

## C.2 FAMILY SUPPORT

### Recommendation and remarks

#### RECOMMENDATION C.2 (NEW)

**Families of preterm or low-birth-weight infants should be given extra support to care for their infants, starting in health-care facilities from birth, and continued during follow-up post-discharge. The support may include education, counselling and discharge preparation by health workers, and peer support.**

*(Conditional recommendation, very-low-certainty evidence)*

#### Remarks

- The recommendation is conditional on shared decision-making with parents; this includes informing parents about the benefits and risks and the need for further research.
- The GDG noted that **education and counselling** also had important effects in improving parent-to-infant interaction, improving breastfeeding and decreasing parental anxiety, stress and depression, though these were not critical outcomes.
- The GDG noted that there were limited data on frequency, duration and intensity of **education and counselling**.
- The GDG noted that **discharge preparation** also had important effects in improving parent-to-infant interaction, improving breastfeeding and decreasing parental anxiety, stress and depression, though these were not critical outcomes.
- The GDG noted that there were limited data on the frequency, duration and intensity of **discharge preparation**.
- Preterm and LBW infants often require care from multiple health workers so the GDG also noted that careful coordination of care is needed post-discharge.
- The GDG made a conditional recommendation on **peer support**, although there were no data on critical outcomes; this was because of the effects on maternal anxiety and the importance of the intervention.
- The GDG noted that there were limited data on frequency, duration and intensity of **peer support**.
- The GDG decided not to make a recommendation on **digital information systems** as there was no evidence of benefits or harms on any critical outcome.

#### Background and definitions

Supporting families to care for their sick, vulnerable, preterm or LBW infant is a basic and integral component of any health system. However, many families still feel ill-equipped to care for their preterm or LBW newborn infant at home (188,189). Families need support at all stages, starting from before conception, and including at the identification of a high-risk pregnancy, at the birth of the baby, in the health-care facility, at discharge and when the baby reaches home. Much of the support that families need to care for their preterm and LBW infants is provided through social services in high-, middle- and low-income countries. However, “what the health system can do” and the “health system building blocks” they can use (i.e. service delivery, workforce, digital information systems, medical products and technologies, financing, leadership and governance) (190) are often overlooked. Two systematic

reviews have recently assessed the effectiveness of communication and peer-support interventions for families of preterm infants (191,192). However, there have been no recent systematic reviews of the effects of other health system “building blocks” on infant mortality, morbidity, growth and neurodevelopmental outcomes.

Overall, the effectiveness evidence was derived from a systematic review of 37 trials (35 RCTs and 2 non-randomized) enrolling a total of 11 758 preterm or LBW infants from 18 countries (193) (Australia, Bangladesh, Canada, China, Denmark, Egypt, Finland, Greece, India, the Islamic Republic of Iran, Jamaica, the Netherlands, Norway, the Philippines, the Republic of Korea, Sweden, the United Kingdom and the USA). No studies were based in low-income settings. Interventions commenced either in the facility (24 trials) or in the home (13 trials). All

began after birth; no intervention started during pregnancy. No studies assessed the effect of the “usual support” that is provided to all babies, while all studies assessed only “extra support” (i.e. additional or strengthened support) needed for preterm and LBW infants. The interventions included in the studies were education and counselling (18 trials), peer support (2), discharge preparation (1), digital information systems (4) and home visits by a trained

health worker or volunteer (9). No studies on the other health system building blocks – including financing, leadership or governance – were identified. The education and counselling, peer support and discharge preparation interventions are described below. Home visiting interventions are described in section C.3. Parental leave, financing and entitlements are described in section C.4.

## Summary of the evidence

OVERVIEW	C.2a Education and counselling	C.2b Peer support	C.2c Discharge preparation	C.2d Digital information
<b>PICO</b>	<p><b>Population</b> – Families of preterm or LBW infants</p> <p><b>Intervention 1</b> – Education and counselling interventions</p> <p><b>Intervention 2</b> – Peer support interventions</p> <p><b>Intervention 3</b> – Discharge preparation interventions</p> <p><b>Intervention 4</b> – Digital information interventions</p> <p><b>Comparator</b> – Usual care</p> <p><b>Outcomes</b> – All-cause mortality, morbidity, growth, neurodevelopment at latest follow-up</p>			
<b>Timing, setting, subgroups</b>	<p><b>Timing of the intervention</b> – Birth to 6 months of age</p> <p><b>Setting</b> – Health-care facility or home in any country or setting</p> <p><b>Subgroups</b></p> <ul style="list-style-type: none"> <li>• Gestational age at birth (&lt; 32 weeks, ≥ 32 weeks)</li> <li>• Birth weight (&lt; 1.5 kg, ≥ 1.5 kg)</li> </ul>			

### Effectiveness: Comparison 1 – Education and counselling versus usual care

#### Sources and characteristics of the evidence

For comparison 1, the effectiveness evidence was derived from the systematic review, which included four trials enrolling a total of 312 preterm or LBW infants (193). The interventions included individual or group education or training (provided by health workers) of families to care for their preterm or LBW infant. Content included well-being strategies (e.g. strategies for managing stress, anxiety, depression, self-efficacy) and basic newborn-care practices (e.g. positioning, bathing, breastfeeding, thermal care, responsiveness and sensitivity). The interventions began in the facility, with some continuing at home following discharge.

