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Chapter

Parent-Carer Education: Reducing the Risks for Neonatal and Infant Mortality

Thillagavathie Pillay

Abstract

In this chapter, the role of engaging parents, family members, partners, significant others and carers (subsequently referred to as parent-carers) as key partners in targeted strategies for reducing the risks associated with neonatal mortality is discussed, especially within the context of less resource-constrained environments. Parent-carer education, sharing information on regionally prevalent risk factors and associations with death in the first 28 days of life and in infancy, can be potentially impactful and could drive behavioural changes, while promoting acquisition of newer life-saving skills such as basic life support training. Such education can be considered participatory learning and action. It affords parent-carers the confidence and knowledge on measures to key risks in infancy, such as the risk of sudden infant death, and how to recognize when their baby may be ill, facilitating timely access to appropriate healthcare services. Potentially, these then empower parent-carers to work with health services proactively in measures to reduce the risks for neonatal mortality.

Keywords: parent-carer education, reducing risks, neonatal mortality

1. Introduction

Neonatal mortality refers to deaths in the first 28 days after birth and contributes to the total burden of mortality in children. Globally, 5.4 million children under 5 years of age died in 2017, of which 2.5 million were neonates [1]. In this millennium alone, there have been overall improvements in survival in children under 5, but the greatest reduction in mortality is seen in those between 1 and 4 years of age. Between 2000 and 2017, there was a 60% worldwide reduction in mortality in this age group. In contrast, neonatal mortality reduced by 41% [1, 2]. Two key factors have influenced this improvement in outcomes: access to healthcare services and maternal education.

A faster rate of decline in childhood mortality rates compared to neonatal death rate results in the latter assuming a higher proportion of the overall burden of deaths in children. This is especially obvious in more developed economies such as in England, where, with relatively lower child and infant death profiles, the proportion of neonatal deaths to those in infancy and childhood is much higher (70%) [3]. As a result, here, the spotlight has now readjusted towards addressing neonatal mortality [4–6]. In this chapter, the potential for further reductions in neonatal
mortality is explored, especially in less resource-constrained environments, by focusing on parent-carer education around risks for neonatal mortality, while using learning points from around the world. Potentially, these initiatives empower parent-carers to acquire the necessary skills to manage their baby at risk and also engage in risk-reducing behaviours for the benefit of their baby.

2. Reducing neonatal mortality through parent-carer education

Before embarking on parent education, understanding the risk factors for neonatal mortality is important. In poorly resourced areas, key risk factors and associations are infection, hypothermia, lack of breastfeeding, failure to recognise signs of illness in their baby and failure to provide adequate basic resuscitation at birth. Education packages focused on improving neonatal mortality therefore include information on maintaining warmth; drying; wrapping; skin-to-skin contact; supporting breastfeeding; infection prevention including handwashing, cord care, recognising signs of illness in their newborn baby and infant and basic life support [7].

For neonatal teams in relatively higher resourced environments, where access to public health facilities and general maternal education are less of an issue, and most of the above are routinely adopted, what are other key risk factors and what other kinds of initiatives are needed in order to make a difference to current neonatal mortality rates, and can they work?

In attempting to address this, the key risk factors here for neonatal mortality need to be identified. The most significant of these is prematurity [8–10]. In a report on perinatal mortality from MBRRACE on 2016 deaths, approximately 70% of all extended perinatal deaths occurred preterm, and almost 40% were in less than 28 weeks’ gestation [9]. Optimising place of birth for the most vulnerable preterm births less than 26 weeks gestation at birth does reduce their mortality rates [11] and optimising nurse staffing for the care of especially preterm babies in neonatal intensive care units appears to be crucial [12]. Evidence-based or consensus medical and nursing care, robust reviews of mortalities and complex morbidities and sound clinical governance are instinctively important. But, simply improving clinical care provided, and in the correct place, is probably not enough.

