight babies (field notes during clinical rounds). Our interviews were conducted between 2 and 9 days of admission, which may have influenced the experiences. Parents may pass through different stages (novice to expert) between the baby's admission and discharge in the NICU.⁵⁸ Further research should explore how previous NICU encounters, timing of interviews and prematurity/ low birth weight influence parent stressors in the NICU.

Strengths and limitations

We believe that this is the first study from an Indian context exploring guardian experiences when dealing with neonatal sepsis while highlighting important illness-related and cultural factors. We did not include staff experiences (to be reported elsewhere) to provide a multifaceted perspective. We did not perform coding in duplicate. Nonetheless, a qualitative expert verified the coding schema and interpretation. Finally, the transferability of findings to other cultural, financial and healthcare contexts should be considered with caution as this study was restricted to a busy private referral level IIIC NICU in coastal South India.

CONCLUSION

Designing an FCC for our context requires consideration of stressors that extend beyond the immediate NICU environment and interactions. Understanding the influence of the nature of illness, financial, familial and cultural contexts helps identify the families who are particularly vulnerable to stress. In our context, families, peers and religion were of particular importance for reinforcing the available support system.

Twitter Shruti Murthy @MurthyShruti

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ORCID iD

Shruti Murthy <http://orcid.org/0000-0002-1523-8244>

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Supplement 1: Protocol

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Background

Neonatal Intensive Care Unit (NICU) hospitalization is traumatic for the neonate and their entire family. Parents of hospitalized premature, low birth weight, critically ill neonates in Level III NICU have reported experiences characterised by stress, insecurity and alienation.^{1,2,3,4} A systematic review of qualitative studies highlighted sources of such stress among parents of hospitalized preterm infants: unmet information needs, infant appearance and pain, separation from neonates/ lack of access to neonates.^{5,6}

Neonates of such primary caregivers are at the greatest risk of cognitive and behavioural problems as compared to healthy neonates.⁷ Maternal anxiety and depression in the NICU can hinder mother-infant bonding, which subsequently affects the neonate's temperature and heart rate regulation, breathing and crying.⁸ For example, perinatal maternal anxiety and depression have been seen to detrimentally affect "early cognitive and 12-month communication process", alter "neurosynaptic or regulatory development" and delay developmental milestones.⁹ In particular, increased maternal anxiety during 2 to 4 weeks after birth (during hospitalization of a VLBW infant) results in worse fine motor skills at 20 months of age (corrected age).¹⁰

Sepsis in the baby, however, can pose different challenges for a family compared to a premature baby or a baby with a non-critical illness.^{2,11,12} Sepsis is a time-critical condition; a continuum, that can range from a localized infection to severe, life-threatening manifestations including septic shock and cardiopulmonary arrest.^{2,12} Its clinical course is frequently unpredictable ranging from non-specific clinical presentation to overt and life-threatening complications. Complications thus can progress suddenly and rapidly leading to multiorgan dysfunction and death, despite corrective measures. The onset and deterioration can be rapid in early-onset neonatal sepsis (EOS). Time-period of EOS varies even within countries, with definitions considering sepsis to occur within 3 days of birth or within 7 days of birth.^{13,14} Late-onset sepsis occurs from 3 (or 7) to 28 days of birth.^{12,13}

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The experience can be a frightening circumstance for parents.¹¹ The stressors involved can be multiple and affect different fronts of lives of families experience a hospitalization for their baby's sepsis.² Qualitative studies from HICs suggest that parents of such acute illness/critically ill infants have been said to be in constant fear, undergo a "shock phase", and face more stress and ill health than counterparts with non-critically ill infants.¹⁵ However, there is scarce and inconclusive evidence on the nature of the neonate's illness influencing parent stress in the NICU, particularly from LMICs including India.

Qualitative evidence from India describing the psychosocial needs of parents of sick neonates from India is scarce. One aimed at 'identifying gaps and challenges post-FCC implementation' by understanding the providers' and families' perceptions and experiences from a government tertiary care NICU.^{16,17} In-depth interviews with 12 parents revealed that parents adapted better to the NICU environment, despite 'infrastructural stress factors' with improved understanding of the care provided, improved competencies, and access to their baby (brought about by the FCC).¹⁶ Another study focusing on maternity care in government secondary healthcare facility study used 24 in-depth interviews with postpartum mothers to understand the user experiences regarding quality of maternal health care services, and focused on intrapartum challenges.¹⁷

Studies have numerically 'scored' parent's experiences using validated quantitative scales to measure NICU-related stress. In such studies, infant behaviour, alteration in parental role, neglect of home affairs, and staff interactions were stressors, of which the first three have consistently received high stress scores.^{6,19} Another study on fathers of hospitalized preterm low birth weight neonates in a public Level III neonatal unit found financial burden to be a significant stressor. Baby's condition, socio-demographics, father's age, family history, understanding technology surrounding the child, were suggested to influence parent stress levels.^{6,18,19} However, a study on 343 parents of neonates admitted for at least 48 hours reported found no significant influence of the nature of the illness or requirement of therapy (e.g. ventilation-required for systemic infections, depending on the type and severity) on parent stress levels.¹⁹ Such quantitative studies can do little to capture in-depth experiences of familial needs and contexts in the Indian context.¹⁹