#### Critical outcomes

For education and counselling compared with usual care, two trials reported growth (weight gain, length gain) and three reported neurodevelopment (cognitive and motor development). No trials reported mortality or morbidity. (Full details are provided in GRADE Table C.2a, in the Web Supplement.)

- **Growth:** Very-low-certainty evidence from one trial with 184 participants suggests an increase in infant weight (in grams) at 60 days (MD 305, 95% CI 228 to 382). Very-low-certainty evidence from one trial with 57 participants suggests an increase in infant weight (in grams) at 120 days (MD 410, 95% CI 406.03 to 413.97). Very-low-certainty evidence from one trial with 184 participants suggests an increase in infant length (in centimetres) at 60 days (MD 1.5, 95% CI 1.08 to 1.92). Very-low-certainty evidence from one trial with 57 participants suggests an increase in infant length (in centimetres) at 120 days (MD 1.2, 95% CI 0.2 to 2.6).
- **Neurodevelopment:** Very-low-certainty evidence from one trial with seven participants suggests little or no effect on motor development (BSID-III) at 6 months of age (MD 0.38, 95% CI -1.15 to 1.19). Low-certainty evidence from three trials totalling 64 participants suggests an increase in cognitive development (BSID-III) at 4–6 months of age (SMD 0.67, 95% CI 0.16 to 1.17).

### Other outcomes

There was little or no effect on infant temperament at 6 months of age (SMD 0.26, 95% CI -0.29 to 0.81; 2 trials, 155 participants). There was an increase in mother–infant interaction at 6 weeks (MD 1.8, 95% CI 0.21 to 3.81; 1 trial, 142 participants), 3 months (MD 0.8, 95% CI 0.6 to 2.2; 1 trial, 196 participants) and 6 months of age (MD 0.21, 95% CI 0.11 to 0.67; 1 trial, 63 participants), but there was little to no effect at follow-up at 12 months of age (MD 0.1, 95% CI -0.01 to 0.21; 1 trial, 93 participants). There was little to no effect on duration of exclusive breastfeeding (EBF) (MD 2.0, 95% CI -5.48 to 9.48; 1 trial, 128 participants), but there was an increase in EBF at 2–3 months (RR 1.71, 95% CI 1.26 to 2.31; 2 trials, 244 participants).

### Effectiveness: Comparison 2 – Peer support versus usual care

#### Sources and characteristics of the evidence

For comparison 2, the effectiveness evidence was derived from the systematic review, which included two trials enrolling a total of 118 preterm or LBW infants (193). The peer supporters were all women who had cared for a preterm or LBW infant in a similar environment and were willing to use their experiences to support others. The interventions all commenced in the facility and took place either following agreement from the parent or were initiated by the parent. Content included well-being strategies and newborn-care practices.

#### Critical outcomes

For peer support compared with usual care, no trials reported mortality, morbidity, growth or neurodevelopment. (Full details are provided in GRADE Table C.2b, in the Web Supplement.)

#### Other outcomes

There was a decrease in maternal anxiety when the baby reached 4 months of age (SMD 0.74 lower, 95% CI 1.32 lower to 0.16 lower; 1 trial, 49 participants). There was little or no effect on EBF (intervention group: median 3 months [range 0–14]; control group: median 4.3 [range 0–13]; 1 trial, 69 participants).

#### Subgroup analyses

The effect of gestational age and birth weight could not be assessed as there were insufficient trials for any critical outcome.

### Effectiveness: Comparison 3 – Discharge preparation versus usual care

#### Sources and characteristics of the evidence

For comparison 3, the effectiveness evidence was derived from the systematic review, which included one trial enrolling 173 preterm or LBW infants (193). The interventions were delivered by health workers in the days just prior to hospital discharge and focused specifically on preparing parents for the discharge of their infant. The content included well-being strategies and newborn-care practices, but also “anticipatory guidance” (i.e. what to expect), financial and social support information, and referral pathways.

#### Critical outcomes

For discharge preparation compared with usual care, one trial reported morbidity (emergency department presentations). No trials reported mortality, growth or neurodevelopment outcomes. (Full details are provided in GRADE Table C.2c, in the Web Supplement.)

