

DR. ROSA MARIA MENDIZABAL-ESPINOSA (Orcid ID : 0000-0003-3977-5471)

MRS. INGA MARIAN WARREN (Orcid ID : 0000-0003-1266-8684)

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Non evidence-based beliefs increase inequalities in the provision of infant and family centred neonatal care

Rosa Maria Mendizabal-Espinosa¹ and Inga Warren²,

¹Institute of Education, University College London, UK.

²University College London Hospital, UK.

Short title: Barriers to infant and family centred neonatal care

Corresponding author:

Dr. Rosa Maria Mendizabal-Espinosa.

Department of Social Science

UCL Institute of Education

18 Woburn Square

London, UK

WC1H 0NR

Email: r.mendizabal@ucl.ac.uk

Abstract

Aim: To identify barriers that might explain why healthcare staff struggle to implement infant and family centred developmental care programmes in two neonatal intensive care units in Mexico.

Methods: Ethnographic fieldwork over the course of ten months examined interactions among healthcare professionals, parents and babies in two Mexican publicly funded hospitals. Data are

drawn from interviews with 29 parents and 34 healthcare professionals and participant

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observations in the hospitals' neonatal units. **Results:** Healthcare professionals believed they acted in babies' best interests by excluding parents from the neonatal unit. Professional frustration with working conditions seemed to be increased by the belief that parents were ignorant and unhygienic. Parents were perceived as a source of infection; in contrast, healthcare professionals failed to see themselves as a possible source of cross-contamination. **Conclusions:** Beliefs and biases increase health inequalities when evidenced-based measures to prevent cross-infection and potentially life-saving programmes, such as kangaroo mother care and breastfeeding, are not implemented. It is imperative to develop context-appropriate education and practice guidelines to implement basic programmes.

Key notes:

- Healthcare professionals in these public hospitals in Mexico struggled to see how they could implement infant and family centred developmental care.
- Inequality in healthcare provision limits opportunities for many parents to engage in potentially life-saving and developmentally significant interventions.
- Identified underlying cultural, political and economic elements might inform others around the world with similar struggles.

Whilst infant and family centred developmental care (IFCDC) is a recognised evidence-based approach in neonatal units (1), many healthcare professionals around the world still struggle to implement its principles (2) in practice. The resulting inequality in healthcare limits opportunities for many parents to engage in potentially life-saving and developmentally significant interventions, such as breastfeeding and kangaroo mother care (KMC), with their vulnerable infants. Taking Mexico as a case study, this paper explores some barriers in the inclusion of parents to care for their babies in the neonatal unit.

Background

IFCDC has the potential to radically transform the experience of neonatal care but progress has been slow (3). The negative consequences for young children separated from their parents in hospital were vividly illustrated by the pioneering work of James and Joyce Robertson in the 1950s, influencing the UK Ministry of Health to report on the “Welfare of Sick Children in Hospital” (4), known as the Platt Report. The recommendation in this report that children in hospital should have unfettered access to their parents met considerable resistance and it was more than 25 years before the majority of paediatric units in the UK made provision for 24-hour parental access. More than 20 years ago campaigners in the UK started calling for parents to be allowed into neonatal units to share in the care of their children (5) but this continues to be a challenge in spite of extensive evidence supporting parental engagement with infant care (6–8). Family centred practices vary both between and within countries (9,10). Even where services are well resourced and the principles of family centred care are widely accepted there are gaps between policies and implementation with poor understanding of how to translate research-based recommendations into practice (11).

Around the world there is much inequality in family centred care. At one end of the spectrum is the example of “Couplet Care” initiated in Sweden, a country that provides relatively generous parental support for childcare, which allows the mother and her newborn baby to be cared for on the same unit 24 hours a day (12), thus combining high tech and family centred care. Information about family centred care in low- and middle-income countries is scarce although the impact of KMC introduced in Colombia in 1978 is well known. In spite of robust supporting evidence for this low-cost innovation in resource-limited settings (12) it has been slow to spread; Abadía-Barrero (13) suggests that the conflict between politics of care and politics of profit play a part in making it difficult for health professionals to accept that a mother’s loving, close contact might be superior to technical advances and scientific training.

