# C. Family involvement and support

## C.1 FAMILY INVOLVEMENT IN ROUTINE CARE

### Recommendation and remarks

**RECOMMENDATION C.1 (NEW)**

**Family involvement in the routine care of preterm or low-birth-weigh infants in health-care facilities is recommended.** *(Strong recommendation, low- to moderate-certainty evidence)*

**Remarks**

- The trials in the systematic review varied widely in intervention content, intensity and effect but all showed consistent and similar effects.
- The GDG noted that the resources needed for and the feasibility of implementing family involvement strategies vary according to setting but that simple family involvement interventions such as the delivery of direct bedside care and involvement in medical decision-making could be implemented in all settings. Other components that can be provided include chairs near the infant's cot, even in busy and crowded hospital wards.
- The GDG also noted that family involvement strategies reduced the length of hospital stay, improved breastfeeding and reduced parental anxiety and stress.

### Background and definitions

Preterm and LBW infants commonly require specialized care, close monitoring and medical interventions *(2,180)*. In some health-care facilities, families are not allowed any physical access to their infants and receive only intermittent verbal updates from health workers *(181-184)*. Family involvement is often defined as the participation of mothers, fathers/partners and other family members in routine care of the newborn while the baby is in the health-care facility *(180,185,186)*. It may include promotion of direct bedside care from the family (e.g. feeding and administration of medicines), inclusion of the family in medical decision-making, infrastructure changes (e.g. beds and chairs near the baby's cot, family rooms), health-care facility culture change and health worker behaviour change. Strategies to increase family involvement have typically focused on packages of one or more of these interventions with the overall aims of increasing the amount of direct hands-on care that parents provide for their infant and empowering families to collaborate in health-care decision-making. Well known packages that are implemented in high-, middle- and low-income countries include family-centred care, family-participatory care and family-integrated care *(180,185,186)*.

### Summary of the evidence

| OVERVIEW | C.1 Family involvement |
|---|---|
| **PICO** | **Population** – Hospitalized preterm or LBW infants<br>**Intervention** – Interventions to involve families in their infant's routine health care<br>**Comparator** – Usual hospital care<br>**Outcomes** – All-cause mortality, morbidity, growth, neurodevelopment at latest follow-up |
| **Timing, setting, subgroups** | **Timing of the intervention** – Birth to 6 months of age<br>**Setting** – Hospital in any country or setting<br>**Subgroups**<br>• Gestational age at birth (< 32 weeks, ≥ 32 weeks)<br>• Birth weight (< 1.5 kg, ≥ 1.5 kg)<br>• Intensity of interventions (high intensity ≥ 12 hours per day, low intensity < 12 hours per day) |

## Effectiveness: Comparison – Family involvement in routine care versus usual hospital care

### Sources and characteristics of the evidence

The effectiveness evidence was derived from a systematic review of 15 RCTs enrolling a total of 5240 preterm or LBW infants from nine countries (Australia, Canada, China, India, the Islamic Republic of Iran, New Zealand, the Republic of Korea, Sweden and the USA) *(187)*. Most infants were born before 32 weeks' gestation or had birth weight below 1.5 kg, and most trials excluded infants with major congenital anomalies. All trials were conducted in NICUs.

All trials evaluated the effect of family-centred models or packages for the hospital care of preterm or LBW infants on infant and parental outcomes. No studies of infrastructure or behaviour change interventions were located. The family-centred packages were heterogeneous, but their common core content was the involvement of family members in the provision of direct bedside care. Skin-to-skin care or kangaroo mother care (KMC) was included in nine trials, though frequency and duration were not described. Other common components included neurodevelopmental care (8 trials), preparation for transition to home (6 trials) and the involvement of parents in medical decision-making (4 trials).

### Critical outcomes

For family involvement strategies compared with usual hospital care, four trials reported all-cause mortality outcomes, eight reported morbidity (6 reported serious infection, 6 necrotizing enterocolitis, 7 bronchopulmonary dysplasia, 8 retinopathy of prematurity and 5 intraventricular haemorrhage), three reported growth (weight gain) and two reported neurodevelopment. (Full details are provided in GRADE Table C.1, in the Web Supplement.)

