

1 **Parents, healthcare professionals and other stakeholders' experiences of caring for**
2 **babies born too soon in a low resource setting: A qualitative study of essential newborn**
3 **care for preterm infants in Kenya**

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38 **Abstract**

39

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

45

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

47

48 **Participants:** Nineteen mothers and family members participated in focus group discussions
49 and twenty key-informant interviews with professionals (healthcare professionals and policy-
50 makers) were conducted. Focus group participants were identified via postnatal wards, the
51 Newborn Unit and Kangaroo Mother Care Unit. Convenience and purposive sampling was
52 used to identify professionals.

53

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

56

57 **Results:** From 27 themes, three global themes emerged from the data; mothers' physical and
58 psychological needs, system pillars and kangaroo mother care.

59

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

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75 **Strengths and limitations of this study**

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- 77 • This is the first report of parents', healthcare professionals and wider stakeholders' views
78 of essential newborn care in the context of development of an early warning score in
79 LMICs
- 80 • A wide-range of parents were recruited to ensure a wide range of opinions were elicited
- 81 • Parents were recruited from a single, large national referral hospital. Though some
82 healthcare professionals had previous experience outside of this hospital.

83

84 **BACKGROUND**

85

86 Globally, fifteen million infants are born prematurely (before 37 weeks gestation); the leading
87 cause of neonatal mortality and morbidity (1). More than 60% of all preterm births occur in
88 Sub-Saharan Africa (2) and over a third of all neonatal deaths are due to preterm birth
89 complications (3). In Kenya the preterm birth rate is 8.6 per 1000 live births (1) and neonatal
90 mortality rate (NMR) is 20.9 deaths per 1000 live births (4), currently double the global goal of
91 a NMR of <10 deaths per 1000 live births by 2035 (3). In this setting, preterm infants should
92 be managed in accordance with national and international evidence-based guidance for
93 essential newborn care (5, 6), including strategies for thermoregulation, resuscitation, feeding,
94 Kangaroo mother care (KMC) and infection management. More than 80% of all preterm births
95 occur between 32 and 37 weeks gestation and most babies could survive with the provision
96 of essential newborn care (2).

97

98 This study is part of a wider programme of work developing an early warning score (EWS) for
99 use in preterm and low birth weight (LBW) infants in low and middle income countries (LMICs).
100 An early warning score is used by healthcare professionals (HCPs) to document vital signs in
101 a standardised way. Whilst they are used for adults in a variety of clinical areas (7-9), there
102 are few EWSs for newborn infants and none developed or used in LMICs (10). An EWS
103 identifies vital signs that require closer monitoring and escalation of care which could result in
104 a reduction in mortality and other serious morbidities. Before adopting an intervention
105 developed for a high-resource setting in a LMIC, it is important to explore the current provision
106 of care for the LMIC setting and to ensure the opinions of parents and HCPs are considered.

107

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

112 **METHODS**

113

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

129

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

141

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

149 *Analysis:* Thematic Network Analysis (TNA) was used (12). TNA is a way of coding, organising
 150 and identifying emergent themes from the data in a systematic way and improves the internal
 151 validity of the results by employing systematic and repeatable methods. Global themes
 152 emerged from the grouping of organising themes into more abstracted and/or structural
 153 categories and was done by both analysts in collaboration. The philosophical underpinnings
 154 of this study are relational dialectic theory (13) as a pragmatic but nuanced way of identifying
 155 effective clinical interventions which would work within the human context of neonatal care in
 156 a less resourced setting where much of the burden of basic nursing care rests on the mothers.
 157 Understanding what is fairly pragmatic data through this epistemological lens has allowed the
 158 researchers to elucidate the spaces where communication and relationship between mothers
 159 and HCPs is either enabled or prevented. This understanding also removes the concept of
 160 “blame” of failures in care from either side, preferring a more salutogenic approach to
 161 designing protocols and practices which support collaborative working (14). Data from FGDs
 162 and KIIIs were analysed together in order to consider consistent themes and gaps between
 163 the two. Table 1 shows an example of a coding tree. Initial coding was undertaken
 164 independently by EJM and PP before being moderated by a third reviewer (MO). Analyses
 165 were conducted using NVivo version 12 (QSR international©). Initial codes were organised
 166 into organising and global themes in accordance with the stages of TNA.

