Parents, healthcare professionals and other stakeholders’ experiences of caring for babies born too soon in a low-resource setting: a qualitative study of essential newborn care for preterm infants in Kenya

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ABSTRACT

Objectives Prematurity is the leading cause of global neonatal and infant mortality. Many babies could survive by the provision of essential newborn care. This qualitative study was conducted in order to understand, from a family and professional perspective, the barriers and facilitators to essential newborn care. The study will inform the development of an early warning score for preterm and low birthweight infants in low and middle income countries (LMICs).

Setting Single-centre, tertiary referral hospital in Nairobi, Kenya.

Participants Nineteen mothers and family members participated in focus group discussions and 20 key-informant interviews with professionals (healthcare professionals and policy-makers) were conducted. Focus group participants were identified via postnatal wards, the newborn unit and Kangaroo Mother Care (KMC) unit. Convenience and purposive sampling was used to identify professionals.

Outcome measures Understanding facilitators and barriers to provision of essential newborn care in preterm infants.

Results From 27 themes, three global themes emerged from the data: mothers’ physical and psychological needs, system pillars and KMC.

Conclusion Meeting mothers’ needs in the care of their babies is important to mothers, family members and professionals, and deserves greater attention. Functioning system pillars depended on a standardised approach to care and low cost, universally applicable interventions are needed to support the existing care structure. KMC was effective in both meeting mothers’ needs, supporting existing care structures and also provided a space for the resolution of the dialectical relationship between families and hospital procedures. Lessons learnt from the implementation of KMC could be applied to the development of an early warning score in LMICs.

Strengths and limitations of this study

- This is the first report of parents’, healthcare professionals’ and wider stakeholders’ views of essential newborn care in the context of development of an early warning score in low and middle income countries.
- A wide range of parents were recruited to ensure a wide range of opinions were elicited.
- Parents were recruited from a single, large national referral hospital, though some healthcare professionals had previous experience outside of this hospital.

BACKGROUND

Globally, 15 million infants are born prematurely (before 37 weeks gestation), the leading cause of neonatal mortality and morbidity. More than 60% of all preterm births occur in sub-Saharan Africa and over a third of all neonatal deaths are due to preterm birth complications. In Kenya, the preterm birth rate is 8.6 per 1000 live births and neonatal mortality rate (NMR) is 20.9 deaths per 1000 live births, currently double the global goal of an NMR of <10 deaths per 1000 live births by 2035. In this setting, preterm infants should be managed in accordance with national and international evidence-based guidance for essential newborn care, including strategies for thermoregulation, resuscitation, feeding, Kangaroo Mother Care (KMC) and infection management. More than 80% of all preterm births occur between 32 weeks and 37 weeks gestation and most babies could survive with the provision of essential newborn care.
This study is part of a wider programme of work developing an early warning score (EWS) for use in preterm and low birthweight (LBW) infants in low and middle income countries (LMICs). An EWS is used by healthcare professionals (HCPs) to document vital signs in a standardised way. While they are used for adults in a variety of clinical areas, there are few EWSs for newborn infants and none developed or used in LMICs. An EWS identifies vital signs that require closer monitoring and escalation of care which could result in a reduction in mortality and other serious morbidities. Before adopting an intervention developed for a high-resource setting in an LMIC, it is important to explore the current provision of care for the LMIC setting and to ensure the opinions of parents and HCPs are considered.

The aims of this study were to gain a contextual understanding of parents’, HCPs’ and other stakeholders’ experiences of essential newborn care in Kenya, to understand barriers and facilitators to caring for a preterm or LBW infant in a low-resource setting and to consider both in the development of an EWS.

