Caring for children with complex needs

Tendai Nzirawa discusses the involvement of the community neonatal sister in the discharge of an infant with chronic lung disease who was born prematurely

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Abstract

This article describes the role of the community neonatal nurse in the discharge of infants with chronic lung disease (CLD), or bronchopulmonary dysplasia. It also explores the use of a common assessment framework in the assessment of such children and development of a nursing care plan. The article includes a case study to illustrate the link between CLD and other diseases, and emphasises the importance of focusing on holistic care from admission, in the neonatal unit and at discharge.

Keywords
Community neonatal nursing, patient discharge, patient care planning, neonate, infant, chronic lung disease, bronchopulmonary dysplasia

THE AUTHOR of this article is a community neonatal sister working at one of England's largest acute trusts, serving a population of around 750,000 people. Every year the trust has almost 10,000 deliveries, and up to 800 infants are admitted to the neonatal intensive care unit. About 200 of these are referred to the community neonatal service for follow up after discharge with around 18 to 20 of these diagnosed with chronic lung disease requiring home oxygen.

A community neonatal sister has been operating in the author's trust since 2009, after funding from the London Perinatal Network to establish a liaison role bwteen parents and the multidisciplinary team was received.

The London Perinatal Network's aim was to achieve early discharge from the neonatal unit, freeing up more cot space to deliver a more effective and efficient service.

One of the benefits of moving some hospital services into the community is that care can be delivered closer to patients' homes, thereby increasing patient or parent choice and satisfaction, and allowing for earlier intervention (Royal College of Nursing (RCN) 2014). To build a sustainable community workforce, investment in support and training is needed to help qualified specialist nurses attain leadership roles (RCN 2014).

The community neonatal nurse is a specialist or advanced nursing role. Such nurses support parents and high-risk infants, and ensure they experience seamless transitions from hospital to their homes. The Department of Health (DH) (2009) states that all neonatal units should have access to staff who are competent in caring for babies who have been in neonatal intensive care and who are available to provide support in the community after the babies are discharged.

The author conducted a literature review of the role of community neonatal nurses in reducing length of stay and readmission to the neonatal unit. Using the keywords and phrases 'neonatal nursing', 'neonatal early discharge', 'neonatal outreach service' and 'neonatal community nurse', she searched the Cinahl, Ebsco and Ovid databases.

Inclusion criteria were that articles had involved qualitative and quantitative original research into infants from birth to two years of age. The articles had to have been published in English between 1999 and 2012 in peer-reviewed journals.

Exclusion criteria were that articles had involved qualitative or quantitative original research into children over two years of age, did not include reference to length of stay or involve community neonatal services, were not in English or were published before 1999.

Initially, the author identified 103 articles but, after applying the criteria, judged that six articles were appropriate for the literature review. After reviewing reference lists to ensure no relevant articles were omitted, she identified three more but, due to financial restrictions, she did not access them.

Research by Cappleman (2004) and Gray *et al* (2006) states that community neonatal nurses help to reduce lengths of stay because they ensure that patients have the continued support of named nurses after they are discharged from the neonatal unit, meaning that infants are less likely to be readmitted within the first year of birth. These findings are supported by the Bliss (2012) Baby Charter Standards, which state that babies and families' ongoing needs should be met at home by identifiable teams of community healthcare professionals who are appropriately skilled in delivering care in the community, and can support families to care for their babies at home. Furthermore, Meeks *et al* (2010) highlight that the role of the community neonatal nurse is to help parents to identify and acquire the essential skills and knowledge they need to care for their babies at home.

In the author's trust, the relationships between community neonatal nurses and parents are built on honesty and agreed nursing care plans. The DH (2010) states that NHS clinicians should work in partnership with patients or parents so that decisions about their babies' care are not made by clinicians alone. Care delivered by community neonatal nurses requires the verbal or written consent from parents. In the author's experience, most parents value the honesty and transparency of the community neonatal nurse service even in difficult scenarios, such as when safeguarding issues are escalated.

Challenges for the community neonatal nurse service include a lack of relevant national guidelines and educational specialist training to develop the role, as a result of which training and orientation vary across the UK. The community neonatal nurse job description states that applicants for the role should be registered nurses with neonatal qualifications. The DH (2009) states that all neonatal units should have access to staff skilled in caring for babies following neonatal care, and that these staff are available to provide support in the community tobabies once they leave hospital.

The RCN (2011) has developed competences for neonatal nurses, while Langley *et al* (2002), Cappleman (2004) and Gray *et al* (2006) describe the role of the community neonatal nurse as an advanced or specialist role with expert neonatal nurse competencies.