- **Morbidity:** Very-low-certainty evidence from one observational study with 173 participants suggests a decrease in emergency hospital visits by 2 months of age (RR 0.62, 95% CI 0.39 to 1.00).

#### Subgroup analyses

The effect of gestational age and birth weight could not be assessed as there were insufficient trials for any critical outcome.

### Effectiveness: Comparison 4 – Digital information systems versus usual care

#### Sources and characteristics of the evidence

For comparison 4, the effectiveness evidence was derived from the systematic review, which included four trials enrolling a total of 902 preterm or LBW infants (193). The interventions used electronic web-based applications, including Skype, audiovisual workshops and telephone media. Content included well-being strategies and newborn-care practices. The interventions commenced either in the facility or at home.

#### Critical outcomes

One trial reported morbidity (emergency department presentations). No trials reported mortality, growth or neurodevelopment outcomes. (Full details are provided in GRADE Table C.2d, in the Web Supplement.)

■ **Morbidity:** Very-low-certainty evidence from one trial with 89 participants suggests little to no effect on emergency hospital visits by two months post-discharge (usual care group: median 1 visit [range 0–6 visits] versus digital information systems group: median 1 visit [range 0–7 visits]).

### Other outcomes

There was little or no effect on maternal–infant interaction by 1 month of age (MD -0.8, 95% CI -1.84 to 0.24; 1 trial, 129 participants) or by 4 months of age (MD -0.9, 95% CI -2.09 to 0.29; 1 trial, 85 participants). There was little or no effect on EBF by 2 months of age (RR 1.02, 95% CI 0.89 to 1.16; 2 trials, 688 participants).

### Subgroup analyses

The effect of gestational age and birth weight could not be assessed as there were insufficient trials for any critical outcome.

### 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, including supporting all newborn-care practices, and want to take an active role in deciding what interventions are given to infants, including what newborn-care practices

they receive and how they are implemented (14). No specific evidence was located about the kinds of support families of preterm or LBW babies value or find acceptable.

### Resources required and implementation considerations

#### Organization of care

Families may need education, counselling, discharge preparation and peer support at all levels of health facility care. Education, counselling and peer support may be needed at home. Support and planning should be started in the antenatal period where possible. Services should follow national and local guidance for health-care facilities.

#### Infrastructure, equipment and supplies

National or local guidance for health-care facilities should be used.

#### Workforce, training, supervision and monitoring

Health workers at all levels can provide family support. Standardized packages can be used for training, supervision and monitoring.

#### Feasibility and equity

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

## Summary of judgements

	Comparison 1. Education and counselling vs usual care (C.2a)	Comparison 2. Peer support vs usual care (C.2b)	Comparison 3. Discharge preparation vs usual care (C.2c)	Comparison 4. Digital information systems vs usual care (C.2d)
<b>Justification</b>	<ul style="list-style-type: none"> <li>Evidence of moderate benefits: increase in weight, length and neurodevelopment (<i>very-low-certainty evidence</i>)</li> <li>No evidence of harms</li> <li>No evidence on other critical outcomes</li> </ul>	<ul style="list-style-type: none"> <li>Evidence of small benefits: decrease in maternal anxiety (<i>very-low-certainty evidence</i>)</li> <li>No evidence of harms</li> <li>No evidence on other critical outcomes</li> </ul>	<ul style="list-style-type: none"> <li>Evidence of small benefits: decrease in emergency department presentations (<i>very-low-certainty evidence</i>)</li> <li>No evidence of harms</li> <li>No evidence on other critical outcomes</li> </ul>	<ul style="list-style-type: none"> <li>Evidence of little to no effect on emergency hospital visits (<i>very-low-certainty evidence</i>)</li> <li>No evidence on other critical outcomes</li> </ul>

Evidence-to-Decision summary				
<b>Benefits</b>	Moderate	Small	Small	Unknown
<b>Harms</b>	None	None	None	Unknown
<b>Certainty</b>	Very low	Very low	Very low	Very low
<b>Balance</b>	Probably favours education and counselling	Probably favours peer support	Probably favours discharge preparation	Unknown
<b>Values</b>	No uncertainty or variability about outcomes	No uncertainty or variability about outcomes	No uncertainty or variability about outcomes	No uncertainty or variability about outcomes
<b>Acceptability</b>	Probably acceptable	Probably acceptable	Probably acceptable	Probably acceptable
<b>Resources</b>	Moderate	Moderate	Moderate	Moderate
<b>Feasibility</b>	Probably feasible	Probably feasible	Probably feasible	Varies
<b>Equity</b>	Probably equitable	Probably equitable	Probably equitable	Varies