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Research Article

Feasibility of Caregiver-Involvement in the Clinical Monitoring of Newborns and Young Infants

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Abstract

Background: Neonatal and infant deaths contribute substantially to under-5 mortality in South Africa, with inadequate monitoring and delayed response to signs of illness remaining important modifiable factors.

Objectives: This study was undertaken to evaluate the acceptability, feasibility and use of a Family Monitoring booklet among caregivers and healthcare workers and assess the impact on caregivers' confidence and knowledge levels.

Methods: A mixed methods descriptive study was undertaken in four KwaZulu-Natal hospitals. Participants included mothers of well preterm babies in Kangaroo Mother Care (KMC) units, post-Caesarean section mothers and healthcare workers. Data collection encompassed caregiver knowledge questionnaires, audits of the completed Family Monitoring tools, caregiver focus groups and healthcare worker questionnaires. The descriptive and thematic analysis was completed in Microsoft Excel.

Results: Overall, 262 mothers were recruited: 109 in the KMC group and 153 in the postnatal group. The reported acceptability of Family Monitoring was good, with completion rates of 92.2% among mothers and 66.7% among healthcare workers. The mean caregiver knowledge score was 78.0% pre-exposure with a mean percentage increase of 4.3% ($p<0.001$). Major themes included initial anxiety, ease of use, increased maternal confidence and knowledge and the importance of explanation and peer support for its use.

Conclusions: Implementing the Family Monitoring tool was acceptable to mothers and healthcare workers at four KwaZulu-Natal hospitals, with modest but significant increases in the mother's knowledge scores and high completion rates among mothers. Further evaluations of family-centred care interventions are needed in South Africa.

***Keywords:** Neonatal, infant, mortality, observation, monitoring, family-centred care, maternal, caregiver, capacitation.*

Introduction

Despite a global decline in child mortality and shift towards ensuring that children thrive, the level of preventable child deaths in South African remains high. The 2015 under-5 mortality rate in South Africa was 37–44/1000 live births, with neonatal deaths (0-28 days) accounting for around one third and infant deaths (29 days-1 year) for approximately 42% (Bamford et al., 2018). Principal causes of neonatal deaths include prematurity-related illness, birth complications and severe infections (Liu et al., 2016; The National Perinatal Morbidity and Mortality Committee, 2021; Rhoda at al., 2018) while diarrhoeal disease, pneumonia and HIV remain leading causes of deaths outside the newborn period (Bamford et al., 2018). Simple and inexpensive interventions including breastfeeding, prevention of hypothermia and infection, as well as the identification and appropriate response to signs of illness are important contributors to improved neonatal and infant health outcomes (Green, 2014).

However, the capacity for consistent implementation of such measures remains a challenge, in both the hospital and the home setting. The KwaZulu-Natal initiative for newborn care (KINC) reported that 12-hourly observations of well babies (post-Caesarean section) were completed in just 23% and daily weight monitoring of all babies in only 30% of hospitals (Horwood et al., 2018). Commonly identified challenges included the failure to appropriately record and manage conditions such as respiratory distress and jaundice. Inadequate observations may in part relate to human resources, as only 50% of hospitals met the staffing norms, and staff rotation was frequent (Haskins et al., 2018).

Nearly half of the reported under-5 fatalities in South Africa occur outside health facilities, and common modifiable factors identified at the community level include delayed recognition of signs of illness/illness severity and delayed care-seeking (The Committee for Morbidity and Mortality in Children under 5 years, 2020). A 2014 pilot study reviewing 707 children referred for post-mortem examination in KwaZulu-Natal and the Western Cape reported that lower respiratory tract infections (LRTI) were a leading cause (51.6%) of infant community deaths and that LRTI deaths were significantly associated with prematurity (OR 1.87 (95% CI: 1.17-2.99), being at home (OR 2.60 (95% CI: 1.44-4.68) and winter season (OR 1.93 (95% CI:1.09-3.41) (Mathews et al., 2016). These findings would suggest that the ability to identify and respond to their child's illness may be a challenge for caregivers and that preterm infants in particular are at risk of dying from infections after being discharged from the hospital. Indeed, during maternal interviews conducted in KwaZulu-Natal, almost half the mothers reported that they had not been taught how to identify signs of illness in their baby, and a third that they did not know how to look for a change in their baby's condition (Haskins et al., 2018). Similar observations have been made in Kenya and Ethiopia, where a low proportion (15.5-50.3%) of new mothers could list at least 3 of 10 neonatal danger signs (Kibaru et al., 2016; Mersha et al., 2017; Welay et al., 2019).