According to the RCN (2014), there are two types of specialist nurse: those who work in a specific environment of care and those who specialise in a specific disease or condition. The former usually have specialist practice qualifications and the latter usually work in the community or between hospital and community settings.

The Nursing and Midwifery Council (NMC) (2015) defines advanced nursing practice as highly experienced and educated members of care teams who can diagnose patients' healthcare needs or refer them to appropriate specialists.

The UK Parents of Premature Babies (POPPY) project has investigated the experiences of parents who had had preterm babies, including the services and facilities with which they were provided by neonatal units (POPPY Steering Group 2009). The project highlights the importance of community neonatal nurses in placing families at the centre of care, providing early interventions, and offering regular home visits during the transitional stage from neonatal unit to home and in the first year of a baby's life.

Walston *et al* (2011) found that, of 183 neonatal units in England, at least 66 (36%) had no community team provision. Moreover, networks in England had set no guidelines for the provision of community teams even though these play an important role in medical and nursing education. However, in 83 (45%) cases, community neonatal teams were based in the same building as the unit or in the unit itself.

The potential advantage of specialised neonatal community teams, especially those allied closely with neonatal units, is that they allow clinical decisions about timing of discharge to be tailored to each infant's circumstances (Walston *et al* 2011). Most of the community teams identified by Walston *et al* (2011) were nurse led and followed up vulnerable high-risk infants, although complications in the home were few because community nursing care can ensure early discharge and prevention of readmission.

Although community neonatal nurses are lone workers, no single professional has a full picture of the needs of a child, and babies' healthcare needs are best addressed when agencies work together. The importance of such child-centred care approaches is illustrated by findings from serious case reviews (HM Government 2015).

A case study concerning discharge of an infant with complex needs is shown on page 34. In accordance with the NMC (2015) code of conduct, the name of the child concerned has been changed to ensure anonymity.

Discussion

Chronic lung disease The World Health Organization (WHO) (2013) defines preterm birth as a baby born alive before 37 weeks of pregnancy. Based on a baby's gestational age, there are three categories of preterm birth: less than 28 weeks, between 28 and 32 weeks, and between 32 and 37 weeks.

According to Bliss (2010), one in nine infants is admitted to a neonatal unit because of prematurity. About one million babies die each year due to complications of preterm birth (WHO 2013). If a baby born preterm survives, he or she is likely to face a lifetime of disability, including learning disability, and visual and hearing problems (WHO 2013).

If a baby is born preterm, acquires in-utero or postnatal infections, has been ventilated, and/or has had an induced lung injury, then lung inflammation, pulmonary oxygen toxicity and oxidant injury are implicated in the pathogenesis of bronchopulmonary dysplasia (BPD), also referred to as chronic lung disease (CLD) (Zhang *et al* 2011). According to Balfour-Lynn *et al* (2009), infants who are at least 28 days old and who require supplemental oxygen at a corrected age of 36 weeks gestation are said to have BPD.

Contributory risk factors for BPD include a gestational age of less than 30 weeks, maternal chorioamnionitis, ventilation-associated pneumonia and more than three blood transfusions (Zhang *et al* 2011). A birth weight of less than 1,500g is a strong dominant predictor for the development of BPD, with signs of the condition identifiable at 36 weeks post-menstrual age (Zhang *et al* 2011). When discharge for babies with CLD are being planned, the babies should be identified as having complex needs.

Groenendaal *et al* (2010) and Philip (2012) state that there are two types of BPD: 'classical'

Case study

Chipo is a female infant born at 30 weeks' gestation by emergency Caesarean section because her mother had deteriorating haemolysis, an elevated level of liver enzyme and a low platelet count (HELLP), as well as pre-eclampsia and intrauterine growth restriction. The mother was given steroids at least six days before delivery.

At birth, Chipo weighed 725g and was admitted to the neonatal unit, where she was given surfactant to reduce surface tension in the alveoli and prevent collapse at end-expiration, thus reducing the work of breathing (Stephenson *et al* 2000). She was ventilated for three days, and put on continuous positive airway pressure and then low-flow oxygen for 61 days. She was also given antibiotics prophylactically from birth until day four to prevent sepsis, and again on day 34 after a blood culture produced a positive result for *Escherichia coli* sepsis. She was also given five transfusions of red blood cells.

Chipo remained hospitalised for almost 12 weeks and her mother visited daily, at times staying until late at night, especially when Chipo was unsettled. On the 46th day after her birth, Chipo was given diuretics. Her oxygen requirement increased from 0.2L/min to 0.4L/min and she was given oxygen therapy. She subsequently remained on continuous low flow oxygen of 0.1L/min.