Coping for such families has been facilitated by emotional and professional support, parent education and facilitation, information support.^{5,6} Understanding families' cultural contexts (e.g. religious and daily life practices) is essential for effectively utilizing their capabilities in designing and supporting FCC. The staff need to help families of septic hospitalized babies

¹⁵ Karlsson C. Health promotion work: Pediatric nurses perspectives on the needs of supporting parents with critically or chronically ill children: A qualitative interview study of Sweden

¹⁶ Sarin E, Maria A. Acceptability of a family-centered newborn care model among providers and receivers of care in a Public Health Setting: a qualitative study from India. BMC health services research. 2019 Dec;19(1):1-1. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6427855/>

¹⁷ Bhattacharyya S, Issac A, Rajbangshi P, Srivastava A, Avan BI. "Neither we are satisfied nor they"-users and provider's perspective: a qualitative study of maternity care in secondary level public health facilities, Uttar Pradesh, India. BMC health services research. 2015 Jun;15(1):1-3. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4584124/>

¹⁸ Hall EO. Being in an alien world: Danish parents' lived experiences when a newborn or small child is critically ill. Scandinavian journal of caring sciences. 2005 Sep;19(3):179-85. Doi: 10.1111/j.1471-6712.2005.00352.x

¹⁹ Varghese M. A study on parental stress in the neonatal ICU using parental stressor. Pediatrics. 2015 Feb 1;135(Supplement 1):S9. https://pediatrics.aappublications.org/content/135/Supplement_1/S9.1. DOI: 10.1542/peds.2014-33300

effectively handle their stress by understanding their context and coping.^{5,20,21} Thus, understanding support systems may prove helpful in understanding parental needs during this stressful time.²¹

India witnesses the highest burden of clinical neonatal sepsis in the world.²² This condition is additionally the leading cause of morbidity and deaths in LMICs.^{11,23} Despite policy recommendations on introducing FCC in public healthcare, progress has been slow in India.^{24,25} Neonatal care continues to be technology-driven and provider-centered, with limited parent involvement.²⁵ Research in India exploring the psychosocial needs of parents of hospitalized neonates is scarce, with none focusing on sepsis.

Aim: This exploratory study therefore aims to explore the experiences of parents and accompanying attendants, having a baby admitted for the treatment of sepsis, at a Level IIIc NICU in coastal South India. The study is anticipated to provide baseline inputs to staff and hospital administrators regarding guardian experiences in the setting. This will inform the design of need-based strategies to improve their NICU experiences and satisfaction (based on the domains found from our study). Our findings may additionally inform the need and subsequent design of a larger mixed-methods intervention study on family-centered care in our setting.

Objectives

Specifically, the objectives of this study, conducted in coastal South India, are to understand the:

1. stressors for parents and accompanying attendants when they have a baby admitted for the treatment of sepsis in a private tertiary care Level III C NICU
2. sources of support for parents and accompanying attendants when they have a baby admitted for the treatment of sepsis in a private tertiary care Level III C NICU

This qualitative study is part of a larger doctoral research using multi-methods to understand the prevention and management of neonatal sepsis in a coastal district in South India. The topic for the research was inspired by and an offshoot of a mixed-methods study titled “Determinants of neonatal pneumonia and the factors associated with mortality of neonatal pneumonia: a systematic review combined with qualitative research approach”, for which SM worked as a research associate. The research design included a cost-of-illness followed by a qualitative study. The qualitative study was planned as an exploratory study to understand the experiences of parents and accompanying attendants of neonates admitted in the NICU with sepsis. This study was thus meant to provide an understanding of why families seek newborn care at a private institution (separate paper), and what their experiences were (in terms of

²⁰ Kokorelias KM, Gignac MAM, Naglie G, et al. Towards a universal model of family centered care: A scoping review. *BMC Health Serv Res* 2019;19:564. doi:10.1186/s12913-019-4394-5

²¹ Hua A, Pham T, Spinazzola R, et al. Support systems for NICU parents [abstract]. *Pediatrics* 2018;141(1 MeetingAbstract):561–561. doi:10.1542/PEDS.141.1_MEETINGABSTRACT.561

²² Panigrahi P, Chandel DS, Hansen NI, et al. Neonatal sepsis in rural India: timing, microbiology and antibiotic resistance in a population-based prospective study in the community setting. *J Perinatol* 2017;37:911–21. doi:10.1038/jp.2017.67

²³ Seale AC, Blencowe H, Manu AA, Nair H, Bahl R, Qazi SA, Zaidi AK, Berkley JA, Cousens SN, Lawn JE., pSBI Investigator Group. Estimates of possible severe bacterial infection in neonates in sub-Saharan Africa, south Asia, and Latin America for 2012: a systematic review and meta-analysis. *Lancet Infect Dis*. 2014 Aug;14(8):731–741.

²⁴ Verma A, Maria A, Pandey RM, et al. Family-centered care to complement care of sick newborns: A randomized controlled trial. *Indian Pediatr* 2017;54:455–9. doi:10.1007/s13312-017-1047-9

²⁵ Maria A, Dasgupta R. Family-centered care for sick newborns: A thumbnail view. *Indian J Community Med* 2016;41:11–5. doi:10.4103/0970-0218.170957

stressors and support system- addressed in this paper) in this setting, in the context of the doctoral research topic of neonatal sepsis.