Reducing inequalities in neonatal health care is a goal of the European Standards of Care for Newborn Health (1), which includes evidence-based recommendations for IFCDC. These propose continuous 24-hour access for families, early contact between parent and child, and skin-to-skin

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contact. Achieving these standards will require an understanding of the little known political, economic and cultural influences on neonatal care and the barriers to change they create.

This paper reports results that emerged from a larger ethnographic study exploring the challenges in implementing family centred care in two public Mexican Hospitals.

Research methods

Ethnographic field work (June 2013 to April 2014) examined interactions among healthcare professionals, parents and babies in the neonatal intensive care units (NICU) of two Mexican public hospitals: Juan Dautt Hospital (JDH) a secondary level unit on the edge of Mexico City with eight NICU cots. Mercedes Duron Hospital (MDH), a tertiary level unit with 17 NICU beds, is a maternity unit serving rural and urban areas in the east-central region of the Mexican Republic. Being a referral unit, the obstetric demand is large and complex. Prematurity is the most common reason for admission to both NICUs.

Ethics approval was obtained from the (former) Faculty of Children & Learning in the Institute of Education and from the ethics committee in both hospitals. All participants received information about the project in advance. NICU staff were informed about observations in the unit through flyers and posters. Consent was obtained from all participants either to be interviewed or for their baby to be observed, and all of them received a copy of their signed consent form. All names, including those of hospitals, have been changed.

Data

Interviews with 29 parents (21 mothers, and 8 fathers) and 34 healthcare professionals (including neonatologists, neonatal nurses, social workers, psychologists, a dietician and a manager) focused on their experiences in the NICU and their perception about how parents could contribute to babies' care. Eighteen families were available for follow up interviews and observations Appendix 1 shows interview guides.

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Participant observations in the NICU concentrated on interactions between staff, parents and babies. Twenty-nine babies were observed (with parents' permission) during different episodes of care either with staff or parents (table 1 shows characteristics of babies, appendix 2 summarises observation guide). Notes from the researcher's diary also included observations from monthly meetings of chiefs of departments and doctors' meetings, teaching sessions for mothers in the lactation room, and other continuing education courses for doctors and nurses. Data included mapping of people's movements around the NICUs and layout of units (square footage of baby's bed area and associated parent space).

Qualitative data analysis consisted of reading and re-reading transcripts and field notes, generating initial codes, searching for patterns to make themes and subthemes (14) and considering how different sources of data illuminated or contradicted one another.

Table 1. Characteristics of babies

Results

The risk of infection from the healthcare professionals' perspective:

Most families in this study came from deprived socio-economic backgrounds; more than half (18 families) accessed neonatal intensive care services through *Seguro Popular* (subsidised health insurance for the most disadvantaged). For 12 families the commute to hospital took longer than an hour. Five women, whose commute took between 90 minutes and five hours, had free accommodation at the hospital (MDH) but meals were not included. Parents in MDH were allowed to 'visit' their baby for half an hour in the morning and half an hour in the afternoon. In JDH only one parent, either the mother or father, was allowed to come into the NICU for an hour in the afternoon.

Healthcare professionals in both hospitals described frustration and exhaustion. Doctors felt there was very little financial recognition of their long working hours; they were stretched due to

insufficient staffing. Nurses, mostly women, struggled to have their voice heard and to be recognised as more than carers within a very hierarchical system. Doctors and nurses constantly expressed a concern that parents were judgemental and demanding about how their babies were treated, and therefore they did not like to be observed while performing procedures or routine care. Some of them also feared that parents who were unable to understand basic scientific information might need extra support if allowed more time in the NICU:

Parents must be well informed and need authentic support from medical staff; however our population lacks hygiene culture and commitment (Doctor).