METHODS

This qualitative study was conducted at a large tertiary referral hospital in Nairobi (Kenyatta National Hospital (KNH)). Focus group discussions (FGDs) with mothers and family members were conducted in parallel to key informant interviews (KIIs) with a range of stakeholders involved in care of or management of preterm or LBW infants. FGDs were chosen for mothers and family members to reduce the risk of a potential power imbalance between participants and the researcher. A trusted staff member (clinical matron) was also invited to the FGDs to support the parents. Furthermore, the collaborative aspects of care were the focus of this study, involving both the relationships between the parents and the HCPs, but also the ‘community’ of mothers with sick babies. FGDs were the most appropriate methodology to capture this dynamic. KIIs were chosen for stakeholders for organisational and convenience reasons. The study was conducted with full ethical approval from the joint KNH–University of Nairobi Ethics Research Committee (reference number: P772/11/2018) and the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of Nottingham (reference number: 161-1812) and is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ).

Recruitment

Training in interview techniques was provided to the team by PP, EJM and SO. Potential mothers and families were identified by a clinical matron on postnatal wards, the newborn unit and KMC unit. Mothers of different ages, different duration of hospital stay and singleton and multiple pregnancies were invited to ensure a diverse sample. Participant information sheets were provided in English or Kiswahili. Convenience and purposive sampling was used to recruit HCPs via the labour suite, postnatal wards and newborn unit. External stakeholders, including policy-makers and non-government organisations (NGO) representatives, were purposively sampled and invited to participate in an interview. Participants’ involvement was somewhat determined by their availability, though the research team made efforts to accommodate an interview at a mutually convenient time. All participants gave their written informed consent prior to taking part.

Data collection

All data collection was undertaken by VK, a Kenyan female social scientist educated to PhD level with over 40 years’ experience, during March and April 2019. Two FGDs, each lasting around 90 minutes, were conducted at KNH. The interview guide consisted of prompts to explore mothers’ and family members’ views of essential newborn care for a premature baby (online supplemental material 1). Face-to-face KIIs lasted around 60 min. All discussions were audio-recorded and transcribed. No identifiable data were included on the transcripts.

Analysis

Thematic network analysis (TNA) was used. TNA is a way of coding, organising and identifying emergent themes from the data in a systematic way and improves the internal validity of the results by employing systematic and repeatable methods. Global themes emerged from the grouping of organising themes into more abstracted and/or structural categories and was done by both analysts in collaboration. The philosophical underpinnings of this study are relational dialectic theory as a pragmatic but nuanced way of identifying effective clinical interventions, which would work within the human context of neonatal care in a less resourced setting where much of the burden of basic nursing care rests on the mothers. Understanding what is fairly pragmatic data through this epistemological lens allowed the researchers to elucidate the spaces where communication and relationship between mothers and HCPs are either enabled or prevented. This understanding also removes the concept of ‘blame’ of failures in care from either side, preferring a more salutogenic approach to designing protocols and practices which support collaborative working. Data from FGDs and KIIs were analysed together in order to consider consistent themes and gaps between the two. Table 1 shows an example of a coding tree. Initial coding was undertaken independently by EJM and PP before being moderated by a third reviewer (MO). Analyses were conducted using NVivo V.12 (QSR international). Initial codes were organised into organising and global themes in accordance with the stages of TNA.

The study is strengthened by the fact that data collection and analyses were performed by teams in Kenya and the UK, since concepts are developed from a more etic perspective. However, although one of the senior academic analysts has substantial clinical experience in...
Table 1  Example of the coding tree

| Global theme                          | Organising theme                                                                 | Basic semantic code                                                                 |
|---------------------------------------|----------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| Mother's physical and psychological needs | Impact on wider family and community                                               | ► Impact of children on mother not being at home                                      |
|                                       |                                                                                 | ► Long inpatient stay                                                                  |
|                                       |                                                                                 | ► Involvement of other siblings                                                       |
|                                       |                                                                                 | ► Emotional impact of preterm death on siblings                                         |
|                                       |                                                                                 | ► Impact on siblings has led to drop in educational performance                       |
|                                       |                                                                                 | ► Anxiety to mothers around leaving older siblings at home                              |
|                                       |                                                                                 | ► Impact on other children and family                                                  |
|                                       |                                                                                 | ► Preterm birth impacts on other children                                               |
|                                       |                                                                                 | ► Daddy panics about mum’s health                                                      |
|                                       |                                                                                 | ► Involvement of dads and wider family                                                 |
|                                       |                                                                                 | ► Less involvement from daddy                                                          |
|                                       |                                                                                 | ► Partner anxiety about premature baby                                                 |
|                                       |                                                                                 | ► ‘You are not a burden’ family member perspective                                    |