167
 168 The study is strengthened by the fact data collection and analyses were performed by teams
 169 in Kenya and the UK, since concepts are developed from a more etic perspective. However,
 170 although one of the senior academic analysts has substantial clinical experience in a similar
 171 setting, the lack of lived experience in the exact context means that more nuanced cultural
 172 understandings may well have been missed as a result. However, all results were discussed
 173 with the wider team (Kenya and UK). The positionality of the researchers was discussed at
 174 each stage of data collection and analysis. Thought was given particularly to the potential
 175 influence of the interviewer in terms of their familiarity with some participants (HCPs) and
 176 potential deference of either the researcher or participants, depending on the relationship
 177 therein.

178

179 **Table 1: Example of the coding tree**

180

Global theme	Organising theme	Basic semantic code
Mother’s physical and psychological needs	Impact on wider family and community	<ul style="list-style-type: none"> • Impact of children for mother not being at home • Long in-patient stay • Involvement of other siblings • Emotional impact of preterm death on siblings

		<ul style="list-style-type: none"> • 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're not a burden" family member perspective
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182 Role of funding source

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

185

186 Patient and public involvement

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

190

191

192 RESULTS

193

194 *Participants:*

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

201

202

203 **Table 2: Focus Group participant characteristics**

Focus group	Gestational age 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

204

205

206 *Key informant interviews:* 31 stakeholders were invited to participate and twenty KIIs were
 207 conducted. Stakeholder characteristics are given in Table 3.

208

209 **Table 3: Key informant interviews participant characteristics**

Participant number	Stakeholder type	Years of professional experience
1	Policy-maker	9
2	NGO representative	28
3	Obstetrician	43
4	Paediatrician	50
5	Paediatrician	35
6	Obstetrician	12
7	NGO representative	13
8	Obstetrician	15
9	Nurse	7
10	Nurse	23
11	Neonatal Nurse	20
12	Neonatal Nurse	27
13	Neonatal Nurse	4
14	Nurse	20
15	Neonatal nurse	20
16	Neonatal nurse	9
17	Nurse	4
18	Nurse	3
19	Nurse	25
20	Nurse	14

210

211

212 *Themes*

213 In total 153 basic semantic codes emerged from the data which were then synthesised into
 214 27 organising codes. Three global themes emerged from the organising codes; 1) mothers'
 215 physical and psychological needs, 2) system pillars, 3) Kangaroo Mother Care (KMC). The
 216 organising codes for each global theme are shown in Figures 1, 2 and 3.

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 218
 219
 220
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 223

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, Kangaroo Mother Care, emerged is given in Table 4.

Table 4: An example of how the third global theme, Kangaroo Mother Care, 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	Conceptual and physical facilities
Simple interventions	Staff parent communication
KMC can be seen as primitive practice	International agenda
Encouragement that KMC helps baby grow	Cultural beliefs
High level strategy helped develop KMC (including generational effects)	Essential newborn care 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	

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Global Theme 1: Mothers' physical and psychological needs

This theme reflected the met and unmet needs of mothers, families and the wider community, whilst 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 whilst moving around the hospital at night and a scarcity of places to sleep.

236 *“the mother must feed well in order to produce milk. Like the mothers here, we have a*
237 *schedule to feed the babies and then do kangaroo care for about an hour. Every two*
238 *hours the routine is repeated. Most of the time the schedules coincide with meal*
239 *times.... You go back to the ward and there's no food!” (mother, FGD 2)*

240

241 Impact of extended inpatient stays on the wider families were noticeably absent from the KIIIs
242 but referred to frequently in the FGD data.