By virtue of these babies being born prematurely, much of the potential factors that could influence outcome predate the birth of baby. These include obstetric, maternal health and social factors [13] and are usually out of the bounds of care of neonatal teams. For example, in the risk factors for neonatal mortality in a region in the West Midlands in England, prematurity, being born with low birth weight, congenital abnormalities, born at the extremes of maternal age, late maternal presentation for antenatal care, smoking, not breastfeeding and sudden infant death syndrome (SIDS) were the key associations with infant mortality [8]. All of these are influenced by upstream issues, that is, before birth (except SIDS). Just focusing on care pathways and postnatal care for these babies on neonatal units and in the community will have little impact on their mortality rate. A more multidisciplinary, lateral approach is needed, and there are lessons too, from developments in parent education in resource-limited environments.

Apart from optimising clinical care, what else can neonatal teams do? An area of focus for neonatal units could potentially be enhanced primary preventive care [4]. There is evidence that early parental interventions in preterm births are effective in promoting child health [14], and there is possible value in targeting parent-carer empowerment in reducing the risks of mortality for their newly born baby in
infancy and beyond. Data on this as a package of care, however, are very limited. Maternal education improves infant, child and maternal mortality globally [15–17]. These relate to mothers’ general awareness through education, which empowers women to make better decisions on the care of their baby and themselves. Engaging them in understanding the regional mortality risks for their baby, and their future babies, and what they could do to minimise these where possible may be of value. This kind of awareness of risk factors for infant mortality could provide parents and carers with knowledge that could drive longer term behavioural change that could influence the outcome of current baby, subsequent pregnancies and, in a cascade effect, those of close family members.

A recent project on parent education around the risks of mortality in a region in the West Midlands [8] in England revealed that parental uptake for the education on understanding risks for mortality was well accepted and supported (Table 1). Educating parents and carers on the basics of life support, how to manage their choking child and how to recognise that their baby is ill may empower parents and carers, enabling them to initiate preventative intervention earlier, which may be life-saving. Evidence that this can affect short-term behavioural change and empowerment through confidence building in parents appears to be possible [8], but more studies are needed in this regard.

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Table 1. 
Selected parent feedback comments for parent/carer training on a neonatal unit in the West Midlands, England. Extracted from [8].
3. The benefits of overall maternal education on infant mortality

The most significant factor globally in reducing mortality for young children under 5 years of age is maternal education, and universal primary education for mothers is an established key focus of the United Nations Millennium Development Goal [17]. Better maternal education decreases not only childhood mortality but also maternal mortality [18] and is evident across resource-constrained and resource-richer environments. This is most striking in the former, where lower levels of maternal education (i.e., less than secondary school education) are significantly associated with neonatal mortality. In resource-richer environments, this effect is less noticeable [19] but prevalent in pockets with lower socio-economic status and lower levels of maternal education [19, 20]. While not easy to tease out, it is assumed that the impact of general maternal education on infant and childhood outcomes relates to empowerment of women to make better decisions over the care of their baby and care of themselves. Therefore, any targeted education, through providing parents and carers with knowledge of risks and associations with neonatal mortality, may contribute to empowering them into making decisions in the best interest of their baby, in an attempt to reduce risks for mortality.

4. Methods of delivering targeted parent-carer education

A synopsis of this can be found in Table 2.

4.1 One-to-one point-of-care education

This refers to education around a reason for a healthcare visit, usually in the home, or a visiting point. This has its benefits, providing an opportunity for maternal and family engagement with health services and focused learning and behavioural change. It is best reported in resource-constrained environments, as evidenced by the impact of health visits and education on behavioural changes and infant mortality, in women who have recently given birth [21]. Keeping baby warm, dry and wrapped to prevent hypothermia, skin-to-skin contact, breastfeeding and infection prevention, including delivering in a clean environment, handwashing, cord care and knowing what the signs of illness are in their baby, are key aspects of shared knowledge [21]. Guidelines for postnatal care of the mother and newborn, especially in resource-limited environments, were produced by the World Health Organisation ([22], Table 3), and these include parent education via home visits in the first week after birth and at least three additional postnatal contact points in the first 6 weeks of life.