Chipo was assessed as a preterm baby with bronchopulmonary dysplasia (BPD) who should be discharged on home oxygen and receive follow-up care due to delayed development and a failed hearing test.

During the daily ward rounds, the neonatal unit's consultant doctor confirmed that Chipo had BPD and plans were made to discharge her with continues home oxygen. Her parents were informed during the visiting time, and the family care co-ordinator gained their consent to order home oxygen equipment. The family care co-ordinator then informed the community neonatal sister, who carried out a home assessment between 48 and 72 hours before discharge. The multidisciplinary team and the parents attended the discharge planning meeting, which was used to finalise a discharge date.

As soon as the multidisciplinary team identified her as medically stable for home discharge, provisions were made to transfer Chipo to the trust's level 1 special care baby unit and for her to have home oxygen. Immediately, the parents were encouraged to be involved in learning how to care for their baby with continuous low-flow oxygen. This gave them an opportunity to build their confidence in caring for Chipo, and their ability to recognise when she was distressed or unwell. Meanwhile, appropriate referrals were made to ensure that follow-up appointments were set to monitor and review Chipo's neurodevelopment and BPD.

and ‘new’. The latter was identified in 1997 after the introduction of the endotracheal administration of surfactant (Groenendaal *et al* 2010). It is identified in babies with arrested alveolar and vascular development of the lungs who require continuous oxygen requirement at 36 weeks gestational age (Gupta *et al* 2012). Management of BPD with steroids has produced positive results (Gupta *et al* 2012), although Zhang *et al* (2011) state that the use of antenatal steroids and surfactant increases incidence of BPD, while steroids such as high-dose dexamethasone can affect neurodevelopment long term (Radermaker *et al* 2008).

Philip (2012) states that diagnoses of BPD can be subject to bias because of the reliance on oxygen saturation monitors in many hospitals. A baby with BPD needs saturation of more than 93% to minimise the risk of apparent life-threatening events, suboptimal growth and impaired sleep quality (Balfour-Lynn *et al* 2009).

According to Zhang *et al* (2011), BPD is the major complication for surviving very premature babies. Gupta *et al* (2012) explain that new BPD may cause reactive airway disease, and asthma in childhood and adolescence. However, new BPD also has non-pulmonary long-term consequences, which include poor co-ordination and muscle tone, difficulty in walking, vision and hearing problems, delayed cognitive development and poor academic achievement (Gupta *et al* 2012). Zhang *et al* (2011) state that increasing survival rates of very low-birthweight babies mean that these babies experience multiple morbidities, which require complex, lengthy and costly medical management.

Balfour-Lynn *et al* (2009) identify that neurodevelopment reviews are more likely beneficial for babies with BPD. However, Allen *et al* (2004) found that higher maternal perception of child vulnerability is correlated with worse developmental outcome in premature infants with CLD at one year adjusted age.

Assessment The DH (2009) points out that each neonatal network should have capacity to provide all levels of neonatal care for at least 95% of babies born to women it has booked for delivery. However, the DH toolkit also states that planned capacity should not exceed an average occupancy of 80% because there is a significant increase in mortality above this level.

On the author’s neonatal unit, the common assessment framework (CAF) is often used to assess and plan for discharge, especially of babies with complex needs. The Children’s Workforce Development Council (2009) describes the CAF as a ‘framework developed to help practitioners working with children, young people and families to assess children and young people’s needs for earlier and more effective services, and develop a common understanding of those needs and how to work together to meet them’. The CAF should ensure that families need to tell their stories only once (Powell 2013).

In such circumstances the nurse’s role is to work with patients to identify their nursing needs and preferences, and to gather information on behalf of other professionals involved in their care (Howatson-Jones *et al* 2012). It is beneficial to have a single assessment integrated into local hospital, community and social services, but nurses must be prepared to share the information on CAF documents and require training to access them on computers (Lees 2007.)

The Department for Education and Skills (2007) explains the use of CAF as a tool for early intervention for children identified as having additional needs. Howatson-Jones *et al* (2012) state that an assessment tool provides a way of mapping a problem or potential problem that can be easily communicated to the multidisciplinary team. They also state that an assessment tool is only as good as the knowledge and expertise of the person using it.

The neonatal unit where Chipo was an inpatient has two teams that facilitate discharge. The first is the family care co-ordinator team, whose role is to identify and support the parents ready to be discharged with their babies. The second is the team of community neonatal sisters, whose role is to follow up babies discharged from the unit and to support parents to care for their oxygen-dependent babies until they have been weaned off oxygen. According to the National Institute for Health and Care Excellence (NICE) (2010), neonatal units must show evidence of having trained and competent multidisciplinary teams who can deliver care in neonatal settings. Bliss (2012) agrees that such resources are needed to ensure that staff can provide seamless and supported patient journeys from unit to home.