Table 2  Focus group participant characteristics

| Focus group | Gestational age (weeks) of infant | Experience of post-natal ward | Infant’s length of stay (days) at time of focus group discussion |
|-------------|-----------------------------------|------------------------------|---------------------------------------------------------------|
| 1           | 34                                | No                           | 18                                                           |
|             | 29                                | Yes                          | 26                                                           |
|             | 34                                | No                           | 12                                                           |
|             | 32                                | No                           | 30                                                           |
|             | 32                                | Yes                          | 30                                                           |
|             | 32                                | Yes                          | 19                                                           |
|             | 32                                | No                           | 17                                                           |
|             | 33                                | No                           | 9                                                            |
|             | 29                                | Yes                          | 23                                                           |
| 2           | 27                                | Yes                          | 10                                                           |
|             | 32                                | No                           | 47                                                           |
|             | 30                                | No                           | 7                                                            |
|             | 31                                | Yes                          | 33                                                           |
|             | 31                                | No                           | 16                                                           |
|             | 31                                | Yes                          | 44                                                           |
|             | 32                                | No                           | 14                                                           |
|             | 33                                | Yes                          | 10                                                           |
|             | 28                                | Yes                          | 10                                                           |
|             | 34                                | Yes                          | 13                                                           |

In a similar setting, the lack of lived experience in the exact context means that more nuanced cultural understandings may well have been missed as a result. However, all results were discussed with the wider team (Kenya and the UK). The positionality of the researchers was discussed at each stage of data collection and analysis. Thought was given particularly to the potential influence of the interviewer in terms of their familiarity with some participants (HCPs) and potential deference of either the researcher or participants, depending on the relationship therein.

Role of funding source
The funder had no role in the collection, analysis or interpretation of data, writing of the report or decision to submit the paper for publication.

Patient and public involvement
Patients and the public were not involved in the design or conduct of this study. However, the views of parents and stakeholders involved in this study will help to shape future research in this area.

RESULTS
Participants
Focus groups: 19 mothers were invited and all agreed to participate in the FGD; three of which were accompanied by the infant’s father and two by other family members (mother-in-law and sister). All mothers had experience of their infant being on the newborn unit and 10 also had experience of the postnatal ward. Infants of the participants were born between 27 weeks and 34 weeks gestation and, on average had spent 20 days in hospital since birth. Participants’ characteristics are shown in table 2.

KII: 31 stakeholders were invited to participate and 20 KIIIs were conducted. Stakeholder characteristics are given in table 3.

THEMES
In total, 153 basic semantic codes emerged from the data, which were then synthesised into 27 organising codes. Three global themes emerged from the organising codes: (1) mothers’ physical and psychological needs, (2) system pillars and (3) KMC. The organising codes for each global theme are shown in figures 1–3.

The three themes were emergent from the process of analysing the organising themes into overarching categories, which were either more abstracted in terms of concepts (for instance, the wider issue of mothers’ biopsychosocial needs) or structures of care. An example of how the third global theme, KMC, emerged is given in table 4.

Global theme 1: mothers’ physical and psychological needs
This theme reflected the met and unmet needs of mothers, families and the wider community, while the baby was in hospital.

Mothers and fathers were generally positive about the support and communication from staff and their own communities, though there was also a recurrent theme of basic physical needs being unmet. This included a lack
of available food and drink, feeling unsafe while moving around the hospital at night and a scarcity of places to sleep.