Family-centred care (FCC) refers to a range of interventions aimed at promoting a partnership between caregivers and healthcare workers where the caregivers participate in the hospital care of sick newborns and young infants. Benefits of a family-centred approach have been documented in neonatal intensive care units in high- and middle-income countries, including improved breastfeeding rates, better weight gain, fewer nosocomial infections, shorter length of hospital stay, reduced readmission rates, better parental skills and knowledge scores and lower parental anxiety and depression scores (Bhutta et al., 2004; Ding et al., 2019; Melnyk et al., 2006; Mianaei et al., 2014; O'Brien et al., 2013; Ortenstrand et al., 2010; Verma et al., 2017; Zang et al., 2018). However, evaluations of family-centred interventions are scarce in our setting. To date, most initiatives addressing the quality of care for newborns in our context have focused on capacitation of health workers and resolving health systems challenges (Haskins et al., 2018; Horwood et al., 2019). To our knowledge, no previous studies have evaluated the role of caregivers assisting in or supplementing the clinical monitoring of neonates and infants in South African hospitals.

This paper describes the development and initial experience with implementing the Family Monitoring tool, an illustrated booklet designed to capacitate caregivers in simple monitoring of their newborns' wellbeing.

Objectives

In a context with limited in-hospital monitoring and the ongoing high mortality among recently discharged babies, the feasibility of capacitating mothers in essential infant care and routine monitoring of their children becomes important. This study was undertaken to evaluate:

1. The acceptability of participatory monitoring among caregivers and healthcare workers.
2. The usability and use of a Family Monitoring tool among caregivers and healthcare workers.
3. The effectiveness of the tool with regards to caregivers' confidence and knowledge levels.

Methods

Study procedures and participants

A mixed methods descriptive study was undertaken in four hospital across KwaZulu-Natal: Prince Mshiyeni Memorial Hospital (PMMH) in eThekwini metro, General Justice Gizenga Mpanza (GJGM) Hospital in iLembe district, Edendale Hospital in uMgungundlovu district and Ladysmith Hospital in uThukela district. The study sites were selected by convenience sampling. Hospitals that expressed willingness to implement the Family Monitoring tool were selected from a pool of hospitals with >1 000 deliveries per annum, perform Caesarean sections and have a functional KMC unit.

The study population included a long-stay group of mothers of well preterm babies admitted to Kangaroo Mother Care (KMC) units and a short-stay group of post-Caesarean section mothers in postnatal wards; and healthcare workers (nurses and doctors) working directly with patient care in KMC units and postnatal wards at the study sites. A sample size for the number of mothers was calculated based on the number of observations needed to compare the following elements before and after implementation with a statistical significance level of 95% ($p<0.05$): Proportion of basic neonatal monitoring and care elements known by the caregiver. The minimum sample size to detect a 25% change from a baseline value of around 50-67% would be 80 caregivers. With an oversampling of 20%, we aimed to include at least 100 mothers in the short-stay/postnatal group and 100 mothers in the long-stay/KMC group.

Mothers were recruited sequentially according to inclusion and exclusion criteria until the sample size for each site was reached. Inclusion criteria included: Mothers of well babies admitted from Monday to Wednesday to the postnatal ward (post-Caesarean section) during the preceding 12-24 hours and mothers admitted to the KMC unit in the preceding 48 hours. Exclusion criteria included: Mothers of babies discharged within 24 hours of birth or on a Saturday or Sunday and mothers of babies in need of intensive care. Teenage mothers <18 years old were excluded due to their inability to consent to non-therapeutic research. One caregiver focus group was conducted per study site and all mothers that had used the Family Monitoring tool and were present on the day of the focus group were invited to participate. All healthcare workers (nurses and doctors) working in the relevant postnatal wards and KMC units during the study period were invited to complete a questionnaire regarding their experience with implementing the Family Monitoring tool.

Description of the intervention

The Family Monitoring tool is a booklet with illustrations, messages and a twice-daily checklist that the mothers complete while in hospital and at home for four weeks post-delivery. The booklet is aligned with the National Road-to-Health Booklet and Side-by-Side campaign including messages emphasizing the role of the mothers, in partnership with healthcare workers, as primary caregivers and crucial to optimising health and developmental outcomes for children. It includes simple but important observations that appraise the baby's and the mother's wellbeing, as well as signs of serious illness. The maternal observations are confirmed by a healthcare worker. Danger signs are highlighted in red with instruction to urgently inform a healthcare worker. The tool was developed by the KwaZulu-Natal Neonatal Coordinator with input from various stakeholders both with and without a health background. The pilot implementation included the issuing of a Family Monitoring booklet together with caregiver orientation, support and monitoring. Mothers were recruited, signed consent, completed a pre-implementation questionnaire and were issued a Family Monitoring booklet 12 -48 hours after admission. Enrolled mothers then attended a group orientation/mentoring session that covered the purpose of the tool, how to complete it and how to look for signs of illness in their babies. In the event that a mother identified a "red sign" (a sign of serious illness), they were instructed to immediately inform a healthcare worker, so that the appropriate action could be taken. Nurses working in the relevant units supervised the mothers' completion of the Family monitoring tool, confirmed the mothers' assessments and added brief notes on any actions required.