Methodology

We will conduct a qualitative study, using principles of grounded theory,^{26,27} in a tertiary care teaching hospital in Udipi, a coastal district in South India, based on methodological aspects previously described elsewhere.²⁸

Setting

We provide a detailed reporting of the setting our study context to understand the transferability of our findings, and add to the rigor of our study.

The unit: The neonatology unit houses a reception-cum-waiting area, NICU (Level III C), a stepdown nursery, a septic ward, a breastfeeding room and a discharge ward (mother-neonate dyads stay together around the time of discharge)- all on the same floor.

Population served: The admissions vary according to type of neonatal units in India. One fifth of all newborn possibly requiring rural SNCU (Level II),²⁹ with an estimated 1.2 million neonates admitted to 525 SNCUs in India.³⁰ Another study reported the following magnitude of neonatal admissions based on sector and level of care: Government secondary 91 (55-138 per month), government medical college 143 (110-176), private medical college 31 (21-45), private tertiary care 47 (38-53).^{30,31}

As per the treating clinician's estimate, roughly over 120 neonates are admitted to the unit per month, of which five to eight cases belong to sepsis. This busy unit, utilized by both urban and rural population belonging to all socioeconomic strata, serves as the referral center for pediatric and neonatal care for eight surrounding districts. The total population of these districts is nearly 0.5 million, of which children aged 0-6 years comprise nearly 0.7 million³² The unit receives both inborn and outborn neonates.

Counseling: Once a neonate is admitted to the unit, parents and accompanying attendants of all hospitalized neonates are mandated to undergo counseling by a consultant (neonatologist) in the presence of the one to two on-call postgraduate(s). On an average, nearly 45 families undergo counseling every day. Each counseling session lasts between 15 to 20 minutes and is provided in the language comfortable to the families. Families are free and encourage to voice their queries during the counseling.

Families, their availability and accommodation: These comprise of mother, grandparents, fathers, other family members (e.g. brothers); either together or individually. Approximately 45

²⁶ Charmaz K. Constructing grounded theory: A practical guide through qualitative analysis. Sage; 2006 Jan 13.

²⁷ Hennink M, Hutter I, Bailey A. Qualitative research methods. SAGE Publications Limited.

²⁸ Nair NS, Lewis LE, Lakiang T, Godinho MA, Murthy S, Venkatesh BT. Risk factors and barriers to case management of neonatal pneumonia: protocol for a pan-India qualitative study of stakeholder perceptions. *BMJ Open*. 2017;7(9):e017403. doi:10.1136/bmjopen-2017-017403

²⁹ Neogi SB, Malhotra S, Zodpey S, Mohan P. Assessment of special care newborn units in India. *Journal of health, population, and nutrition*. 2011 Oct;29(5):500. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3225112/>

³⁰ Hanson C, Singh S, Zamboni K, Tyagi M, Chamarty S, Shukla R, Schellenberg J. Care practices and neonatal survival in 52 neonatal intensive care units in Telangana and Andhra Pradesh, India: A cross-sectional study. *PLoS medicine*. 2019 Jul 23;16(7):e1002860. <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002860>

³¹ Karambelkar G, Malwade S, Karambelkar R. Cost analysis of healthcare in a private sector neonatal intensive care unit in India. *Indian Pediatr*. 2016 Sep 1;53(9):793-5. <https://www.indianpediatrics.net/sep2016/793.pdf>

³² <https://www.census2011.co.in/>

to 48% of families reside in towns outside that of the study site. Such families choose to stay at an accommodation (a 'dormitory' opposite to the hospital) provided by the hospital for the duration that their baby is hospitalized. Mothers of inborn babies are usually admitted in wards one to two floors above or a floor below the neonatal unit until their post-delivery recovery is complete (anytime between 3 days to few weeks). Families (including the mother) can choose to stay in the dormitory.

Mothers do not have limitation on the 'visiting hours' and are allowed inside the NICU whenever they wish. Attendants other than mothers are allowed inside the NICU only during the visiting hours. Mothers are allowed to breastfeed every two hours, provide kangaroo mother care (KMC) and bond with their baby (depending on the clinical condition of the baby, adequacy of breast milk, and physical condition of the mother to breast feed) in the NICU. Mothers sit on a chair next to the baby's bed while breastfeeding and providing KMC. They usually smile and talk to neighbouring mothers (when present) involved in similar activities for their babies.

Fathers, grandmothers and others usually helped the mother by bringing food and beverages (from home or canteen), medicines, clothes or anything that was needed for her. They additionally help pump her breast milk, and transport it (every two hours) to the staff for the baby. This was important for babies whose could not be breast fed directly due to the type and severity of the systemic infection, and thus their clinical condition. Families also helped when the staff required them for the baby.

Mothers: First-time mothers followed the practice of spending the few months of before and after childbirth at their maiden homes. Hence grandmothers typically accompanied the mothers for pre-delivery hospital visits, during and after childbirth. It was also possible that mothers were absent from the study site, during their baby's hospitalization, for a few days to a fortnight. Reasons for this included that the mother had delivered at the referring facility and had not completely recovered when the baby had to be referred to the study site. In such cases, only grandmothers would be available at the NICU as the baby's father would be away at work.