In resource-richer environments, for example, England, similar 1:1 point-of-care visits at home usually occur post-delivery, initially by midwives and later by healthcare workers. NICE Guidelines on 1:1 postnatal care [23] guide the basic requirements for routine postnatal care for women and their babies and their partners and families. Support for feeding, advice on safe sleeping, recognising and dealing with health problems for both mother and baby are included in the quality standard, but there are limitations to its success to date [24]. These are usually delivered by midwives or health visitors, as the primary healthcare contacts for a mother and family with a newly born baby.

Educational engagement with parents and carers on the neonatal unit occurs as per unit policy and can include a wide variety of information supported by online
<table>
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<td>Home visits by community health care workers [69]</td>
<td>Home visit by community-based worker after birth in India: information shared included breastfeeding, basic care of the baby—temperature control, hygiene, care of the umbilical cord stump, danger signs in the baby and how to use the healthcare system, especially for the sick, or preterm, or low-birth weight baby. There was a significant reduction in neonatal mortality rate in those who received the education (35.7 deaths per 1000 live births compared to those who did not (53.8 per 1000 live births)]</td>
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<td>Regular community group sessions by Lady Health Workers [70]</td>
<td>Group sessions by lady health workers in Pakistan included sharing information on immediate newborn care, cord care (cleaning and avoiding the use of traditional materials, such as ash and lead powder), and promotion of exclusive breastfeeding. There was also additional sharing of information on early breastfeeding (within the first hour) use of colostrum, thermoregulation, home care of low-birth weight infants, treatment of neonatal pneumonia, recognising the sick baby and danger signs needing treatment. Here the neonatal mortality rate significantly decreased from 57.3 to 41.3 per 1000 live births.</td>
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<td>Community-based package of care in [71]</td>
<td>In India, this package included birth preparedness, clean delivery and cord care, thermal care (including skin-to-skin care), breastfeeding promotion, and danger sign recognition, and in one group a hypothermia indicator. Compared with controls, neonatal mortality rate was significantly reduced by 54%.</td>
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<td>Participatory learning and action via women’s groups [25]</td>
<td>This was a meta-analysis of seven trials in India, Bangladesh, Nepal, Malawi, estimating the effect of women’s group interventions on behavioural outcomes. Women’s groups practising PLA showed improved behaviours during and after home deliveries, including the use of safe birthing kits, sterile blade to cut the cord, birth attendant washing hands before delivery, delayed bathing of baby for at least 24 hours and wrapping baby within 10 minutes of birth. Here, neonatal mortality was 32% lower in the clusters that had the intervention.</td>
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**In resource-richer environments**

| Organised support groups                                   | Peer support groups may work on one-to-one or group basis, face-to-face, via telephone, social media or social engagement and include online and physical resources for training and guidance to parents on antenatal, birth and child issues. E.g.: Child birth peer support groups, supporting antenatal, birth and parenting in the UK (NCT); https://www.nct.org.uk/ E.g.: BLISS charity for sick and preterm babies; https://www.bliss.org.uk/ |
| Support groups: local, regional, national and international [72] | E.g.: Breastfeeding support may be delivered on one-to-one or group format, at the bedside while in hospital and in the home. Breastfeeding support workers, nurses and breastfeeding buddies may be local and regional and hospital or community based. There also exists international organisational support through La Leche League International; https://www.llli.org/ |
| Support for specialised conditions/congenital anomalies     | These are usually groups based on national or international need and include for example the national Down syndrome group in the UK, and its international counterpart—Down syndrome international, which co-ordinates working with and advocating the case for children with Down syndrome in over 136 countries around the world. |

Table 2.

*Examples of parent-carer engagement: examples from around the world.*
resources and paper reading material. Guidance on basic life support is offered by some, but specific packages of information targeting knowledge around key risk factors on neonatal mortality are usually not presented in such a format to parents and carers. These may, however, be a useful point-of-care opportunity for education and training [8].