- **Mortality:** Very-low-certainty evidence from four trials totalling 2378 participants suggests little or no effect on all-cause mortality by hospital discharge (OR 1.05, 95% CI 0.53 to 2.09).
- **Morbidity:** Low-certainty evidence from six trials totalling 2843 participants suggests a decrease in serious infection by hospital discharge (OR 0.79, 95% CI 0.53 to 1.16). Low-certainty evidence from six trials totalling 2809 participants suggests little or no effect on necrotizing enterocolitis by hospital discharge (OR 0.81, 95% CI 0.46 to 1.44). Low-certainty evidence from seven trials totalling 3085 participants suggests decreased bronchopulmonary dysplasia by hospital discharge (OR 0.74, 95% CI 0.53 to 1.03). Moderate-certainty evidence from eight trials totalling 2551 participants suggests decreased retinopathy of prematurity by hospital discharge (OR 0.52, 95% CI 0.34 to 0.80). Very-low-certainty evidence from five trials totalling 2555 participants suggests decreased intraventricular haemorrhage by hospital discharge (OR 0.74, 95% CI 0.36 to 1.54).
- **Growth:** Moderate-certainty evidence from three trials totalling 2215 participants suggests increased in-hospital growth velocity (grams per day) (MD 2.09, 95% CI 1.27 to 2.91).
- **Neurodevelopment:** Low-certainty evidence from two trials totalling 422 participants suggests increased neurodevelopment (measured using the Neonatal Neurobehavioral Examination – Chinese version [NNE-C] test) by hospital discharge or term corrected age, i.e. 37 weeks PMA (MD 1.11, 95% CI 0.21 to 2.01) *(187)*.

### Other outcomes

There was a decrease in length of hospital stay (in days) (MD -2.91, 95% CI -5.15 to -0.68; 11 trials, 4452 participants). There was an increase in the proportion of infants predominantly or exclusively breastfeeding by hospital discharge (OR 1.34, 95% CI 1.10 to 1.65; 3 trials, 1739 participants). There was an increase in "any" breastfeeding by hospital discharge (OR 2.60, 95% CI 0.77 to 8.79; 5 trials, 2546 participants).

### Subgroup analyses

For gestational age and birth weight, differences for weight gain and neurodevelopment could not be assessed as there were insufficient studies. For the other outcomes there was no evidence of a subgroup difference.

For the intensity of intervention, differences for intraventricular haemorrhage, weight gain and neurodevelopment could not be assessed as there were insufficient studies. For the other outcomes there was no evidence of a subgroup difference except for bronchopulmonary dysplasia, which decreased after high-intensity interventions (RR 0.18, 95% CI 0.05 to 0.66; 1 study, 366 participants) but not after low-intensity interventions (RR 1.04, 95% CI 0.68 to 1.58; 6 studies, 2719 participants) (test for subgroup differences, $Chi^2$ =7.22, *P*=0.007).

## Values and acceptability

The systematic review about what matters to families about the care of the preterm or LBW infant (see Table 1.1) reported that families want to be involved in delivering care to infants, and want to take an

active role in deciding what interventions are given to infants, in the routine care of the newborn, in direct bedside care, including feeding their baby and in medical decision-making, and that they value hospital infrastructure changes (e.g. beds and chairs near the baby's cot, family rooms) *(14)*. No other specific evidence was located.

### Resources required and implementation considerations

#### Organization of care

Family involvement strategies can be implemented at all levels of newborn care (primary, secondary and tertiary). Health-care facilities should ensure that families have access to beds, food, bathing and toilet facilities throughout the infant's hospital stay.

#### Infrastructure, equipment and supplies

No special infrastructure, equipment or supplies are needed to support family involvement in the care of their preterm or LBW infants. However, many arrangements can make the infant and mother more comfortable, e.g. reclining beds and chairs. More structured packages may include infrastructure changes such as beds and chairs near the infant's cot, and family rooms.

If couplet care or maternal–newborn intensive care units (M-NICUs) are used, they should have all the infrastructure, equipment and supplies that NICUs have for small or sick babies and that maternity wards have for mothers. For infants, this includes CPAP machines, pulse oximeters, and radiant warmers or incubators if the infant is not in KMC. For mothers, this includes adult beds and an examination area where she can receive the health care she needs.

#### Workforce, training, supervision and monitoring

Health workers at all levels can support family involvement in the routine care of their preterm or LBW infant. Standardized packages can be used for training, supervision and monitoring. This can include the promotion of direct bedside care from the family (e.g. feeding and administration of medicines), inclusion of the family in medical decision-making, health-care facility culture change, health worker behaviour change and infrastructure change.

### Feasibility and equity

There was no specific evidence on the feasibility and equity of promoting family involvement for preterm or LBW infants.

## Summary of judgements

| **Comparison: Family involvement in routine care vs usual hospital care (C.1)** | |
|---|---|
| **Justification** | • Evidence of moderate benefits: decreased morbidity (infection, intraventricular haemorrhage, retinopathy of prematurity, bronchopulmonary dysplasia), increased weight and length, and increased neurodevelopment *(low- to moderate-certainty evidence)*<br>• No evidence of harms<br>• Evidence of little or no effect on: mortality, necrotizing enterocolitis, and weight and head circumference *(low- to very-low-certainty evidence)*<br>• No evidence on other critical outcomes |
| **Evidence to-Decision summary** | |
| **Benefits** | Moderate |
| **Harms** | Trivial or none |
| **Certainty** | Low to moderate |
| **Balance** | Favours family involvement strategies |
| **Values** | No uncertainty or variability about outcomes |
| **Acceptability** | Acceptable |
| **Resources** | Vary |
| **Feasibility** | Varies |
| **Equity** | Probably equitable |