Fathers: Fathers typically would be available during lunch time, evening and night, as they were away at work during the day. Some fathers would not be available, for weeks, as they were employed in different Indian districts/states, or country. Many fathers (except daily wagers) come on alternate days during the weekdays (Monday to Saturday).

Grandparents: The mother's mother typically accompanies the mother at the study site during the baby's hospitalization, also reported in literature from our context.¹⁶ Working grandmothers staying in the proximity of the study site, are available part-time with the mother. Such grandmothers also bring home-cooked food on a daily-basis for the mother, and return to their residence during the night. Non-working grandmothers, not staying in the vicinity, stay with the mothers in the dormitory between days to weeks, depending on their responsibilities at their homes. Some grandparents would be available next to the mothers full-time in the wards as well. Maternal fathers and paternal parents rarely stay with the mothers or fathers during the hospitalization, and might visit on a weekend.

Others: Occasionally, the paternal brother or uncle, or maternal sister represents the parent for a day or during counseling during the baby's hospitalization, typically when the father was unable to visit.

Payment during hospitalization: Costs typically comprise: baby's hospitalization; accommodation, food, clothing, transport and other (religious activities) costs for the families. The costs are borne partially or completely by the families, depending on availability and utilization of health insurance (private or public) and other local financial assistance schemes. Limited financial assistance for certain segments of the population (e.g. below poverty line, religious minorities) are provided by charities/trusts, based on official recommendation by the unit. The coverage and type of payment mechanisms of health insurance varies by the provider. For example, the insurance may pay the provider directly eliminating the need for families to pay during the hospitalization (as opposed to reimbursement of expenses paid by the families, and subject to submission of bills). Out-of-pocket expenses (e.g. transport) were not covered under any health insurance in this setting.

Participants and eligibility

Participants will include parents or grandparents of neonates (0-28 days) admitted to the NICU for the management of one or more systemic infections. The systemic infections in this study could include one or more of the following: septicemia, pneumonia, meningitis, osteomyelitis, arthritis and urinary tract infections.³³ A purposive sampling will be used to include parents and accompanying attendants immediately or within the first few days after diagnosis. This was done to capture and understand their experiences as soon as they knew of their baby's condition. Thus, some a priori exclusions are (i) a parent or the spouse who was unavailable at the study site during the data collection period, and (ii) parents with babies who are in the midst of treatment (e.g. meningitis which requires 21 days of treatment) or closer to discharge/ have been discharged from the unit). Additionally, parents and accompanying attendants who refuse to provide written informed consent will be excluded from the study. Both early- and late- onset sepsis cases were included. No other exclusion criteria were applied.

Recruitment

Recruitment of the parents and accompanying attendants will be done on a rolling basis (prospectively, as admissions occur), at the study site, within the first two days of admission with a diagnosis of a systemic infection. SM will visit the neonatology unit Monday through Saturday and collect the list of babies admitted in the NICU every day. This means that, at the time of recruitment, the baby was admitted and would have just started receiving treatment for the infection in the unit. For days which were missed due to SM's absence (e.g. sickness, some Sundays), this list would be updated on the subsequent day. SM will subsequently make a list of babies diagnosed with a systemic infection by consulting the staff and reviewing the baby's medical charts each day. The baby is typically identified in the unit as "Baby of <Mother's name>" in the records, unless the family has already named the baby.

Parents and accompanying attendants will be approached when they are seated in the waiting lobby, by telephone or personal visits to the hospital dormitory where they reside. SM will identify and approach the parents/ accompanying attendant responding to this identifier in the

³³ Sankar MJ, Agarwal R, Deorari AK, Paul VK. Sepsis in the newborn. *Ind J Pediatr.* 2008;75(3):261–266

reception area, between 10 am to 5.30 pm. For mothers admitted in the ward (See “Setting” above), SM approached the mother in the ward, taking assistance of the nursing staff to identify the mother. Additionally, SM will take assistance of the unit staff to identify a particular parent/ accompanying attendant was present inside the unit. This was deemed necessary; in case the parents/ accompanying attendant would be unavailable in the reception area or the wards. SM will aim to identify and approach the parents/ accompanying attendant on the same or next day of diagnosis of sepsis. If this was not possible (e.g. absence of SM, diagnosis made between 5.30 pm to midnight, unable to locate parents/ accompanying attendant), an attempt will be made on the subsequent day.

Once the parents and accompanying attendants are approached, SM will brief them in a private room beside the reception area. They will be invited to participate by providing a participant information sheet and informed consent form in the language preferred by the parent(s). SM will explain the contents of these documents in a language preferred by the participants (e.g. about the voluntary nature of the research study and right to withdraw at any point; need, aim and methods of research; why they are being invited; what data will be collected and how; anticipated harms and possible benefits to the participant, and dissemination modalities). The details of the researcher (e.g. present position of the researcher, objective of this doctoral research study and how it ties to the larger career aims of the researcher) will also be explained.