243

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

249

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

255

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

259

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

263

264 *“We intervene at grassroots level. We provide guidelines and capacity building through*
265 *training at community level.” (Participant 2, KII)*

266

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

270

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

274

275

276 **INSERT Figure 1 HERE**

277

278 Global Theme 2: System Pillars

279

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

283

284 Using the “Too Much Too Soon (TMTS, Too Little Too Late (TLTL)” model (15), we initially
285 examined the data on resources allocated to the care of premature babies. Overall, the
286 Kenyan context seemed to indicate that the latter (TLTL) was the most problematic in terms
287 of both the incidence of preterm birth and the survival rate thereafter. Stakeholders discussed
288 resource issues at length, particularly in regards to differences between rural and urban (and
289 tertiary and primary) care settings.

290

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

294

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

299

300 *“I mean in the cots in unit X. Some babies have long legs, so they have to be folded in*
301 *order to share the limited space with others. The baby cannot sleep freely as they are*
302 *squeezed.” (Mother, FGD 2)*

303

304 Stakeholders discussed recent technological and care protocol advances in neonatal care and
305 the adoption across Kenya. Newer equipment and medicines seemed to be mostly available
306 in the urban units but adaptations in rural areas were also discussed.

307

308 *“I would like this simple technology to continue, particularly in facilities that are not well*
309 *equipped. Then put a sufuria [cooking pot] of boiling water at a corner of the room. The*
310 *humidity acts like an incubator” (Participant 3, KII)*

311

312 More strategic stakeholders discussed that national and international training programmes
313 were constantly rolled out, and whilst staff retention was a problem, upskilling of existing staff
314 was felt to be on an upward trajectory.

315

316 *“We developed a curriculum for training for use. Right now our staff is in [a region]*
317 *developing training curriculum. We have trained over 9000 health care staff in the past*
318 *three to four years.” (Participant 1, KII)*

319

320 Finally, the implementation of new and existing protocols and the roll-out of new technology
321 and training, in line with key global priorities, was discussed by all stakeholders.

322

323 *“As we evolved now we have ventilators and at [the hospital] we have even mechanical*
324 *ventilators. We also have CPAP [continuous positive airway pressure] machines”.*
325 *(Participant 4, KII)*

326

327 **INSERT FIGURE 2 HERE**

328

329 Global Theme 3: Kangaroo Mother Care (KMC)

330

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

336

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

340

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

343

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

347

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

350

351 *“You can look at it from the infrastructure. Incubators are obviously inadequate for the*
352 *number of babies needing them...., but KMC is skin to skin and need no regulation”*
353 *(Participant 7, KII)*

354

355

356 **INSERT FIGURE 3 HERE**

357

358

359 **DISCUSSION**

360

361 This study gives voice to mothers and families, healthcare professionals, and wider
362 stakeholders in Kenya. Its results empower them to be heard and understood such that any
363 further plans to improve the care for preterm and LBW infants in this setting are built on their
364 priorities. The emergent themes are discussed here in the context of the development of an
365 EWS for preterm infants in LMICs, with the third global theme, “Kangaroo Mother Care”,
366 considered an exemplar of an intervention which meets the needs’ of the two previous global
367 themes. Public partnership and stakeholder engagement in research and quality improvement
368 initiatives is of particular importance in low resource settings, since it encourages participation
369 from previously marginalized populations (16). The results of this study were shared with a
370 group of 78 stakeholders with a key interest in preterm birth.

371

372 Participants in the KIIs discussed the importance of the development and implementation of
373 simple interventions and initiatives supported by the government, ensuring that such initiatives
374 were aligned with national and global priorities for newborn health. If an EWS was developed
375 for use in a LMIC, it would therefore be important to ensure “buy-in” from a wide range of
376 stakeholders, including the state. Consistent and standardised approaches to the provision of
377 healthcare for newborn infants was considered important. Any effective interventions should
378 be scaled up rapidly to all groups within countries, in line with the World Health Organisation’s
379 goal to provide universal health coverage and to enable progress towards the Sustainable
380 Development Goals by 2030 (17). KII participants commented upon lack of infant monitoring

381 and poor documentation on the newborn unit. This is consistent with an observational study
382 conducted by the same team showing record-keeping was poor with many infants' having few
383 vital signs recorded (18) and a previous newborn study in Nairobi showing that vital signs
384 charts were only completed for around a third of infants (19). These issues are not uncommon
385 in low-resource settings. A qualitative study of health facility leaders in Ethiopia also found
386 that human resource issues such as training and staffing levels are critical in caring properly
387 for preterm infants (20).