Data collection and analysis

The quantitative data collection included pre- and post- exposure caregiver knowledge questionnaires and audits of the completed Family Monitoring tools. Mothers in the short-stay group were required to have at least three Family Monitoring observations (1.5 days) and the long-stay group 14 observations (7 days) between the pre- and post-implementation data collection. A single caregiver knowledge questionnaire for both pre- and post-exposure, was administered by a healthcare worker in the mother's local language. It contained a question about the mother's confidence (graded 1-5) in caring for her baby and multiple-choice questions on what the mother could do to keep her baby healthy; how she could show that she loved him/her; what signs would indicate that the baby is well; and what signs would indicate that the baby is sick and needs to be taken to the clinic urgently. The completed Family Monitoring tools were audited to document the completeness of recording by the mothers and nurses, whether or not danger signs were detected and if appropriate responses were recorded for danger signs detected by the mothers.

Caregiver focus groups and healthcare worker questionnaires were conducted at each site 2-3 weeks after the introduction of the Family Monitoring tool. The focus group discussions were facilitated by two fieldworkers in isiZulu according to a structured interview guide, were audio-recorded and subsequently transcribed and translated into English. The healthcare worker questionnaires were self-administered and included ratings (graded 1-5) of their general experience with using the Family Monitoring tool in their ward and their impression of the mothers' ability to cope with the tool. The focus group guides and healthcare worker questionnaires included prompts and questions to identify key elements of feasibility such as benefits and disadvantages of the concept; the usability/user-friendliness of the tool; and the impact on the healthcare worker workload.

The responses and scores from caregiver knowledge questionnaires, Family Monitoring record audits and healthcare worker questionnaires were captured in a Microsoft Excel database. The statistical analysis was completed in Microsoft Excel and included descriptive statistics, a comparative analysis of the pre- and post-exposure caregiver knowledge and confidence levels (i.e. calculation of confidence intervals for the chance in mean and paired t-tests for two sample means) and regressions to assess associations between the characteristics of the mothers (age, education, parity, site/hospital and the number of observations in the Family Monitoring booklet) and their baseline confidence scores, baseline knowledge scores and their percentage change in knowledge scores. Associations were considered significant at the confidence level 95% ($p<0.05$). Transcripts from caregiver focus group discussions were reviewed and coded independently by three authors and an analysis of emergent themes was conducted using Microsoft Excel.

Ethics

All participants signed informed consent before inclusion and all data was anonymised. Ethical approval was obtained from uMgungundlovu Health Ethics Review Board, the KwaZulu-Natal Department of Health Research & Knowledge Management Unit and from the management of the relevant hospitals/study sites.

Results

Characteristics of participants

The three groups of participants consisted of mothers using the Family Monitoring tool; mothers using the tool and participating in focus groups; and healthcare workers from the relevant postnatal wards and KMC units. Across the four hospitals, 262 mothers were included: 109 mothers in the KMC (long-stay) group and 153 mothers in the postnatal (short-stay) group. The mean (range) age of the mothers was 28 (18-43) years, the mean parity was 2.2 children and the majority (56.5%) had completed secondary school. Table 1 outlines the characteristics and outcomes of participants in the KMC group and the postnatal group respectively. Age, education and parity were similar in the two groups, although a larger proportion of postnatal mothers (19.0% vs 12.8%) had a higher level of education.

Table 1: Key characteristics and outcomes of participants.

Group	KMC	Postnatal	All mothers
Participants, *n* (%)	109 (41.6)	153 (58.4)	262 (100.0)
Age			
Mean age in years (SD)	28 (6.2)	28 (5.6)	28 (5.9)
Education			
No/some primary (%)	1 (0.9)	2 (1.3)	3 (1.1)
Completed primary (%)	33 (30.3)	34 (22.2)	67 (25.6)
Completed secondary (%)	61 (56.0)	87 (56.9)	148 (56.5)
Higher education (%)	14 (12.8)	29 (19.0)	43 (16.4)
Parity			
One child (%)	33 (30.3)	39 (25.5)	72 (27.5)
Two children (%)	32 (29.4)	55 (35.9)	86 (32.8)
Three children (%)	29 (26.6)	49 (32.0)	78 (29.8)
Four children (%)	11 (10.1)	8 (5.2)	19 (7.3)
Five children (%)	4 (3.7)	2 (1.3)	6 (2.3)
Family Monitoring tool exposure & completion			
Mean number of twice daily observations (*SD*)	14.0 (3.1)	3.8 (1.0)	8.0 (5.5)
Mean % score for mom's completion (*SD*)	91.6 (18.3)	92.7 (10.8)	92.2 (14.4)
Mean % score for nurses' completion (*SD*)	66.7 (40.5)	66.6 (39.6)	66.6 (39.9)
Caregiver knowledge			
Mean % score pre-exposure (*SD*)	77.4 (9.3)	78.5 (9.1)	78.0 (9.2)
Mean % score post-exposure (*SD*)	80.3 (8.3)	80.8 (8.0)	80.6 (8.1)
Difference in mean post- vs pre-exposure [95% CI]	2.975 [1.244, 4.706] *	2.357 [0.913, 3.801] *	2.614 [1.503, 3.725] *
Caregiver confidence* **			
Mean score pre-exposure (*SD*)	4.6 (0.8)	4.6 (0.8)	4.6 (0.8)
Mean score post-exposure (*SD*)	4.7 (0.7)	4.7 (0.8)	4.7 (0.7)
Difference in mean post- vs pre-exposure [95% CI]	0.074 [-0.070, 0.218]	0.072 [-0.056, 0.199]	0.073 [-0.023, 0.168]**