### 4.2 Centre-based peer group education

Participatory learning and action programmes promoted by the World Health Organization drive behavioural change through parent and community engagement [25].
Support groups work through community engagement, in which mothers develop and implement their own strategies for improvement, through shared peer group learning with a facilitator. The women are empowered to make improvements for their own communities, which result in behavioural changes that were more effective than simple traditional teacher/student model. In a trial in India, neonatal mortality reduced by 45%, with behavioural changes towards better hygiene practices and better newborn care, such as cord care, delivering in a clean environment and early breastfeeding [26].

In higher resourced environments, participatory learning and action can apply as well, with parents being offered information on risks for neonatal and infant mortality, knowledge on basic life support and choking, reducing the risks for sudden infant death and promoting safe sleeping and recognising signs of illness in their infant [8].

4.3 Local, regional and national support groups

In resource-richer environments, peer groups supporting the new mother may be driven by health care or by the community. Mother and baby peer groups or new parent groups are a useful way of engaging parents and family members [27] and can be local, regional or national such as BLISS, which is a national charity for sick and premature babies [28] in England. These may be one-to-one engagements or group interaction depending on resources and availability and include online resources for learning and communicating. Examples of these are shown in Table 2.

The benefits of these kinds of educational thrust on reducing mortality may be less obvious where health care is equitable to all [19], but still of value as such environments do have pockets of poorer educational levels [20], linked with greater mortality. It may be appropriate to extrapolate that the benefits of maternal peer and group education in contributing to behavioural changes that reduce the risk of mortality can possibly also apply to resource-richer environments. In the USA, an Advisory Committee on Infant Mortality identified the value of a multimedia approach in the preventive campaign needed to reduce infant mortality [29]. They suggest a life course perspective on infant mortality reduction, urging an approach that includes health promotion and optimisation throughout the course of life, in a clinical and population-based manner. Such a perspective should include focused parent-carer education and empowerment through education on risks for infant mortality. This could mean that parents have a better idea of how best and when to seek help for their baby who may be getting ill, that is, early initiation of preventative care. Although widely prevalent in higher resourced economies, very little has been studied in this regard, and this is being mapped better in more resource-constrained settings [30].

5. What should a parent-carer education package aimed at reducing the risks for infant mortality comprise?

Key parameters are driven by local epidemiological needs. It is likely that even in areas that do adopt a primary prevention package the contents will change depending on societal needs. In resource-limited environments with poor access to health care, basic hygiene around delivery, cord care, keeping baby dry, wrapped and warm, immunizations, basic life support and breastfeeding may be key [21, 22]. In less resource-constrained environments, where most of the above are standard practice, other areas may be relevant. In the sections below, some of these are described.
5.1 Breastfeeding education and infant mortality

The benefits of breastfeeding on reducing infant mortality and morbidity are widely accepted. In 2003, the Lancet published data [31] that of all children who died under the age of 5 years, 12% of these deaths could have been prevented if they were effectively breastfed as infants. This amounted to roughly 800,000 lives in low- and middle-income countries per year. In their systematic review, Sankar et al. [32] showed that the relative risk for all-cause mortality in infants under 6 months of age and not breastfed was 14.4, 4.8 in those partially breastfed and 1.5 in those completely breastfed. For children 6–23 months of age, they demonstrated up to a two-fold higher mortality (RR 1.97 [1.45–2.67]) if not breastfed, when compared to those who were. Exclusive breastfeeding are also associated with lower mortality and infection rates [33], and this impact can be seen as early as with breastfeeding given within the first hour of life [34–36]. Maternal awareness, education and support for breastfeeding to improve breastfeeding rates are therefore a critical part of the parent empowerment, in reducing infant mortality.

These benefits exist in all resource settings. For example, in Washington, Alaska, Maine, Nebraska and Ohio, promotion of the Baby Friendly Hospital Initiative saw benefits of this for mothers of lower education which were significant, increasing the breastfeeding rates for >4 weeks of life here (p = 0.02) [37]. These provide evidence for the continued thrust for promoting breastfeeding as a potential protective factor against the risk of neonatal and infant mortality, even in resource-richer environments. The Baby Friendly Initiative, developed by UNICEF, promotes breastfeeding as part of its thrust to support families with feeding, enabling the development of close relationships for the best start in life for babies.