‘the mother must feed well in order to produce milk. Like the mothers here, we have a schedule to feed the babies and then do kangaroo care for about an hour. Every two hours the routine is repeated. Most of the time the schedules coincide with meal times … . You go back to the ward and there’s no food!’ (Mother, FGD 2)
Impact of extended inpatient stays on the wider families were noticeably absent from the KIIs but referred to frequently in the FGD data.

‘My first child is twelve-year-old and is at home. I delivered preterm twins about a month ago. One died on the third day and I was called to see the body before they removed him. My child was informed I delivered twins but he did not get to see them. Children are not allowed in this unit. He keeps wondering when I will go back home. I worry a lot about my child.’ (Mother, FGD 2)

One of the most positive themes was the value placed on the mothers’ care (and in some cases, other family members) of the baby. The newborn unit is crowded and the staff to patient ratio is low, so training and valuing the mothers input is a pragmatic solution, but the concept of maternal love and the importance of the mother baby bond also added an extra emotional and spiritual dimension to this theme.

‘We feel included in everything to do with our baby care. We alert the nurse if baby seems uncomfortable. You get used to your baby. And if you have any question, you ask nurse or matron.’ (Mother, FGD 1)

The impact on and support of the wider community was seen as key. The mother’s absence from the home and the community costs (direct and indirect) was noted but families and staff also spoke of the importance of support and training from their communities.

‘We intervene at grassroots level. We provide guidelines and capacity building through training at community level.’ (Participant 2, KII)

Cultural aspects of the conceptualisation of preterm birth led some mothers to feel stigmatised, but where community and wider support was given, families felt the outcomes were better for all.

‘When I delivered this baby even my husband was anxious, let me say disappointed. He stated, ‘why did you deliver this one?’ This is ‘Mtoto wa kisirani.’ … (meaning an ill-fated baby).’ (Mother, FGD 1)

Global theme 2: system pillars
This theme refers to the intra-hospital and pan-Kenyan organisation of care for premature and LBW babies. Much of this data is taken from the KIIs though mothers and families did comment on the structures of care within their units.

Using the ‘Too Much Too Soon, Too Little Too Late (TLTL)’ model, we initially examined the data on resources allocated to the care of premature babies. Overall, the Kenyan context seemed to indicate that the latter (TLTL) was the most problematic in terms of both the incidence of preterm birth and the survival rate thereafter. Stakeholders discussed resource issues at length, particularly in regards to differences between rural and urban (and tertiary and primary) care settings.

‘If we have to reduce infant deaths we must ensure mothers are aware of danger signs. This can be addressed during ANC clinics. For example, if a mother notices spotting they should go for check-up.’ (Participant 7, KII)

Facilities were mentioned by almost all stakeholders, irrespective of role or years of experience. The crucial issue in preterm care seemed to be physical space, with nurseries being overcrowded and thus adequate monitoring and infection control being almost impossible to reliably achieve.

| Table 4 | An example of how the third global theme, KMC, emerged |
|-----------------|-----------------------------------------------------|
| **Basic codes** | **Organising themes** |
| Kangaroo care helps mum cope | Mothers being in control of care |
| KMC as a simple intervention | Valuing and training mothers |
| Low-tech solutions to lack of high-tech solutions | Conceptual and physical facilities |
| Simple interventions | Staff parent communication |
| KMC can be seen as a primitive practice | International agenda |
| Encouragement that KMC helps baby grow | Cultural beliefs |
| High-level strategy helped develop KMC | Essential newborn care |
| (including generational effects) | Impact on wider family and community |
| KMC=mother and baby bond | |
| KMC allows mum to always be with baby | |
| KMC keeps your baby warm | |
| KMC and feeding | |
| Better brains—ongoing development | |
| Importance of baby staying with mum | |
| KMC improves weight gain | |
| Role of KMC in infection reduction | |

KMC, Kangaroo Mother Care.
KMC units were identified as a valued and useful intervention in the FGDs and the KIIs alike. For mothers and families, being an integral part of the infant’s care on a KMC unit was seen as psychologically supportive. They felt more positive about the baby’s chances of survival, more comfortable balancing their own needs with the needs of their feeding baby and more involved in their wider care.