Notes. Continuous variables were described by the mean and standard deviation (*SD*). Categorical variables were described by count (*n*) and percentages (%). CI = confidence interval. * = p <0.001. **= p =0.20 . ***The caregiver confidence was graded on a rating scale from 1-5 where 1 is very insecure and 5 is very confident.

Of the 262 mothers, 24 participated in focus group discussions that ranged from 4-8 participants per group at the four sites. Thirty-six healthcare workers responded to the questionnaire, of which 34 (94.4%) were female, 17 (47.2%) were professional nurses, seven (19.4%) were enrolled nurses, six (16.7%) were medical officers, one (7.8%) was a registrar and four (11.1%) were paediatric specialists. The mean (range) age of the healthcare workers was 39.9 (27.0-58.0) years. The mean (SD) time in the current post was 8.3 (6.5) years and the mean (SD) duration of experience in newborn care was 7.2 (5.4) years.

The acceptability of Family Monitoring to mothers and healthcare workers

Twenty-two out of twenty-four (91.7%) mothers participating in focus groups said they would complete Family Monitoring if they had a baby in the future, whereas two said they did not plan to have additional children. Similarly, 91.7% of healthcare workers stated they would like to continue using the tool in their ward. The health care worker's mean rating of their experience with implementing Family Monitoring on a scale from 1-5 was 4.5. When asked what impact implementing the tool in their ward had on the monitoring of newborns, 63.3% said it improved whereas 36.1% said there was no change. No one said the monitoring deteriorated.

Table 2: Major themes from caregiver focus group discussions.

Acceptability	Feasibility/usability
Added to their stress/anxiety until they were familiar with it	Needed explanation
Gained knowledge and confidence in infant care and danger signs	Easy to complete
Helpful to track the baby's feeds	Purpose well understood
	Peer influence and support
	Antenatal introduction

Major themes from the caregiver focus group discussions are outlined in Table 2. Some mothers expressed that being asked to complete the Family Monitoring tool had added to their anxiety and stress after delivery and that it felt like a burden initially (Textbox 1, quote 1 and 2). However, many said they gained helpful knowledge and confidence regarding infant care and danger signs (Textbox 1, quote 2, 3 and 4). A few mothers made specific mention of their wish to track their baby's feeding and requested more space to record the feeding times and their comments.

Textbox 1: Quotes from the caregiver focus group discussions.

Quote 1: '*To be honest I was confused and shocked as my baby was different from other babies in the ward and I asked myself why am I given the booklet as I still have to come into terms with my baby's condition. The booklet seemed like unneeded extra stress, so I did not complete the booklet at first and then I saw other moms completing it so I then started. I was at ease when my baby's condition was explained to me and that made my anxiety to ease, hence I started completing the booklet*.'

Quote 2: '*When I first received the booklet the doctors explained to us and at first I felt the booklet was an additional task but after reading I saw the booklet was very helpful and was easy to complete. There was a time when my baby stopped breathing and turned blue and I recalled what was written in the booklet and I called doctors for assistance immediately*.'

Quote 3: '*It was not difficult to complete the booklet and it made me aware that there are some areas where I was not confident enough on the care of my baby and I learnt that it is my responsibility to care for my baby and I was also made aware that being a mother is not an easy task*.'

Quote 4: '*I think the booklet helped me and it will be helpful for other mothers and those that are pregnant as well. I will recommend that the booklet is also given to expecting mothers before they deliver and once delivered it can be continued at home*.'

Quote 5: '*The purpose of the booklet is to inform us as mothers on our babies' condition and how to care for our babies which will help us when we also at home*.'

Quote 6: '*It helped as many of us are first time mothers and we have learnt a lot from the booklet and as you complete the booklet every day the following day you remember what you had come across the day before that was seen in your baby*.'

Similarly, healthcare workers frequently stated that the Family Monitoring increased the mothers' knowledge and promoted their awareness and engagement with their baby's condition. They did, however, often indicate that some mothers were reluctant or needed frequent reminders and much support to complete the booklet.