According to the unit’s guideline, if a neonate requires more than 0.1L/min of oxygen and/or has failed to be weaned off oxygen at least once, provision should be made to discharge on home oxygen. Bliss (2012) states that decisions made in a baby’s best interest are based on evidenced and best practice, and are informed by parents who are encouraged and supported in the decision-making process. The POPPY Steering Group (2009), meanwhile, states that improved communication and parental involvement in their babies' care promote positive parent-child interaction and wellbeing while reducing preterm infants' lengths of stay in neonatal units, their need for re-hospitalisation and their long-term morbidity.

The Department of Education (2012) states that the pre-CAF is the first assessment that enables practitioners to make decisions about the types of referral needed, safeguarding, and specialist or holistic assessment. Field and Smith (2008) state the purpose of an assessment is to identify what treatments, services or care patients need and want.

Howatson-Jones *et al* (2012) argue, however, that using an assessment tool incorrectly can under- or overestimate a patient's risk of a particular problem or lead to inappropriate use of resources. Therefore, healthcare professionals must know how to use assessment tools, and use it continuously to develop their skills and confidence (Howatson-Jones *et al* 2012).

Discharge planning Bliss (2010) found that only slightly more than half of parents in neonatal units in England had agreed plans at discharge. Guidelines set by the British Thoracic Society (Balfour-Lynn *et al* 2009) describe the importance of discharge planning meetings with the involvement of parents to ensure safe and smooth transitions into the community, and to avoid repeated or unnecessary hospitalisation. However, when discharging babies with oxygen dependency home, hospital staff must ensure that each baby's oxygen saturation levels are stable, with a mean of 93% or above and no episodes of desaturation.

Additionally and importantly, the parents should have undertaken structured educational programmes and feel competent to care for their baby (Balfour-Lynn *et al* 2009).

In the initial assessment and discharge planning for a baby on home oxygen, lead professionals must ensure that care is co-ordinated, and that discharge is safe and effective (DH 2009). Parents should not only be involved in their babies' care, but should consent to it from admission to discharge (DH 2009, Powell 2013). According to Powell (2013), each lead professional should be selected at a discharge planning meeting and given responsibility to act as a single point of contact and co-ordinate the action plan, which should be reviewed regularly.

High-risk infants remain vulnerable after discharge from neonatal units (Gray *et al* 2006). Before discharge, therefore, families should be empowered and supported by neonatal nurses to deliver all aspects of their babies' care at home (Bliss 2009).

The POPPY Steering Group (2009) emphasises the importance of neonatal units giving parents ongoing support after discharge. Home visits from professionals with specialist knowledge in caring for premature babies is highly valued and Langley *et al* (2002) found that the median length of stay was reduced by 12.6% where a community neonatal service was provided.

Box 1 describes the preparation required by nurses and other healthcare professionals before an infant can be discharged home. Table 1 is the community neonatal service discharge checklist used by the author's trust.

Box 1 Discharge planning

- Discharge planning meetings should be arranged and held between 24 and 48 hours before discharge to ensure relevant issues are addressed early. Parents, carers and appropriate multidisciplinary team members should be encouraged to attend.
- Neonates should be breast or bottle feeding and clinically stable.
- Oxygen saturation monitoring should be performed every four to six hours, including while neonates are awake or asleep and during their feeds, to spot desaturation, diagnose sleep apnoea and monitor ambulatory oxygen flow rate. Saturation should be maintained above 93% on oxygen and there should be no frequent episodes of desaturation and/or bradycardia.
- Neonatal nurses should ensure that good records of activities and observations are kept to monitor how many L/min of oxygen neonates require before their discharge home. Oxygen requirement should be 0.5L/min or less.
- Neonates should not be sent home with nasogastric tubes and oxygen therapy to avoid increasing stress on parents or carers.
- All medications for neonates should be reviewed and ordered from pharmacies between 24 and 48 hours before discharge to minimise delay and ensure parents are taught how to administer them before discharge.
- Neonates must be medically stable and fit for discharge under consultant reviews.
- Parents or carers should be encouraged to spend at least one or two nights in the hospital parents' room caring for their babies before discharge to build their confidence. They should also be informed and encouraged to participate in teachings to care for their babies on oxygen therapy.
- Discharge should be timed at the beginning of the working week to optimise the number of home-support visits.
- Parents or carers should be given telephone numbers, including emergency numbers, for all relevant healthcare professionals and the company providing oxygen therapy.