If the spouse/parent is unavailable, SM will enquire regarding their availability in the hospital to invite them for the study. The parents/ accompanying attendant was requested to provide the spouse/ parent’s phone number for subsequent contact. Details of when the spouse or parent would be subsequently available will be noted for subsequent contact (if contact details were not provided). Parents and accompanying attendants will also be requested to provide their contact number and/or their location in the hospital (e.g. room number in dormitory) to contact them after one to two days for their decision to participate. If they refuse to provide this information, they will be informed that SM would approach them in the unit after the counseling, after one to two days, for their decision. Parents and grandparents will be requested to participate individually for the interview.

The same process will be followed to recruit the spouse/parent on subsequent contact. If they agreed to participate, SM will take written informed consent in duplicate and subsequently recruit the participant. After recruitment, participants will be requested to provide a date and time for interview.

In-depth interview guide

A semi-structured IDI guide will be used to interview participants. We recognize that there is a scarcity of qualitative studies exploring the experiences of parents’ experience in the NICU, particularly in the context of illnesses like sepsis. Thus, we intended to keep the questions broad and allow the participant to freely express themselves. Qualitative literature review informed our IDI guide in understanding the concepts, developing questions and probes. In addition, consultation with experts and revised following a pilot study on 5 parents (not included in the main study) informed the final IDI guide. The analysis from the pilot study will inform (i) the refinement of the IDI guide, and (ii) the development of deductive codes for the two deductive themes (described in “Data analysis” below). The final IDI guide had the following domains: participant background, experience of baby in the NICU, stressors, positive

and negative emotions, what their baby may go through, their coping mechanism, who they discuss their experiences with, prior experience with sick baby, finances for NICU-related costs, financial impact on family and current financial coping, perceived support that they wished to have received. Participants will be encouraged to describe their feelings or emotions they experience during a stressor and support.

Pilot testing

Three fathers and two mothers were recruited for pilot testing, which served to revise the IDI guide. In addition to modifying probes and the language/structure of questions, it modified the following aspects of the study:

- Challenges in operationalising the conceptual framework: We planned to use the concepts from the Transactional Model of Stress and Coping as a guiding framework for data collection and analysis. However, we found operational challenges during the pilot study, which made it extremely difficult to operationalize this model as recommended by the “Transactional Model of Stress and Coping” (TMSC) to develop the IDI guide.³⁴ For example, we were unable to administer the “Ways of Coping Questionnaire” (an essential component of the model to understand coping mechanisms) due to contextual challenges. For example, mothers were repeatedly reluctant to respond to the questionnaire in addition to giving an interview citing health-related issues after childbirth. Many fathers simply lacked the time to participate in interview, as they juggled between tasks of delivering food to the wife and arranging to pay for NICU-related costs. Participants during the pilot study thus simply refused to accept the questionnaire. We had to thus modify our methodology to fit our research inquiry and study context, and proceed without using the conceptual framework. We finally decided to explore the concepts of stress and support system. Further, we will attempt to capture the factors that enable parents and accompanying attendants to adapt to the neonatal environment, and those which make the stay more difficult.^{12, 35}

About TMSC: Since our interest was to study the stress and coping among parents during their baby’s hospitalization, we intended to use TMSC as it evaluates the process of stress and coping during important life events. TMSC assesses how people appraise a situation as being stressful (in the form of emotions, thoughts, behaviour) and subsequently judge their ability to cope (demands versus resources) if the event is found stressful. TMSC measures and explores coping strategies through a “Ways of Coping” Questionnaire. The original version is a 66-item checklist with responses to be scored on a four-point Likert scale, denoting the extent to which the listed strategies were used/ not used in a particular situation considered stressful. The model further also suggests that certain people are particularly more vulnerable to ‘stressful’ events, because of their background, environment and/or personality.^{34,36}

- Including grandparents as participants: Our initial eligibility criteria included only parents. This posed challenges during the pilot study as grandparents were frequently present with mothers in the unit. Mothers refused to be interviewed without the presence of their mothers, and their mothers also responded to the questions (despite

³⁴ Lazarus RS, Folkman S. Stress, appraisal, and coping. Springer publishing company, 1984

³⁵ Hall SL, Hyman MT, Phillips R, Lassen S, Craig JW, Goyer E, Hatfield RF, Cohen H. The neonatal intensive parenting unit: an introduction. *Journal of Perinatology*. 2017 Dec;37(12):1259.

³⁶ Folkman S. Ways of coping checklist (WCCL). *Encyclopedia of behavioral medicine*. 2013;2041-2. https://link.springer.com/referenceworkentry/10.1007%2F978-1-4419-1005-9_222

briefing them not to, before the interview began). The mother was also emotional and mentioned that she felt more confident to answer in the presence of her mother. Thus, we considered including the grandparents in such circumstances, as they were equally (and sometimes more) involved as the parent, in the activities in NICU.

- An explicit finance-related question: We had included 'finance' as a probe in the initial version of IDI guide. We found, during pilot testing, that participants spoke about the different mechanisms of arranging money, which was a struggle in itself and stressful. Thus, an explicit finance-related question with tick boxes served as a guideline for the interviewer to go deeper according to the option mentioned by the participant (ticked by the interviewer).
- Recruitment and interviewing: Participants were also requested on feedback if they were comfortable with the way they were approached during recruitment. We also learned that fathers might decide for their wife's participation in the study, or can insist that they themselves participate in their wife's stead and speak for their wife.
- Participant checking and feedback: We were unable to perform participant checking for other interviews due to contextual challenges. For example, participants repeatedly cited a lack of time, ill-health or being too worried to give time after interviews. Additionally, we were unable to meet many fathers again during the data collection timings.