388

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

397

398 The third global theme that emerged was Kangaroo Mother Care, an evidence-based
399 intervention commonly practiced in this setting, which was considered an exemplar where the
400 resources and issues of each group, and the tensions between them, are met in and answered
401 by the KMC unit. From a staff and system perspective, KMC units alleviated some of the
402 resource challenges in the Kenyan context. Fewer incubators and fewer interventions with
403 feeding and infection control were necessary and participants felt babies were usually
404 discharged home earlier. Importantly, KMC is strongly supported by the government who are
405 working with NGOs to roll-out this initiative more widely across the country. From a strategy
406 perspective, KMC is an established priority and included in national guidance (21). The
407 emergence of KMC as a strong theme demonstrated that any new intervention developed
408 must be suitably adopted to support uninterrupted KMC.

409

410 The key principles of relational dialectics, contradictions, totality, process and praxis, whereby
411 seemingly opposing needs, views and ontological perspectives are processed and brought to
412 agreement and then practically implemented (13) are met in this study. If, as the mothers do
413 so much of the "work" of nursing a sick baby, one sees them as colleagues as well as patients
414 of the HCPs, understanding the blending of roles and relationships inherent in this may well
415 open spaces of both better communication and a better mutual meeting of needs and
416 responsibilities. The principal exemplar of this is in the provision of KMC Units which served
417 both mothers physical and psychological needs, reduced the burden of care and

418 interventionist medicine on the health care system both on a unit and hospital level and
419 allowed more discussion and co-production of care between mothers and HCPs on the Unit.
420 In this way, the physical existence of the KMC Unit, as opposed to the practice of KMC itself,
421 becomes vital for enabling this relational collaboration to exist in the “openness” it engenders
422 (14). The enthusiasm and praise for the KMC Unit is seen clearly in the data from all
423 stakeholders and this can be seen as a practical and as an emotive value placed on that which
424 makes the participants feel at ease and feel successful in their shared goals of the babies’
425 care (13).

426

427 KMC Units are highly valued, from a mother’s perspective, ensuring use (22), they meet
428 national and international guidelines for the care of premature and LBW babies (23) and they
429 utilise existing resources – beds, nurses and mothers (24). However, roll-out of facility-based
430 KMC, at scale, is not without challenges. A systematic review of implementation of KMC from
431 a health systems perspective (86 studies) identified a range of barriers and enablers, including
432 buy-in from staff, availability of training and resources and time to train and provide KMC (25).
433 Research focussing on the implementation of KMC is indeed in the top 10 research priorities
434 for improving newborn health and birth outcomes by 2025 (26). This is in contrast to the
435 possible difficulties in implementing an intervention on newborn units which relies heavily on
436 having adequate resources in place and, in particular, the availability of senior clinicians to
437 see acutely unwell infants and expensive technology to support thermoregulation, infection
438 control and infant feeding. This issue was discussed in our meeting of 78 stakeholders in
439 Kenya, all of whom are involved in the care or provision of care for newborn infants. Whilst the
440 majority of stakeholders were positive about the concept of EWS, human resource issues
441 were seen as key barrier that would need to be overcome for successful implementation (18).
442 In addition, there is a strong evidence base for KMC. Studies have shown it improves
443 outcomes for neonates, especially preterm and LBW babies (27, 28), which in turn reduces
444 the financial and strategic burden on paediatric services as a whole in this context. Therefore,
445 mothers, HCPs and policy-makers can clearly see value and benefit in its provision and
446 implementation. For an EWS to be implemented widely across LMICs, in addition to the
447 potential benefits of standardised record-keeping and visual simplicity of such a chart,
448 evidence would need to be generated in its ability to reduce neonatal mortality and morbidities.
449 Further work has been funded to examine the feasibility and acceptability of implementing the
450 EWS on several newborn units in Kenya and the key themes drawn from this study will ensure
451 the next step of this programme of work considers the views of mothers, families, HCPs and
452 other stakeholders. If feasibility is demonstrated, then a study to investigate the possible
453 clinical benefits would be warranted.