‘When a baby is weighed today, there is an increase from yesterday’s weight and tomorrow weight will be higher than today. I attribute this to kangaroo care. The mother is always with her baby. The baby grows fast.’ (Mother, FGD 1)

Furthermore, ‘baby wearing’ was seen as culturally acceptable and considered a normal way to care for any infant, normalising the practice and easing the transition from hospital to home.

‘In our traditional setting, we don’t like pushing our babies as they look in empty space [a pram]. We like direct contact with our babies. In this setting then Kangaroo mother care is commendable and embraced much more easily.’ (Participant 3, KII)

Participants also referred to the benefits of KMC in alleviating infrastructure and resource issues and the wider Government strategy for roll-out of KMC.

‘You can look at it from the infrastructure. Incubators are obviously inadequate for the number of babies needing them …, but KMC is skin to skin and need no regulation.’ (Participant 7, KII)

DISCUSSION
This study gives voice to mothers and families, HCPs, and wider stakeholders in Kenya. Its results empower them to be heard and understood such that any further plans to improve the care for preterm and LBW infants in this setting are built on their priorities. The emergent themes are discussed here in the context of the development of an EWS for preterm infants in LMICs, with the third global theme, ‘KMC’, considered an exemplar of an intervention which meets the needs of the two previous global themes. Public partnership and stakeholder engagement in research and quality improvement initiatives are of particular importance in low resource settings, since it encourages participation from previously marginalised populations. The results of this study were shared with a group of 78 stakeholders with a key interest in preterm birth.

Participants in the KIIs discussed the importance of the development and implementation of simple interventions and initiatives supported by the government, ensuring that such initiatives were aligned with national and global priorities for newborn health. If an EWS was developed for use in an LMIC, it would, therefore, be important to ensure ‘buy-in’ from a wide range of stakeholders, including the state. Consistent and standardised approaches to the provision of healthcare for newborn infants was considered important. Any effective interventions should be scaled up rapidly to all groups within countries, in line with the WHO’s goal to provide universal health coverage and to enable progress towards the Sustainable Development Goals by 2030. KII participants commented on lack of infant monitoring and poor documentation on the newborn unit. This is consistent with an observational study conducted by the same team showing record-keeping was poor with many infants having few vital signs recorded and a previous newborn study in Nairobi showing that vital signs charts were only completed for around a third of infants. These issues are not uncommon in low-resource settings. A qualitative study of health facility leaders in Ethiopia also found that human resource issues such as training and staffing levels are critical in caring properly for preterm infants.

Mothers, other family members and HCPs all placed importance on the mother’s involvement in their newborn infant’s care and, in particular, the communication...
between the HCP and the mother. The EWS provides a standardized method of monitoring infants, which could also provide more focused communication between the HCP and mother. It could serve as a visual aid to the mother, so she can easily see how her baby is doing; however, this would need to be done with care and sensitivity to avoid causing undue anxiety. Communication with parents would be an essential element to be included in the provision of training provided to HCPs.

The third global theme that emerged was KMC, an evidence-based intervention commonly practiced in this setting, which was considered an exemplar where the resources and issues of each group, and the tensions between them, are met in and answered by the KMC unit. From a staff and system perspective, KMC units alleviated some of the resource challenges in the Kenyan context. Fewer incubators and fewer interventions with feeding and infection control were necessary and participants felt that babies were usually discharged home earlier. Importantly, KMC is strongly supported by the government who are working with NGOs to roll-out this initiative more widely across the country. From a strategy perspective, KMC is an established priority and included in national guidance. The emergence of KMC as a strong theme demonstrated that any new intervention developed must be suitably adopted to support uninterrupted KMC.