The usability and use of Family Monitoring among caregivers and healthcare workers

The degree of the mothers' completion of the Family Monitoring booklets was high (mean: 91.6%) and relatively consistent between sites (range: 87.7-98.8%). Red signs were noted by the mother in 25/262 (9.5%) of Family Monitoring booklets. Out of 28 red signs, 8 (28.6%) constituted feeding problems, 5 (17.9%) jaundice, 3 (10.7%) swollen or red eyes, 3 (10.7%) difficult breathing (apnoea or fast breathing), 3 (10.7%) less than 3 wet nappies per day, 2 (7.1%) signs of an infected cord area, 2 (7.1%) a saturation reading >94% whilst receiving oxygen, 1 (3.6%) pallor and 1 (3.6%) a stool elimination problem. In 15 (60.0%) of the booklets with red signs recorded by the mother, no comment or response was documented by a healthcare worker. Compared to the mother's completion of the Family Monitoring booklets, the nurses' completion was lower (mean 66.7%) and varied more between hospitals (range 30.6-98.1%). The health care worker's mean rating of the mother's ability to understand and complete the tool on a scale from 1-5 was 3.6. When asked about the impact of Family Monitoring on their workload, 41.7% responded that it did not change, 41.7% reported an increase and 16.7% that it decreased. Tasks often reported to increase included counselling and record keeping and tasks reported to decrease included support for breastfeeding and KMC.

Most mothers stated that they needed an explanation and mentoring in how to complete the booklet. Once they were familiar with the checklist, they generally expressed that it was easy to complete (Textbox 1, quote 2 and 3) and demonstrated a good understanding of its purpose (Textbox 1, quote 5 and 6). Peer support and seeing other mothers complete the booklet emerged as important factors for use (Textbox 1, quote 1). Introducing the tool antenatally was suggested by mothers (Textbox 1, quote 4) and healthcare workers. Healthcare workers indicated that the mother's understanding of the Family Monitoring tool was variable and repeated explanations were necessary for some. Having time to teach and counsel the mothers was difficult due to staff shortages. Challenges were also reported in orienting post-Caesarean mothers who were often in pain or sedated at the time of admission to the postnatal ward.

Changes in mothers' confidence and knowledge levels

During the knowledge questionnaires mothers were asked to rate their confidence in caring for their new baby on a scale from 1-5. The mean score was 4.6 pre-exposure and 4.7 post-exposure to Family Monitoring, with a mean change in score of 0.073 (3.2%) that was not statistically significant (p=0.20). The confidence scores did not differ between the KMC and postnatal groups (Table 1).

The mean knowledge score was 78.0% pre-exposure (77.4% for the KMC group and 78.5 % for the postnatal group) and 80.6% post-exposure (80.3% for the KMC group and 80.8% for the postnatal group). Figure 1 illustrates the distribution of the pre- and post-exposure knowledge scores. The improvement in caregiver knowledge was statistically significant (p<0.001), both overall and for the two subgroups (Table 1). The mean percentage change in knowledge scores was 4.3% overall, 4.7% for the KMC group and 3.9% for the postnatal group.

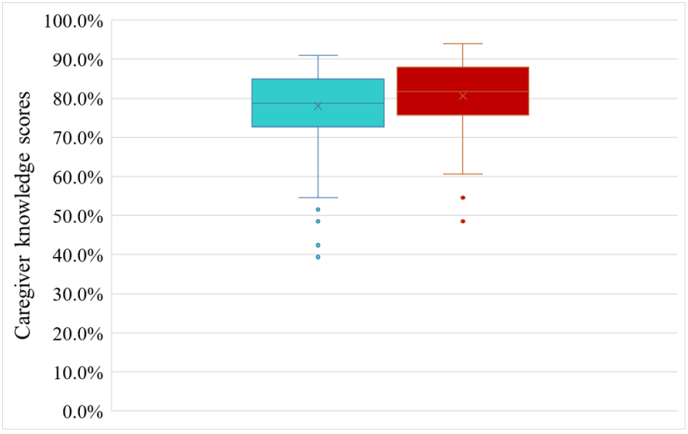

Figure 1: *Box plot of the caregiver knowledge scores pre-exposure (green) and post-exposure (red) to Family Monitoring.*

No associations were found between the mothers' age, education, parity or site/hospital and their pre-exposure confidence or knowledge scores. However, higher mean increases in the mother's knowledge scores were seen at GJGM (6.8%) and Ladysmith hospitals (7.5%) compared to PMM (0.2%) and Edendale (3.0%) hospitals (p=0.039).

The mean scores and changes in mean score for the knowledge questionnaire pre- and post-exposure are outlined in Table 3. Correct and incorrect responses were relatively consistent between the groups (KMC and postnatal) and across sites.