5.2 Smoking cessation and infant mortality

The negative effects of prenatal, natal and postnatal smoking on morbidity and mortality in infants are widely described [38, 39] and include premature births, low-birth weight babies which are themselves at risk for mortality and an increased risk for sudden infant death. Smoking cessation in pregnancy or prenatally, or even postnatally, is complex. Risk factors for smoking include having a smoking partner, with a lower risk where there is higher maternal education level [40]. Mass campaigns can potentially influence smoking cessation rates in pregnancy [41]. In three states in the USA, those smokers exposed to a CDC smoking cessation campaign in pregnancy had a reduction in smoking by the third trimester compared to those who were not exposed to the campaign (34.7 vs. 32.9%; p < 0.001). In a systematic review and meta-analysis of 54 studies encompassing 55,584 women who smoked before their pregnancy, Riaz et al. [42] noted that higher educational level, higher socio-economic status, low exposure to second-hand smoke and planned breastfeeding were associated with cessation of smoking during pregnancy. So, there is potential value, extrapolating from these that an awareness programme could influence smoking cessation rates in association with pregnancy/after birth, targeting not only mothers, but their partners, significant others and family members.

Education versus incentive-based systems to reduce smoking may work to different degrees. These modern alternatives to conventional educational and awareness campaigns could include mobile apps, ipad programmes and text messages [43, 44]. But simply offering education may not be adequate, and there is much more to be done to understand this. Barriers to smoking cessation are multi-fold and may exceed support pathways. In an NIHR HTA assessment of these [45], partners’
support, willingness to change smoking behaviour and the smoking dynamics within relationships mattered, and delivery of information is a key barrier than can potentially be overcome with the appropriate educational drives. At the same time, it is important to note that up to 50% of women who stop smoking during their pregnancy resume within 6 months after birth [46]. There may be a hard core of individual mothers/parents who are unable to stop smoking, even knowing the risks to their baby. Some evidence exists that specific behavioural techniques may have an impact on prenatal smoking cessation [47–49], but the complexities around cessation in relation to pregnancy and childbirth need further interventional analysis. Despite these limitations, there may still be the benefit of incorporating smoking cessation information into parent awareness packages [8], while awaiting more effective interventions and primary preventive packages.

5.3 Safe sleep

Safe sleep programmes can make a difference to the risks of sudden infant death syndrome. In parts of the USA, interventions such as these halved the rate of infant deaths from 1.08/1000 to 0.48/1000. Research suggests that education of caregivers does result in improved understanding of behaviours that promote safe sleep and reduce the risk of SIDS [50]. Simple measures such as position of sleeping have changed SIDS rates dramatically [51]. And parent and carer education is a key directive for future reductions in this area [52]. Evidence that discharge from hospital programmes do make a difference is also emerging [53] in a pilot trial of promoting safe sleep patterns in mothers of preterm babies, who have a doubled risk of SIDS, and there is also acknowledgement that this group especially should be targeted for educational interventions to reduce the risk of SIDS. Simple educational campaigns en masse may not have the desired effect [54, 55] and additional measures may be needed such as 1:1 educational drives. These can comfortably be delivered in 1:1 or peer group packages supported by neonatal units, midwives and health care visitors as part of the point-of-care programme of education for parents and carers.

5.4 Basic life support training

Basic life support at birth is critical, and a standard practice in higher income settings where healthcare support exists at the time of birth. However, even for home births and births outside of healthcare facilities, this skill is essential. In their review on neonatal resuscitation in low-income settings, Wall et al. [56] noted that the major burden of resuscitation at birth (approximately 10 million babies do not breathe at birth, of which 6 million require basic life support) is in low-income settings. Here, they suggest that local education of community health workers can make a difference to the rate of deaths at the time of birth (termed intrapartum deaths).