454

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

461

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

471

472 **CONCLUSIONS**

473

474 Ensuring the needs of parents, HCPs and policy-makers in the development of any
475 intervention is important. A range of issues emerged that will be important to consider in the
476 development and potential implementation of an EWS and lessons can be learnt from the
477 emergent theme of KMC. KMC is already widely accepted as a gold standard intervention to
478 increase newborn survival, especially in the preterm and low birth weight populations (28).
479 This paper adds the valuable perspective that KMC units may also help to alleviate system
480 pressures, both within units and in a national health provision and is invaluable to mothers
481 and families in terms of their physical and psychological wellbeing.

482

483 **Acknowledgements**

484 We thank all participants and our funders.

485

486 **Research in context**

487

488 ***Evidence before this study***

489 In the context of the development of an early warning score (EWS), we conducted a literature
490 search using PubMed in June 2018 for studies on neonatal EWSs, using the search terms
491 “early warning score” and “neonatal early warning score”. We identified only a small handful

492 of publications relating to neonatal EWS and one non-systematic review of available EWS,
493 however none were from LMICs. We found no studies which included the views of parents in
494 the development of an EWS.

495 ***Added value of this study***

496 This is the first study to importantly include the views and opinions of parents, family members,
497 healthcare professionals, policy-makers and non-government representatives in the context
498 of the provision of newborn care and development of an EWS. A range of issues, important to
499 parents/family members and stakeholders should be considered if an EWS were to be
500 implemented, including: ensuring a consistent and standardised approach to newborn care,
501 communication between parents and healthcare professionals, parental involvement in the
502 newborn's care. Kangaroo Mother Care was viewed positively by all participants and should
503 be considered as an exemplar in the development of other initiatives to improve newborn care.

504 ***Implications of all the available evidence***

505 The perspectives of a wide range of stakeholders, including parents and wider family
506 members, should be considered in the development of an intervention designed to improved
507 newborn care. In the context of a LMIC setting, where Kangaroo Mother Care (KMC) is
508 commonplace, any new intervention implemented should be considered alongside KMC.
509 Further research is required to test the feasibility and acceptability of an EWS in hospitals in
510 LMICs.

511

512 **Contributorship statement**

513 EJM was the Principal Investigator; conceived the idea, data analysis and wrote the first draft
514 of the manuscript. PP analysed data and had a major role in writing the manuscript. SO was
515 the clinical lead for the study. MO moderated data analysis. ZQ was the lead at KNH,
516 supported by JO who provided study coordination. Qualitative data collection was undertaken
517 by VK. FW, AO and GG all provided clinical input at KNH. JD provided mentorship to the team.
518 All authors contributed to interpretation of the data, draft manuscripts and approved the final
519 version of the manuscript prior to submission.

520

521 **Competing interests**

522 SO declares grants from NIHR. No other conflicts of interest are declared by the authors.

523

524 **Funding**

525 University of Nottingham Global Challenges Research Fund (GCRF) (Ref: RIS 630122).

526

527 **Data sharing statement**

528 Data are available upon reasonable request to the corresponding author.

529 **Ethics statement**

530 Ethical approval was granted by the joint Kenyatta National Hospital-University of Nairobi
531 Ethics Research Committee (ref P772/11/2018) and the Faculty of Medicine and Health
532 Sciences Research Ethics Committee at the University of Nottingham (ref 161-1812).

533

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605 **Figure 1: Global theme 1: mothers’ physical and psychological needs**

606 **Figure 2: Global theme 2: system pillars**

607 **Figure 3: Global theme 3: Kangaroo Mother Care**

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