Holistic care Early parenthood is especially complex for parents of preterm and term infants with ongoing medical issues (Cowan and Cowan 1992). When mother and infant are separated for long periods due to prolonged hospitalisation, contact is needed to facilitate mother-infant attachment and increases the infant's responsiveness to care giving (Lee *et al* 2009).

Table 1 **Community neonatal service home oxygen therapy discharge checklist**

Neonate's name.. **Date of birth**...

Hospital number.. **NHS number**...

Checklist	Yes (tick)	Date	Name	Signature
The neonate has a prescription for home oxygen				
A discharge planning meeting has taken place				
All equipment necessary for the supply of home oxygen has been supplied				
The parents or carers have been trained in the technique and management of home oxygen delivery, and are confident in using the equipment				
They have had written and verbal information about home oxygen therapy safety				
They have been taught how to observe their child's breathing pattern, know how to interpret it and can act on this information				
They have been taught how to use the apnoea monitor or respiratory monitor				
They have had basic life support training				
They have been given a list of contact details for health professionals involved in their baby's care after discharge from hospital				
They have been informed of the systems that enable them to order and reorder supplies, including nasal cannulae, oxygen cylinders and tapes to secure cannulae				
They have been given information about travelling outside the home				
They have been given safety information				
They have informed their car and home insurance companies that they must carry and store oxygen				
They have informed that they can apply for disabled parking badges for as long as their baby is on home oxygen therapy				
They have informed that they can apply for disability living allowance for as long as their baby is on home oxygen therapy				
They are aware of the importance of early contact with the community neonatal sister, health visitor or GP				

(Adapted from Balfour-Lynn *et al* 2009, Department of Health 2009, Bliss 2012)

Parents' experiences Between January 2010 and April 2011, the author and two medical professionals conducted a survey to identify how parents of infants on home oxygen coped. To avoid bias in the survey, 24 questionnaires were sent out by post to all eligible participants. Eighteen responded. One parent stated: 'I have to stay home and take care of [my baby] because I did not want to expose him to cold and infection'. Another parent commented that 'home oxygen is mildly irritating but considering what it is for it is worth it'.

According to Murdoch and Franck (2012), mothers with infants on home oxygen dependency found it challenging and felt unable to leave the house due to the infant's daily medical needs. Furthermore, it has been found that the mothers of infants with especially low birth weight and BPD displayed greater anxiety than other mothers (Allen *et al* 2004). Although, Discenza (2009) states that mothers whose babies are in neonatal units dislike talking about their fears in case their babies are taken away from them. It is part of the role of healthcare professionals to reassure such mothers and provide them with as much support as possible.

Discharging babies home on oxygen can improve their neurological development, and parent-baby attachment, while reducing the risk of the babies acquiring nosocomial infection (Bliss 2011).

If such babies develop respiratory infections, their discharge can place a burden on their families (Bliss 2011). Murdoch and Franck (2012) point out that, a few months after hospital discharge, mothers start taking a more positive view of the future for their babies. However, Cappleman (2004) and Gray *et al* (2006) state that the first year is more difficult for parents of preterm infants than for those of term infants.

It is therefore important for neonatal nurses to support and teach mothers to identify infant behaviours and acquire care-giving skills to enable them to cope (Cappleman 2004). In this context, community neonatal nurses can reassure parents, who often form relationships with them that continue after community discharge (Cappleman 2004).

Conclusion

As this article makes clear, CLD in neonates requires multidisciplinary team input to achieve successful hospital discharge on home oxygen. Community neonatal services are also needed to reduce lengths of stay and support parent-infant relationships. In-depth financial analysis of the effect of neonatal services would be helpful, especially in the present cost-saving economic situation that is forcing some trusts to make potentially short-sighted savings (Bliss 2010). However, other trusts are investing in community neonatal services to reduce length of stay and reduce readmission (Bliss 2011).

Recommendations for practice

- Consider how neonatal units can develop or enhance community neonatal services.
- Ensure that community neonatal nurses have specialist knowledge and skills in neonatal units to reduce lengths of stay and minimise parental anxiety, especially after discharge.
- Develop community neonatal nurses competences.
- Provide allocated time for education of theory and skills for community neonatal nurses so that they can enhance their knowledge and maintain registration.
- Ensure national policy and guidelines for community neonatal nurses are in place.
- Monitor nurse-patient ratios to ensure the safe delivery of neonatal nursing care in the community.

Online archive

For related information, visit our online archive and search using the keywords

Conflict of interest
None declared

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