Data collection

Data will be collected using face-to-face in-depth interviews. Participants will be contacted telephonically or in-person (when available) on their preferred date and time of interview. Attempts will be made to include both the mother and father, and to interview them separately (i.e. not in each other's presence) in order to avoid one influencing the other's views. If the parents are unwilling for this arrangement, data will be collected from them seated together. Interviews will be conducted in a language (English, Kannada, Tamil, Marathi, Hindi), location and time preferred by the participants. Additionally, observations (in the form of field notes) during clinical rounds and patient counseling will be made to understand the baby's clinical condition and progress, the participant- baby and participant- staff interactions in the NICU environment. Observations of patient counseling included the regularity of the participant to counseling sessions, and the number and relation of people accompanying/ substituting the participant for the counseling. This information was collected from the unit staff and registers after each patient counseling session. Multiple sources of data collection will thus help us understand if this converges or diverges with the participants' responses regarding these aspects during the interview.

Privacy will be ensured by interviewing the participants only in the presence of the researcher. Participants will be contacted for repeat interviews in instances where a deeper understanding of concepts/ clarification of concepts is required after the initial interview. Data will be collected until information saturation is reached and no new meaningful concepts emerge from subsequent interviews.^{26,37}

³⁷ Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C. Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity*. 2018 Jul 1;52(4):1893-907. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5993836/>

Audio-recording, with prior permission from the participant, of the interviews will be done on an electronic voice recorder (Sony ICD-PX440). Interviews will be hand-written for participants who deny permission for audio-recording. The recordings will be transferred and stored on a computer for subsequent transcription. Field notes will be recorded both during and after the interviews to record: concepts or keywords that emerge from the interview, participant non-verbal cues and post-interview reflections (e.g. participant hesitations; interaction and behaviour between the couple, and individually, during couple interview; codes which need further exploration). Audio recording of the interviews will be done to avoid missing information, to retain participant narratives as is said by the participants themselves, and to focus on the expressions in the text, and minimize researcher interpretations. For hand-written interviews, the notes made during the interview will be read out to the participant immediately after the interview to verify the information. These will add to the dependability of the study.³⁸

We will maintain a detailed report of the research plan, its stage-wise implementation, challenges faced and strategies instituted. Additionally, a thick description of the results will be first written up, from which the manuscript will be prepared. These will be shared for external review with research team members. The researcher was adequately trained in qualitative research and analysis, and mock interviews conducted- all of which helped to be constantly mindful of subjective interpretations to minimize its influence on the data. This will be done to ensure that interpretations are derived from data to add to the rigor in terms of confirmability of the findings.⁴¹

Data management

The IDIs will be transcribed (SM) verbatim, translated, and supplemented with field notes, if and when necessary. Hand-written observations and field notes will be typed, and will undergo the same cleaning and analysis process as IDI transcripts. Transcripts and field notes will be cleaned only to anonymize and remove any potential identifiers.³⁹ Signed informed consent sheets will be stored in a separate physical cabinet and will not be linked to the unique code. Anonymized transcripts, field notes and analysis files will be stored separately on a password-protected cloud server.

Data analysis and reporting

ATLAS.ti software will be used to facilitate the management and analysis of qualitative data. A thematic analysis will be performed, as recommended in literature.²⁶ We will derive our sub-themes conceptually (instead of from an existing theoretical framework) by closely examining our interview transcript data, based on the patterns and ideas that repeatedly emerged from our data.²⁶ Interviews will be transcribed, and field notes will be typed following each interview. This will be followed by repeated listening of the interview, and reading and re-reading of the transcripts and field notes to get an understanding of the entire experience described by the participants. Immersion in the data will thus help in rigor by ensuring the credibility of our findings. Coding of the data will be done (explained later in this section). Data will be organized to list the stressors and support systems mentioned by the participant. Emotions associated with the stressor and support system will be listed. Observations from

³⁸ Korstjens I, Moser A. Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*. 2018 Jan 1;24(1):120-4. <https://www.tandfonline.com/doi/pdf/10.1080/13814788.2017.1375092>

³⁹ Kaiser K. Protecting respondent confidentiality in qualitative research. *Qual Health Res* 2009;19:1632-41. doi:10.1177/1049732309350879

field notes will be explored during subsequent interviews (e.g. patterns or repetition of emotions, and while describing a particular stressor or support system; similarities and differences during couple interviews). These concepts/ phrases will guide the further exploration in the subsequent interviews until no new concepts emerge and data saturation is attained.^{28,40} This will also allow guide in actively identifying disconfirming sources for data that “does not fit” or different from that which repeatedly occurs, to aid in the credibility of our study.³⁸

Two cycles of coding will be conducted as recommended in literature.²⁶ The first cycle will provide a list of codes which will be closer to the data. Codes could range from a single word to a phrase to a short statement. We will list inductive (emerging from data) codes, in addition to codes already identified (IDI guide, identified during pilot study), until we achieve data saturation. A code book will be developed by SM under the guidance of HH and AB. The second cycle will generate code families or categories, by grouping similar codes in a meaningful way. Subsequent grouping and categorization will be under two themes to address our research questions. A second qualitative researcher/expert (HH) will check the coding cycles, referring to the IDI guide to add to the confirmability of the study. The coders will discuss the coding schemes and reach consensus. Codes will be renamed as deemed appropriate.