Staff thought that babies benefited from parents being with them and from skin-to-skin care yet class was a constant concern:

Parents in the Mexican Republic, as well as the socioeconomic status our population belongs to and their low levels of study make it difficult to inform and help them conduct themselves carefully in the NICU, which evidently increases the risk of infection (Nurse).

Longstanding beliefs that outside service users bring disease and infection into the unit underlie reasons for strategies that restricted parental access to their babies.

Risk of infection from the parents' perspective:

Similar to professionals, mothers and fathers talked about keeping good hygiene to prevent infection:

The most important thing, as the doctor says, is hygiene and when [my son] is very delicate not to touch him, or not to talk to him and try not to make it worse by moving him. (Father)

With his comment, Gerardo also alluded to the perceived dangers that non-medically trained people posed in the unit. Parents became very frustrated when they felt their babies were exposed to unnecessary risks:

I don't like when the psychologist comes into the unit because she caresses all the babies without washing her hands (Mother)

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Many parents were able to identify inconsistencies and contradictions in infection control practices, which greatly worried them, but felt unable to contest them.

Infection control and the hierarchy of cleanliness:

Mapping of people's movements in the unit and field notes revealed that healthcare professionals failed to see themselves as a possible source of cross-contamination. Gowns, masks and hats were used not only to prevent cross-infection but also (and maybe more importantly) to differentiate doctors (as scientific, high ranked professionals), nurses (as technical workers) and parents as (lowly) service users.

Figure 1 shows the path of a mother 'visiting' her baby for about half an hour. She washed her hands before entering the unit and spread antiseptic gel on her hands as she came into the unit. As required for all parents she wore a gown, a hat and a mask.

Figure 1: Path that a mother followed when coming to see baby in cot 3

Figure 2 shows movements of three healthcare professionals in the same unit: a nurse, a consultant and a physician. Records also show every time they washed their hands and every time they touched either a baby or an object within the babies' immediate environment (such as monitor or clinical chart). This episode of care lasted for one hour approximately. Hand-hygiene measures were followed poorly. Similar to parents, the nurse wore a hat and a mask within the unit. Doctors were only required to wear them during detailed clinical procedures.

Figure 2: Path followed by nurse and two doctors when caring for babies in the NICU

Figure 3 shows the path of a Catholic priest performing the ritual called *Anointing of the Sick* in the same NICU. He approached each bed and anointed oil on every baby's forehead. The priest was not required to wash his hands before coming into the unit, nor did he wash his hands before touching babies and he did not wear a gown, a hat or a mask.

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Figure 3: Priest's path when anointing oil on babies

The fact that religious stamps and religious ceramic figurines were allowed inside the units (contradicting sanitary measures) was telling. In a mostly Catholic country, having the priest performing a ritual might be perceived as an added layer of protection, one that clinicians working in these ill-funded institutions could not guarantee.

Mr. Diaz, a senior manager, recognised that lack of resources posed a threat to maintaining high standards in the management of the hospital. His frustration translated into what he saw as the inevitable fate of babies in the unit:

...we have a demand [of service] that exceeds the supply in a relation of three to one [so] we have two [options], we either infect them or they die...

He also compared standards in public and private hospitals:

There are many doctors from here who also work in (he names two well-known private hospitals). If you see them [working] here I don't need to tell you about it, you have seen them in action. Let's go to (one of the private hospitals) [...] and see if he [sic, the doctor] washes his hands or how much his patients are exposed [to infection] and you will find a big discrepancy. In there he follows the guidelines [...] because the patient pays [...] it is a client [...] and he can be sued... and he can lose his licence, but not in here [...] I don't know how to say it, it is...it is unpunished. (Manager)

Discussion

Shortages of staff and lack of leadership are key issues in delivering IFCDC. Healthcare professionals in this study believed they acted in babies' best interests by excluding parents and it was difficult for them to imagine an alternative to the type of care they provided, even when they knew it was deficient. Despite their hard work and ambitions to save life, they were frustrated not only by the scarce resources at all levels and high demand on the service, but also lack of clear policies and direction that could support change without which they were unable to implement even basic, low resource and potentially life-saving programmes such as KMC and breastfeeding.