Regarding infant care, most mothers said they would breastfeed their baby, clean the cord with chlorhexidine, have the baby immunised, wash their hands and keep the baby skin-to-skin. However, 21.9% of mothers said they would give their baby traditional medicine and 37.0% that they would leave their baby with an alternative caregiver (e.g. the grandmother). These statements were particularly common at GJGM hospital. The majority of mothers said it was important that they worked to provide for their baby (95.0%) and made sure their baby had pretty clothes (89.1%). Mothers generally scored high on knowledge of signs of health and illness, both pre- and post-exposure to Family Monitoring. However, 29.0% of mothers missed the illness sign of less than three wet nappies per day and 22.7% of mothers missed the sign of the baby feeling hot or cold to the touch. Additionally, 87.4% of mothers said their baby should be taken urgently to the clinic if she/he was sweating or had a nappy rash. The largest improvements in knowledge scores were seen for the following signs of the baby's health: 'my baby looks pink' (17.2%) and 'my baby has more than three wet nappies per day' (13.0%).

Table 3: Mean score and mean change in score per question for the caregiver knowledge questionnaire.

Question	KMC (*n*=109)	Postnatal (*n*=163)	All mothers (*N*=262)
How can you keep your baby healthy?			
Mean % pre-score	82.7	78.4	80.2
Mean % post-score	84.9	82.7	83.6
Mean % change in score	2.2	4.3	3.4
How can you show your baby that you love him/her?			
Mean % pre-score	75.5	78.6	77.4
Mean % post-score	78.0	79.0	78.6
Mean % change in score	2.4	0.3	1.2
Which of the following signs indicate that your baby is well?			
Mean % pre-score	79.7	84.7	82.6
Mean % post-score	84.3	87.4	86.1
Mean % change in score	4.6	2.7	3.5
Which of the following signs indicate that your baby is sick and needs to be taken to the clinic urgently?			
Mean % pre-score	71.5	74.2	73.1
Mean % post-score	74.3	75.5	75.0
Mean % change in score	2.8	1.3	1.9
Overall scores			
Mean % pre-score	77.4	78.5	78.0
Mean % post-score	80.3	80.8	80.6
Mean % change in score	4.7	3.9	4.3

Discussion

Main study findings

The mothers in the KMC (long-stay) group and the postnatal (short-stay) group were comparable with regards to their age, education level, parity, and the baseline confidence and knowledge scores. A tendency towards lower education level in the KMC group is consistent with existing literature where the risk of preterm birth has been associated with maternal demographics such as ethnicity, high or low age, single marital status and low educational and socioeconomic status (Goldenberg et al, 2008).

The healthcare workers responding to questionnaires (2/3 nurses and 1/3 doctors) were relatively experienced with a mean duration of 7.2 years working with newborns. The reported acceptability of Family Monitoring was high, with 91.7% of both mothers and healthcare workers wishing to continue using the tool in the future. The most frequently mentioned benefit was an improvement in the mothers' awareness and knowledge regarding their babies condition, a major theme that also emerged in a qualitative evaluation of family-centred care in India (Butler et al, 2014). A high completion rate (mean 92.2%) among the mothers could speak to the ease of use which many mothers confirmed during focus group discussions. The ease of use and supervision by healthcare workers was more equivocal, with lower completion rates (mean 66.7%) among nurses who often said they did not have enough time to teach and mentor the mothers due to understaffing, a frequently listed barrier to implementing high quality healthcare locally and in India (Haskins et al., 2018; Sarin et al, 2019). Healthcare worker reservations around caregiver involvement in the hospital care of newborns have been previously described for family-centred care interventions (Butler et al, 2014; Sarin et al., 2019).

In 60.0% of the booklets with red signs recorded by the mother, no comment or response was documented by a healthcare worker. The data collection methods did not allow for establishing in which of these cases: 1. the mother did not report the danger sign to a healthcare worker; 2. the mother reported the danger sign but it elicited no response from the healthcare worker; 3. the healthcare worker responded but did not record their actions in the booklet. However, based on the local experience, incomplete record keeping is likely a contributing factor (Haskins et al., 2018; Horwood et al., 2019).

Although mothers reported (during focus group discussions) that completing the Family Monitoring tool had increased their confidence in caring for their baby, the overall increase in confidence rating was small and not statistically significant. This could owe in part to the high baseline confidence scores (mean 4.6 out of 5); that completing the checklist could have created awareness around infant care elements the mothers were previously unfamiliar with; and the fact that just 27.5% were first time mothers. The mothers' baseline knowledge scores regarding basic neonatal monitoring and care elements were high (mean 78.0%) which would have limited the potential for a knowledge increase. The mothers generally answered well regarding infant care and signs of their baby being well but struggled more to differentiate mild from serious signs of illness which is consistent with reports evaluating mothers' ability to list danger signs in Ethiopia and Kenya (Kibaru at al., 2016; Welay et al., 2019). Interestingly, 95.0% of mothers said it was important they work to provide for their baby and 37.0% that they would leave their baby with an alternative caregiver, which could reflect a high proportion of single mothers with limited opportunities to take time off work after delivery. A modest but significant increase in knowledge scores may indicate that Family Monitoring tool can contribute to improved knowledge and care practises among mothers but should ideally form part of a combination of antenatal, perinatal and postnatal interventions.