Stressors will be coded by identifying those factors that the participant describes as making them feel strained, tensed, distressed, or something which avoided/did not prefer. Descriptions, by participants, of what supported them/ helped them feel better or cope/reduce their stress, and how, will be analyzed under the deductive theme of “Support System”. Participants may report more than one feeling or emotion for a stressor/ support system (found from pilot-study). This will be captured during the analysis and reported in text and tabular formats. Interpretation will be done by the interviewer (SM), two qualitative research experts (AB, HH) with inputs from a neonatologist (LL). The findings will be shared with research team colleagues and doctoral advisory committee members for external review to ensure confirmability and credibility of the findings.^{38,41}

Data will be presented in textual and tabular (e.g. participant characteristics and background) formats. Select participants’ quotations will be provided throughout the text to support the interpretation of the results. Non-verbal cues from field notes will be reported (where present) in the participant quotations in parenthesis and in the overall description of results/ sub-themes. In addition, the limitation in terms of context will be provided, all of which will add to rigor in terms of understanding the transferability of findings.³⁸ Reporting of the study will be informed by “The Standards for Reporting Qualitative Research” (SRQR)⁴² and the “Consolidated criteria for reporting qualitative research” (COREQ).⁴³

⁴⁰ Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C. Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity*. 2018 Jul 1;52(4):1893-907. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5993836/>

⁴¹ Mirlashari J, Brown H, Fomani FK, de Salaberry J, Zadeh TK, Khoshkhou F. The challenges of implementing family-centered care in NICU from the perspectives of physicians and nurses. *Journal of pediatric nursing*. 2020 Jan 1;50:e91-8. [https://www.pediatricnursing.org/article/S0882-5963\(18\)30402-0/fulltext#back-bb0160](https://www.pediatricnursing.org/article/S0882-5963(18)30402-0/fulltext#back-bb0160)

⁴² O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*. 2014 Sep 1;89(9):1245-51.

⁴³ Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*. 2007 Dec 1;19(6):349-57.

Ethics and anonymity

Principles in the Declaration of Helsinki will be followed. A scientific committee approved the study protocol. Administrative permissions were obtained from the medical superintendent of the hospital, and the head of the neonatology unit. Subsequently, ethical clearance was provided by the Institutional Ethics Committee of the hospital. Privacy and confidentiality of participants will be maintained throughout the study. Each participant will be provided with a "unique identification code" identifying the type of participant (e.g. father, mother, grandmother). Transcripts will be cleaned and anonymized to remove any identifiers. Participants will continue to remain unidentifiable in all study reports.

Rigor

Trustworthiness of our data will be ensured by instituting measures for credibility, confirmability, dependability, transferability and positionality.^{44,45}

Credibility and confirmability: Multiple sources of data collection (participant accounts, field notes from observation of interactions) will help us understand and triangulate the data from participants' responses. Audio recording of the interviews will be done to avoid missing information, to retain participant narratives as is said by the participants themselves, and to focus on the expressions in the text, and minimize researcher interpretations. For hand-written interviews, the notes made during the interview will be read out to the participant immediately after the interview to verify the information. SM has been adequately trained in the methods and analysis of qualitative research, and has previously conducted 63 IDIs for a pan-India qualitative study on neonatal health. These will help to be constantly mindful of subjective interpretations to minimize its influence on the data, and that interpretations are derived from data. A second qualitative expert (HH) will check the coding cycles. Interpretation will be done by the interviewer (SM), two qualitative research experts (AB, HH) with inputs from a neonatologist (LL). We will continuously immerse in the data (active and repeated listening of interviews, reading and re-reading of interview transcripts). The findings will be shared with the research team colleagues and doctoral advisory committee members for external review to maximize confirmability and credibility of the findings.

Dependability: We will maintain a detailed report of the research plan, its stage-wise implementation, challenges faced and strategies instituted. Additionally, a thick description of the results will be first written up, from which the manuscript will be prepared. Description of analysis, direct quotations and emotions described by the participants will be provided.

Transferability: An explicit protocol has been developed and reported here, which helps in understanding the study design and context. The study's limitation in terms of context will be provided in the manuscript.

Positionality: The interviewer (SM) is an unmarried female PhD student (in the third year at the time of interviewing), who was external to the NICU and not a member of the clinical NICU team. She has formal qualifications in dentistry (BDS) and public health (MPH), and has research experience since 2011. SM is not related to, and is not a part of, the neonatology unit where the study was conducted.