Healthcare professionals in this study and policy makers generally recognise the potential benefits of KMC and breastfeeding. The Mexican Government's General Health Advice Committee (Consejo de Salubridad General) regards patient and family centred care as a pillar of good

practice (15,16). An evaluation of clinical benefits and cost-effectiveness of NICU care in Mexico concluded '[NICU care] offers exceptional value for money even in the youngest GA group' because of the many practices in the NICU that have proved to be successful such as '...kangaroo care, early initiation of breast milk feeding, and infection control measures that include family members as stakeholders' (17). Yet, the lack of protocols and guidelines in these two hospitals prevented the implementation of these programmes.

Shortages of staff in public hospitals leads to increased staff empowerment at the expense of parent engagement. Nurses in this study, as in others (18,19), acted as gate-keepers and decided when parents could have contact with their babies. They did not feel that they had time to empower parents and thought it would be risky to do so. Breast-milk extraction seemed to be more valued than breastfeeding, resulting in little support for mothers to initiate and maintain breastfeeding even when the benefits of the latter (20) were widely known by healthcare professionals and mothers.

Concerns about being observed by parents made staff feel vulnerable. In the era of mobile phones and social media this is indeed a risk that would reinforce reluctance to allow parents to be present. It seems difficult to ask healthcare professionals to be supportive, understanding and caring of parents when they feel unsupported themselves, with lack of recognition for the sacrifices they make by working long hours with poor resources. Management style in such hierarchical organisational structures may discourage the initiatives required for quality improvement and stressed staff might find it more difficult to cope with change (21).

Deprived socio-economic background creates a double burden on families. Professional frustration with working conditions seemed to be increased by the belief that parents were ignorant and unhygienic, ultimately unable to care for the babies the staff desperately tried to save. Deep beliefs about the hierarchy of cleanliness in relation to professional status seem to be widely shared in public and professional networks, and might be partly responsible for resistance to change, prejudices of social class, ethnicity and gender prevent doctors, nurses and parents from working together and increase health inequalities when evidenced-based measures to prevent

cross-infection (22) are not implemented. The divide between public and private healthcare provision seems to exacerbate preconceptions about social class.

Political forces may play a part in the way infants and families are cared for. Similar problems of restricted parental contact and concerns about infection control are common in other settings. For example, in post-communist countries old practices of separating infants from their mother on obstetric wards to prevent infection (23) appear to have carried over into many modern neonatal services. Mothers are expected to be resident in the hospital, often in shared dormitories, in order to provide breast milk but may only be permitted short visits to the neonatal unit to view their baby. As in the Mexican case, in these settings the belief that parents are an infection risk, is cited as a reason for parents being expected to wear more protective clothing (shoe covers, hair covers, gowns, masks) than staff. The ideology behind these practices may have been displaced but the habits that it generated have yet to be surmounted.

The perception that staff are clean and parents are dirty is based on belief and bias rather than evidence, but to take the risk of discovering that increased parent participation might reduce infection and improve outcomes might be a worrying challenge to professionals' perception of their competence and superiority.

Literature on IFCDC is largely unavailable for non-English speaking countries. Even where training materials are available in multiple languages, the skills required to deliver the training may not be available or affordable. The fight for equality is not only at the systems level (policies and practice) it is also in access to education and information. It is imperative to develop context-appropriate education and practice guidelines.

Wider views from parents in this study are discussed elsewhere(24). More needs to be understood about how they experience separation from their babies (25,26), how this might affect both parents and babies in the future and how parents might be able to contribute to the care of their baby in neonatal units and whether this might alleviate the workload of nurses.