Studies from Ethiopia report higher maternal knowledge of infant danger signs in multiparous women and women with higher education levels (Demis et al., 2020; Mose et al., 2021). Extremes of maternal age (<18 and >35 years) and parity have also been associated with higher neonatal and infant mortality (Kozuki et al., 2013). We could not find associations between the mothers' knowledge scores and their age, education or parity in our analysis. Possible explanations may include limitations in the data collection methods for the knowledge questionnaires; the exclusion of mothers younger than 18 years; and an insufficient sample size to assess associations.

The KMC (long-stay) and postnatal (short-stay) groups differed little with regards to the completeness of their Family Monitoring or their increases in knowledge and confidence scores, which would indicate that the tool can be successfully used also by mothers with a relatively short (2-3 days) hospital stay.

Study strengths and limitations

Study strengths include a relatively good sample size and triangulation of data sources to obtain the experiences of both mothers and healthcare workers. With participants from hospitals in four districts, our findings should be representative of the situation in KwaZulu-Natal province and similar low- and middle-income contexts. The study had a few limitations in the data collection methods. Firstly, our ability to standardise and quality assure the administration of the caregiver knowledge questionnaires was limited as we relied on hospital staff on duty for this task. Secondly, we did not have permission to access other clinical records to form a more complete picture when no healthcare worker response was recorded for the danger signs the mothers recorded in the Family Monitoring booklet.

Recommendations

More family-centred care initiatives are needed in South Africa. The Family Monitoring tool could be introduced antenatally and reinforced postnatally as a part of a package of interventions aimed at improving newborn and infant survival and wellbeing. Further studies are needed to investigate the benefits of Family Monitoring, preferably in combination with other family-centred care interventions, with a longer timeframe and with assessment of the impact on neonatal/infant outcomes.

Conclusions

Implementing the Family Monitoring tool was acceptable to mothers and healthcare workers at four KwaZulu-Natal hospitals, with significant increases in the mother's knowledge scores and high completion rates among mothers indicating its ease of use. Incomplete record keeping by healthcare workers remains a challenge in our context. Further evaluations of family-centred care interventions are needed in South Africa, preferably initiatives that both cover the antenatal and postnatal period and assess the impact on neonatal and infant outcomes.

Conflict of Interest

No potential conflict of interest was reported by the authors.

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Author contributions

NHM, CJ and RD conceptualised the article. CJ coordinated the data collection while PA, LAC, SD, TNG, NN, TN, SS and PS enrolled participants and collected data. CJ captured the data and generated tables and charts. CJ, NHM and RD analysed the data and CJ & NHM wrote the article. All authors reviewed and approved the final manuscript.

References

Bamford LJ, McKerrow NH, Barron P, et al (2018). Child mortality in South Africa: fewer deaths, but better data are needed. *The South African Medical Journal* 108(3a):S25–S32. DOI: 10.7196/SAMJ.2017.v108i3b.12779.

Bhutta Z, Khan I, Salat S, et al (2004). Reducing length of stay in hospital for very low birthweight infants by involving mothers in a stepdown unit: An experience from Karachi (Pakistan). *The British Medical Journal* 329:1151-1155. DOI: 10.1136/bmj.329.7475.1151.

Butler A, Copnell B and Willetts G (2014). Family-centred care in the paediatric intensive care unit: an integrative review of the literature. *Journal of Clinical Nursing* 23(15-16):2086-2100. DOI: 10.1111/jocn.12498.

Demis A, Gedefaw G, Wondmieneh A, et al (2020). Women's knowledge towards neonatal danger signs and its associated factors in Ethiopia: a systematic review and metaanalysis. *BMC Pediatrics* 20(217). DOI: 10.1186/s12887-020-02098-6.

Ding X, Zhu L, Zhang R, et al (2019). Effects of family-centred care interventions on preterm infants and parents in neonatal intensive care units: A systematic review and meta-analysis of randomised controlled trials. *Australian Critical Care* 32(1):63-75. DOI: 10.1016/j.aucc.2018.10.007.

Goldenberg RL, Culhane JF, Iams JD, Romero R (2008). Preterm Birth 1. Epidemiology and causes of preterm birth. *The Lancet* 371(9606):75-84. DOI: 10.1016/S0140-6736(08)60074-4.

Green RJ (2014) *Coovadia's Paediatrics & Child Health Seventh Edition*. Cape Town: Oxford University Press Southern Africa, pp.103-154.

Haskins L, Nyasulu D, Davidge R, et al (2018). First experiences of accrediting district hospitals for excellence in newborn care in KwaZulu-Natal, South Africa: Successes and challenges. *Journal of Hospital Administration* 7(3):25-34. DOI: 10.5430/jha.v7n3p25.