44 Korstjens I, Moser A. Practical guidance to qualitative research. Part 4: trustworthiness and publishing. *Eur J Gen Pract* 2018;24:120–4. doi:10.1080/13814788.2017.1375092

45 Lincoln YS, Guba EG. *Naturalistic inquiry*. New Delhi: SAGE Publications India Pvt Ltd 1985

Supplement 2: In-depth Interview Guide

1. Let us talk about your baby. Can you tell me why you are here?

Probe: present condition, knowledge about diagnosis

2. Talking about your experience, how do you feel about having your baby admitted here?

Probe: different feelings- positive and negative, spouse's feelings

3. What stresses you about having your baby admitted here?

Probe: baby, environment, peers, staff

Alternate question if the participant doesn't respond: Can you tell me an instance when you felt negative (e.g. anxious/ sad/ angry/ helpless)

And positive (e.g. happy) such emotions in the NICU?

Probe for various emotions mentioned in Question 2

5: What do you feel/think the baby goes through? Do you discuss it with anyone?

Probe - Pain?

- Discuss with immediate family, peers, neighbours, NICU staff.

6. How do you cope when you are faced with this situation?

Probe: present condition, knowledge about diagnosis

7. Do you have any earlier experiences with seeking care for sick babies?

Probe - In your family? Among you friends?

8. Let us discuss about the expenses related to your baby's condition. Can you tell me how you and/or your family mobilized the money for your child's treatment? *(assess if guardian is willing to speak. If yes, continue. If not, reassure him/her and ask if they can answer now. Else, come back again)*

| Source | Yes? |
|---|------|
| It was free | |
| Salary/Savings | |
| Working overtime | |
| Mortgaging of assets (jewellery, land, livestock, etc) | |
| Selling of assets (jewellery, land, livestock, etc) | |
| Borrowed from relatives/friends without interest | |
| Borrowed from relatives/friends with interest | |
| Loan (moneylender, bank) | |
| Health insurance a) BPL free/poor free b) Government employee c) RSBY d) Private Insurance e) NRHM scheme f) ESI g) Any other, specify..... g) None | |
| Others, specify | |

9. Has the illness affected the family financially? What changes or adjustments did you have to make in your daily life due to your child's illness?

Probe- cutting down costs), Work, Household chores, Accommodation, Baby sitting

Others- child education, food security, changes in spouse's life

Closing questions:

10. What is the one thing that is on your mind right now?

11. What help could you have received to make this entire experience better?

Probe- Health, finances, support (peer, family, health system)

Is there anything else you would like to tell me? Do you have any questions for me?

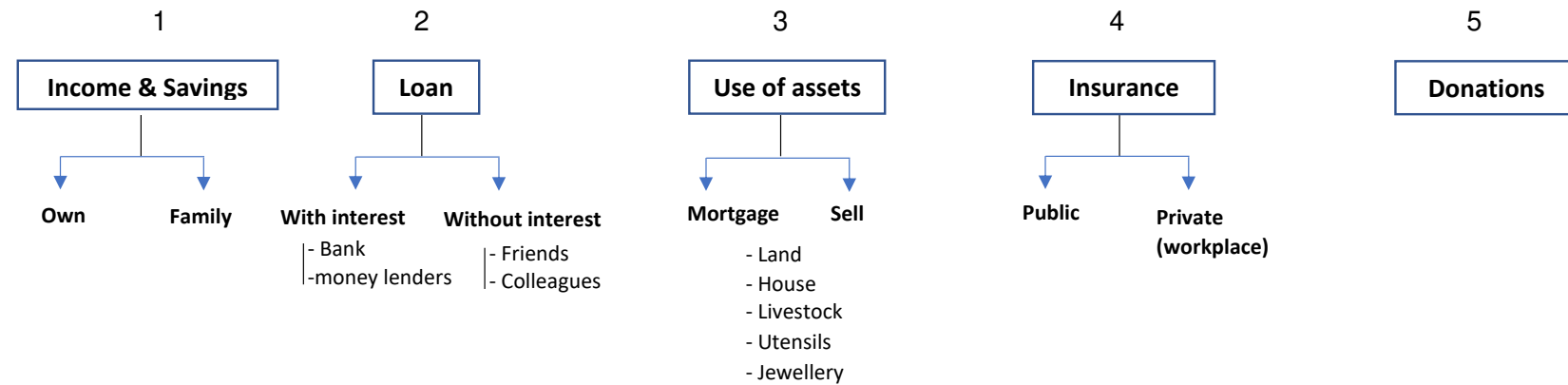
-Thank you for your patience and time.

- End of interview-

Supplement 3**a. Reasons for exclusion**

| Number of participants | Reason for denial of consent/exclusion |
|-------------------------------|--|
| 6 | Too stressed to talk |
| 2 | Repeatedly (more than three times) unavailable for interview despite providing consent |
| 1 | Shifted (against medical advice) the baby to a government facility after agreeing to participate |

Supplement 4: Financing of NICU-related costs



Strategies of financing: There were 3 ways in which families financed for the NICU-related costs:

1. Completely out of pocket: Families paid entirely through out-of-pocket financed through savings and/or income, contributions by relatives and friends, sale or mortgaging of physical assets
2. Combination: Families arranged to pay by a combination of out of pocket payments, acquiring loans, partial insurance cover (private/public) and/or donations from charities or financial trusts (only for those below poverty line).
3. Completely covered by insurance: A final type was where the entire expenses was covered by insurance.