This study is limited in that it draws on the experiences of parents and healthcare professionals in only two hospitals, yet we have identified some cultural, economic and political aspects that underpin policies and practices in the Mexican healthcare system which might similarly affect other hospitals. The results of this qualitative study warrant a much deeper understanding and rigorous evaluation of effective use of resources, hospital organisation and medical practices that truly promote parental involvement and respect for babies' individuality and their primary need for good parenting.

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List of abbreviations:

IFCDC - infant and family centred developmental care

KMC – kangaroo mother care

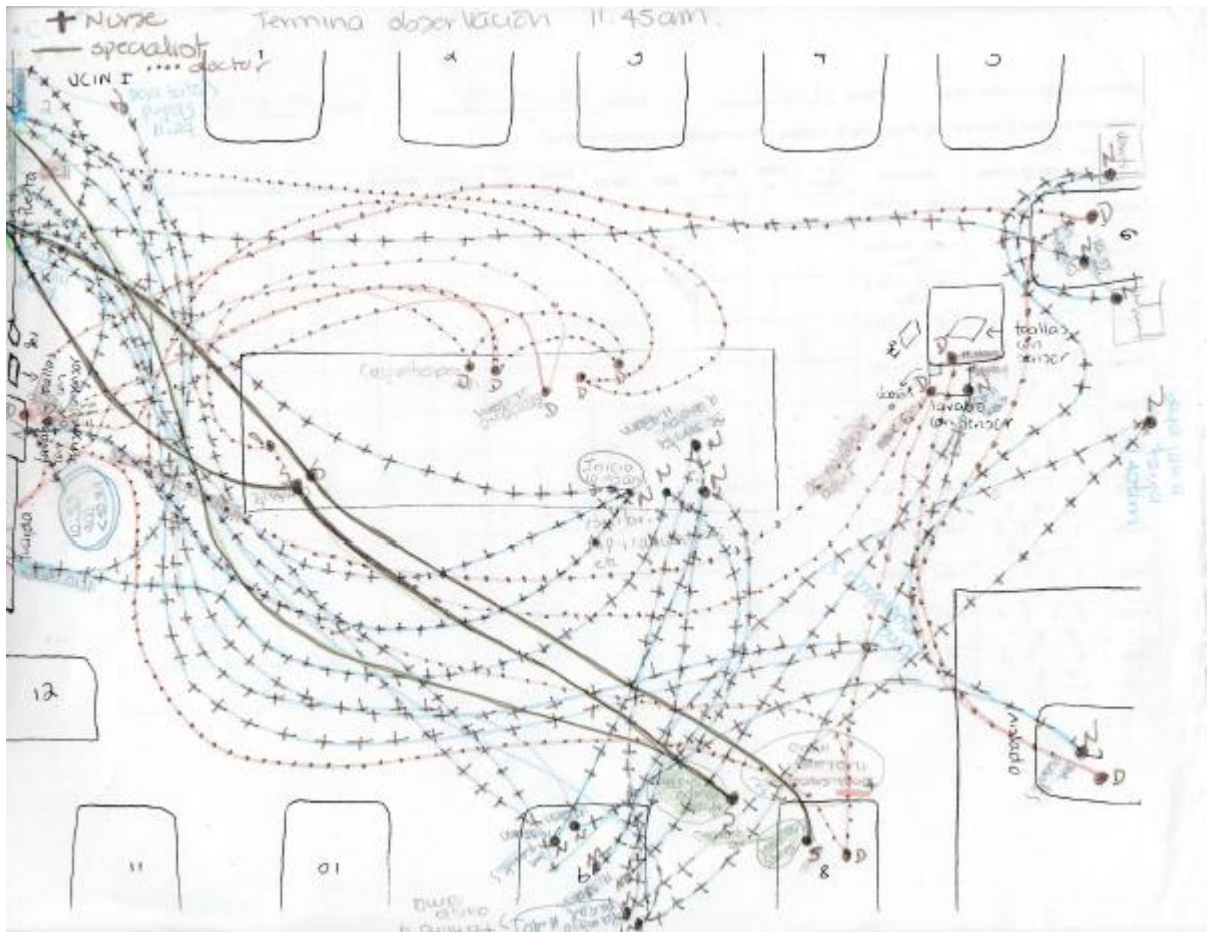
UK – United Kingdom

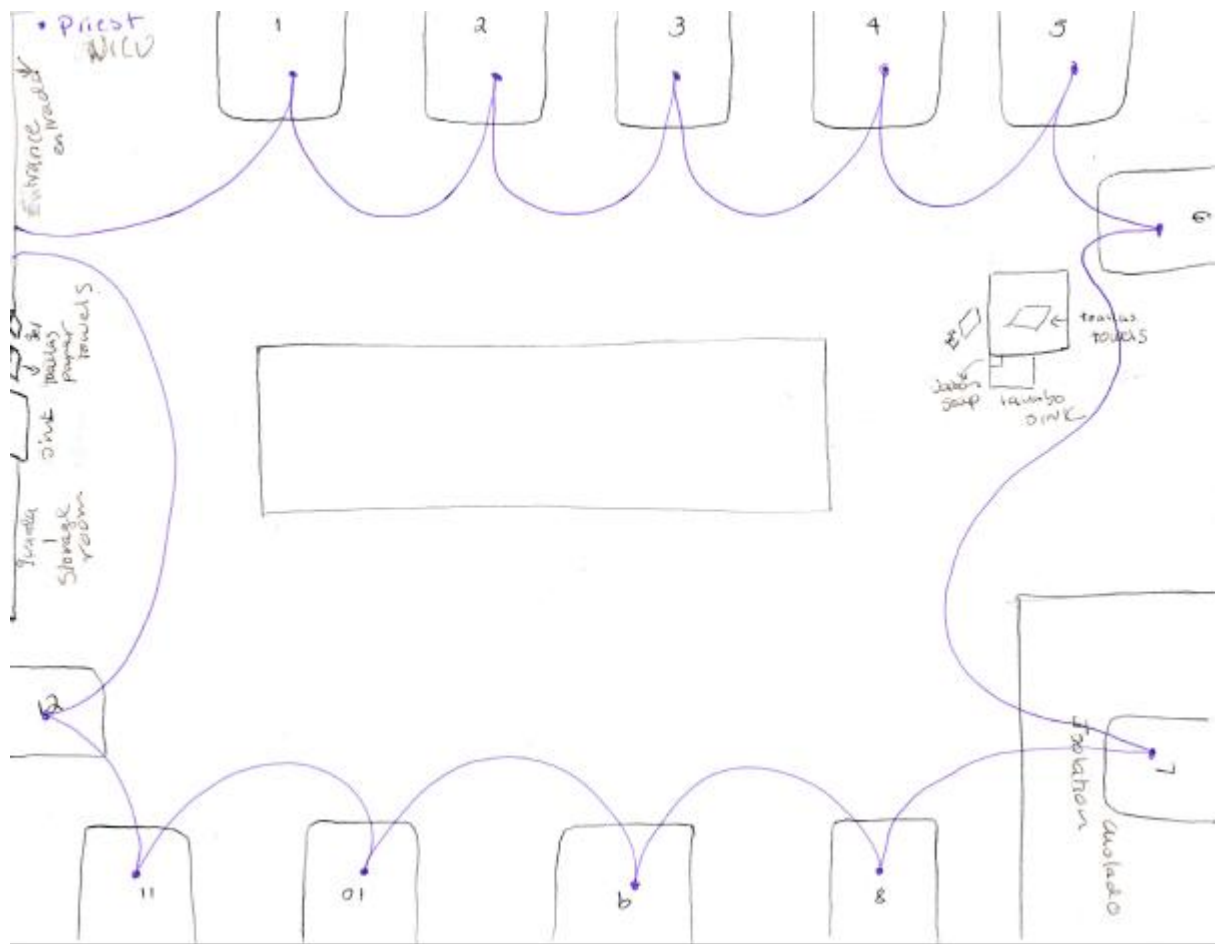
NICU – neonatal intensive care unit

JDH - Juan Dautt Hospital

MDH – Mercedes Duron Hospital

GA – gestational age





Appendix 1:

Interview guide parents

How did your baby come to need special/intensive care?

What was the first time that you saw your baby in the unit like?

How did the staff support and inform you?

How much were you able to care for your baby in the unit? (Prompts feeding, touching, holding, changing, other)

Can you tell me about your best time in the unit?

Can you tell me about your worst/hardest time in the unit?

How do you believe your baby felt while in the unit, can you describe some of the experiences?

How would you describe your relationship with the staff?

Were you able/did you want to share in making decisions? For example?

How did you find the other parents?

What help did you have about going home and after your baby left the unit?

On the whole, how do you think being in the unit affected your relationship with your baby?

And your partner's relationship with your baby?

Are there any other things you would like to talk about?

Interview guide staff

Would you like to tell me about your role in the unit?

What do you like/don't like about working here?

What are the challenges of looking after very sick babies?

What do babies need the most when they are here?

How do babies feel when they are here? How do they let you know?

How do parents feel?

What is it like when parents come to see babies?

Can parents contribute a little? How could they help (if at all)? (basic care, stressful events, decision-making)

How would you describe your relationship with the parents?

What do parents need when they are here?

What do parents need when they take their baby home?

What can you tell me about your relationship with colleagues? (If prompt needed communication, support, environment, multi-disciplinary work)

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If you could change something what would it be?

Are there any other things you would like to talk about?

Appendix 2: Guide to observing babies

Naturalistic observations during different episodes of care such as routine care (nappy change, blood pressure recording, taking the temperature, bedding changes, feeding and fluids aspiration) medical interventions (blood samples, eye check) and interactions with parents during visiting time.

Type of interaction/intervention

Babies' behaviour before and during episode of care **

How baby was approached (talked to, pace, visual contact)

Environment: number of people, light, noise.

Who was with baby?

Positioning (nest, head alignment, arms and legs)

Self-soothing strategies

External strategies to help baby sooth (talking, touch, positioning, rolls)

Signs of pain or discomfort (facial gestures, hands, feet, vital signs)

What happened afterwards? (Comforting strategies, babies' reactions)

How did it feel over all?

What went well?

** Some behavioural cues to remember

Physiological	<ul style="list-style-type: none">• Breathing pattern; gagging, hiccough, gasps.• Skin colour• Oxygen saturation• Digestive movements.• Tremors
Motor	<ul style="list-style-type: none">• Muscle tone• Position of extremities (flexed, extended)• Quality of movements (smooth/sudden)• Arching, squirming• Facial expressions• Hand movement: fisting, splaying fingers, bringing hands together.
States	<ul style="list-style-type: none">• Deep sleep, light sleep, drowsy, quietly awake, actively awake, fussing or crying (quality, definition and transition)

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Attentional	<ul style="list-style-type: none">• Yawns, sneezes, cooing, looking in, looking away, mouth movements.
Regulatory	<ul style="list-style-type: none">• Looking in, cooing, hands together, hand to mouth/face, clasp ing feet, grasping, sleeping/quietly awake, smooth movements, modulated muscle tone, stability in vital signs.

Guide developed by first author (RM): behavioural state before, during and after medical, nursing or parental interventions (from sleeping to calming to crying) (1), different behavioural responses during intervention (2), baby's positioning (3), approaching the baby, types of medical or nursing interaction and attempts to make baby feel comfortable (4).

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