In higher income settings, where there are healthcare workers trained in basic life support, there still exists a need for parent-carer education and awareness. Acute life-threatening events in infancy are the next area of concern and can affect babies as young as 0–3 months of age [57]. Bystander CPR with and without dispatcher instructions improved 1-month neurological outcomes favourably (adjusted OR 1.81 and 1.68) when compared to no bystander CPR in children with out-of-hospital cardiac arrests [58], and survival after shockable arrests was higher when delivered by a first responder or public AED rather than a paramedic (83.3 vs. 40% p = 0.04) [59]. In reporting on the Committee on Pediatric Emergency Medicine in the USA, Callahan and colleagues advocate that paediatricians should
encourage training of basic life support to parents, children, caregivers, school personnel and lay members of the public [60]. Many neonatal units do offer basic life support training for parents and carers when their baby is due to leave their unit; these boost parent confidence in being able to cope with their infant after discharge from hospital.

5.5 Kangaroo care and infant mortality

Skin-to-skin contact via Kangaroo care [61] is also an important part of a care package especially for preterm births. When compared to conventional care, Kangaroo mother care was associated with 36% lower mortality (RR 0.64), a lower risk of neonatal sepsis (RR 0.53), hypothermia (RR 0.22), hypoglycaemia (RR 0.12), hospital readmission (RR 0.42) and increased rate of exclusive breastfeeding (RR 1.50; 95% CI 1.26, 1.78) [62]. Educating and empowering mothers, on the value of such care packages, is important in reducing morbidities especially in low-birth weight infants.

5.6 Reducing the risks for congenital abnormalities

Congenital abnormalities are a major cause of infant mortality in higher resource environments, with variation between ethnic groups and a strong association with consanguinity [63, 64]. Reducing the risks for life-threatening congenital abnormalities [65] (either through the condition itself, or through its association with preterm birth) is dependent on parental awareness regarding the risks of congenital abnormality pre-conceptually, availability and uptake of screening for major congenital abnormalities, the potential for intervention, and parent perspectives on termination of pregnancy, should they carry a baby with a lethal/potentially lethal condition in utero. Where possible, parent education to raise awareness regarding the likelihood of a congenital abnormality should be discussed in the context of consanguinity and the elderly mother.

5.7 Reducing the risk of preterm birth

Risk factors for preterm birth include, among a wide array of clinical scenarios, poor maternal health, maternal infections, smoking and alcohol use in pregnancy, multiple births and extremes of maternal age [66]. The World Health Organisation [67] has set out basic advice to reduce preterm births and these include promoting a healthy pregnancy by supporting: (a) a healthy diet, (b) optimal nutrition, (c) advice on tobacco use in pregnancy, (d) advice on alcohol use in pregnancy, (e) antenatal support and scanning to detect gestational age and multiple births, (f) better access to contraceptives, (g) management of risk factors such as infections and (h) increased maternal empowerment.

In higher resource settings, strategies for prevention of preterm births include: (a) prevention of non-medically indicated late preterm/early term births, (b) progesterone supplementation, (c) cervical cerclage, (d) tobacco control and prevention of smoking in pregnancy, (e) judicious use of fertility treatments and (f) dedicated preterm birth prevention clinics [68].

All of these aspects relate to upstream events prior to birth of the baby, but still hold benefit in parent-carer education, for the ripple effect that it may have on communities, and also for guiding care around the subsequent pregnancy.
6. Conclusion

Parent education programmes, targeted around understanding and, thereby, empowering parents with knowledge around the risks of neonatal and infant mortality, are an intuitively important adjunct to neonatal clinical care. Its role in preventive neonatal care may be strong, for its potential benefits on behavioural changes that enable reduced risks for the current and subsequent pregnancies. Getting parents actively engaged in programmes that work with them for the betterment of their baby, their subsequent babies and their communities may be the key to change for the future. This embraces patient and public (i.e., parents/family members/significant others and carers) involvement in taking ownership of, and making a greater contribution to their overall health, and to that of their families.

What is now needed are focused thrusts around parent education and empowerment, based on local risk factors and associations with neonatal mortality, combined with robust scientific research to assess the impact, if any, of such programmes.

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Conflict of interest

There is no conflict of interest.

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