Horwood C, Haskins L, Phakathi S, et al (2019). A health systems strengthening intervention to improve quality of care for sick and small newborn infants: results from an evaluation in district hospitals in KwaZulu-Natal, South Africa. *BMC Pediatrics* 19 (29). DOI: 10.1186/s12887-019-1396-8.

Kibaru EG and Otara AM (2016). Knowledge of neonatal danger signs among mothers attending well baby clinic in Nakuru Central District, Kenya: cross sectional descriptive study. *BMC Research Notes* 9(481). DOI: 10.1186/s13104-016-2272-3.

Kozuki N, Lee ACC, Silveria M et al (2013). The associations of parity and maternal age with small-for-gestational-age, preterm, and neonatal and infant mortality: a meta-analysis. *BMC Public Health* 13(S2). DOI: 10.1186/1471-2458-13-S3-S2

Liu L, Oza S, Hogan D, et al (2016). Global, regional, and national causes of under-5 mortality in 2000-2015: an updated systematic analysis with implications for the Sustainable Development Goals. *The Lancet* 388(10063):3027-3035. DOI: 10.1016/S0140-6736(16)31593-8.

Mathews S, Martin LJ, Coetzee D, et al (2016). The South African child death review pilot: A multiagency approach to strengthen healthcare and protection for children. *The South African Medical Journal* 106(9):895-899. DOI: 10.7196/SAMJ.2016.v106i9.11234.

Melnyk BM, Fischbeck-Feinstein N, Alpert-Gillis L, et al (2006). Reducing premature infants' length of stay and improving parents' mental health outcomes with the COPE NICU program: A randomized clinical trial. *Pediatrics* 118(5):1414-1437. DOI: 10.1542/peds.2005-2580.

Mersha A, Assefa N, Teji K, et al (2017). Mother's Level of Knowledge of Neonatal Danger Signs and Its Predictors in Chencha District, Southern Ethiopia. *American Journal of Nursing Science* 6(5):426-432. DOI: 10.11648/j.ajns.20170605.17.

Mianaei S, Karahroudy F, Rassouli M, et al (2014). The effect of Creating Opportunities for Parent Empowerment program on maternal stress, anxiety, and participation in NICU wards in Iran. *Iranian Journal of Nursing and Midwifery Research* 19(1):94-100.

Mose A, Adebe H, Shitu S et al (2021). Determinants of maternal knowledge of neonatal danger signs among postpartum mothers in Southern Ethiopia: institutional-based cross-sectional study. *The British Medical Journal Open* 11 (9):e048888. DOI: 10.1136/bmjopen-2021-048888

O'Brien K, Bracht M, Macdonell K, et al (2013). A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy Childbirth* 13(S12). DOI: 10.1186/1471-2393-13-S1-S12.

Ortenstrand A, Westrup B, Broström EB, et al (2010). The Stockholm Neonatal Family Centered Care Study: Effects on length of stay and infant morbidity. *Pediatrics* 125(2):278-285. DOI: 10.1542/peds.2009-1511.

Rhoda NR, Velaphi S, Gebhardt GS, et al (2018). Reducing neonatal deaths in South Africa: Progress and challenges. *The South African Medical Journal* 108(3a):S9-S16. DOI: 10.7196/SAMJ.2017.v108i3b.12804.

Sarin E and Maria A (2019). Acceptability of a family-centered newborn care model among providers and receivers of care in a Public Health Setting: a qualitative study from India. *BMC Health Services Research* 19(184). DOI: https://doi.org/10.1186/s12913-019-4017-1

The Committee for Morbidity and Mortality in Children under 5 years (2020) *The 4th Triennal Report of the Committee on Morbidity and Mortality in Children under 5 years (CoMMiC).* Report for the National Department of Health. Pretoria, South Africa.

The National Perinatal Morbidity and Mortality Committee (2021). *Saving Babies. Triennial report on perinatal mortality in South Africa 2014-2016.* Report for the National Department of Health. Pretoria, South Africa. Available from: https://www.westerncape.gov.za/assets/departments/health/napemmco triennial report 2014-2016 saving babies.pdf (accessed 25 August 2021).

Verma A, Maria A, Pandey RM, et al (2017). Family-Centered Care to Complement Care of Sick Newborns: A Randomized Controlled Trial. *Indian Pediatrics* 54:455-459.DOI: 10.1007/s13312-017-1047-9.

Welay FT, Kassa NA, Gebremeskel GA, et al (2019). Knowledge of neonatal danger signs and associated factors among mothers who gave birth during the last 4 months while attending immunization services in Harar town public health facilities, Ethiopia, 2017. BMC Research Notes 12(651). DOI: 10.1186/s13104-019-4677-2.

Zhang R, Huang RW, Gao XR et al (2018). Involvement of Parents in the Care of Preterm Infants: A Pilot Study Evaluating a Family-Centered Care Intervention in a Chinese Neonatal ICU. *Pediatric Critical Care Medicine* 19(8):741-747. DOI: 10.1097/PCC.0000000000001586.

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