The key principles of relational dialectics, contradictions, totality, process and praxis, whereby seemingly opposing needs, views and ontological perspectives, are processed and brought to agreement and then practically implemented are met in this study. If, as the mothers do so much of the ‘work’ of nursing a sick baby, one sees them as colleagues as well as patients of the HCPs, understanding the blending of roles and relationships inherent in this may well open spaces of both better communication and a better mutual meeting of needs and responsibilities. The principal exemplar of this is in the provision of KMC units, which served both mothers’ physical and psychological needs, reduced the burden of care and interventionist medicine on the healthcare system both on a unit and hospital level and allowed more discussion and co-production of care between mothers and HCPs on the unit. In this way, the physical existence of the KMC unit, as opposed to the practice of KMC itself, becomes vital for enabling this relational collaboration to exist in the ‘openness’ it engenders. The enthusiasm and praise for the KMC unit is seen clearly in the data from the HCPs and other stakeholders. If feasibility is demonstrated, then a study to investigate the possible clinical benefits would be warranted.

This is the first study to report views on the provision of newborn care in the context of the development of an EWS for preterm and LBW infants in LMICs. A limitation of the study is that mothers and families were recruited from a single national tertiary referral hospital and, therefore, may not represent wider views. However, many HCPs who were interviewed, while based at KNH, also had clinical experience outside of this single hospital, in addition to the wider expertise of two representatives at a national level.

In summary, while, at least theoretically, an EWS could potentially reduce neonatal mortality and serious morbidities, this is, as yet, unknown. If these potential benefits of an EWS were to be demonstrated in future studies, many of the issues identified in this study, including lack of space and overcrowding on newborn units, lack of trained neonatal staff and family involvement and communication, could be met. Results from this study may also help to identify areas for improvement in the provision of essential newborn care in a low-resource setting. For example, developing strategies to improve
communication between mothers and HCPs and ways in which interventions, shown to be effective, can be rolled out rapidly across different levels of healthcare.

CONCLUSIONS
Ensuring the needs of parents, HCPs and policy-makers in the development of any intervention is important. A range of issues emerged that will be important to consider in the development and potential implementation of an EWS and lessons can be learnt from the emergent theme of KMC. KMC is already widely accepted as a gold standard intervention to increase newborn survival, especially in the preterm and LBW populations. This paper adds the valuable perspective that KMC units may also help to alleviate system pressures, both within units and in a national health provision and is invaluable to mothers and families in terms of their physical and psychological well-being.

RESEARCH IN CONTEXT
Evidence before this study
In the context of the development of an EWS, we conducted a literature search using PubMed in June 2018 for studies on neonatal EWSs, using the search terms ‘early warning score’ and ‘neonatal early warning score’. We identified only a small handful of publications relating to neonatal EWS and one non-systematic review of available EWS; however, none were from LMICs. We found no studies which included the views of parents in the development of an EWS.

Added value of this study
This is the first study to importantly include the views and opinions of parents, family members, HCPs, policy-makers and non-government representatives in the context of the provision of newborn care and development of an EWS. A range of issues, important to parents/family members and stakeholders should be considered if an EWS were to be implemented, including: ensuring a consistent and standardised approach to newborn care, communication between parents and HCPs, and parental involvement in the newborn’s care. KMC was viewed positively by all participants and should be considered as an exemplar in the development of other initiatives to improve newborn care.

Implications of all the available evidence
The perspectives of a wide range of stakeholders, including parents and wider family members, should be considered in the development of an intervention designed to improved newborn care. In the context of an LMIC setting, where KMC is a commonplace, any new intervention implemented should be considered alongside KMC. Further research is required to test the feasibility and acceptability of an EWS in hospitals in LMICs.

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