Growing up: The future for neonatal unit graduates

Those who survive neonatal disease and graduate from intensive care are at risk of many diverse complications for which monitoring and surveillance are necessary. However currently there is no agreed model for such care. External influences impact on our ability to provide this care, thereby necessitating discussion regarding how to deliver high quality programmes of neonatal follow-up over the next decades.

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Key points

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1. There is a need for skilled monitoring and surveillance of survivors of neonatal intensive care.
2. There is no agreed model nationally or internationally for neonatal follow-up services.
3. Assessment for neurodevelopmental delay and neurological disability remain one of the most important parts of the follow-up service.
4. Future delivery of follow-up services remains uncertain due to potential reconfiguration of paediatric care in the UK.
5. A networked multi-professional programme may provide the most successful option.

To the casual observer, successful neonatal care may appear to end at the door of the neonatal unit along with the appreciations and farewells. However this is merely the end of the beginning, as the reality of life outside the neonatal unit commences for infant and family. This article examines the role of neonatal follow-up and some of the factors that determine how such services are currently delivered and the options for the future.

Why undertake neonatal follow-up?

Although less adrenaline-fuelled than neonatal intensive care medicine, long term neonatal follow-up care is important in its own right. The combination of our ability to maintain life and increase the chance of survival of the sickest and most preterm of infants, coupled with advances in intensive care treatment, creates an environment where long term management of ongoing clinical problems may be necessary[1]. Furthermore, complications in neonatal survivors may take time to manifest and therefore clinical surveillance for such uncertainties is necessary.

Clinical scenarios requiring active clinical management are obvious. Infants requiring domiciliary oxygen require a high level of medical and nursing expertise to ensure that treatments are sufficiently sensitive to the infant's changing health and requirements (**FIGURE 1**). Despite the centralisation of organisation of domiciliary oxygen supply in the UK[2], there is still a requirement for local technical and nursing input.

A small proportion of infants will be discharged home with supplemental feeding requirements that may include a nasogastric tube or gastrostomy feeding. Both initial and longer term nursing support for such infants and their carers are crucial including direct access to skilled paediatric medical and nursing care. In all scenarios, there is a major advantage in ensuring appropriate communication between all of the health professionals involved. Such coordination can be facilitated under the umbrella of the neonatal follow-up programme.

Probably the most significant other role of neonatal follow-up is to ensure adequate monitoring and surveillance for potential complications of either prematurity or neonatal treatment. Monitoring may include serial growth measurements or calculation of dose changes for medication, such as diuretics or drugs employed in treating infantile gastro-oesophageal reflux. Whilst some general practitioners have experience in calculating medication dose changes for infants and children, many do not and are reluctant to embark upon prescribing unfamiliar, unlicensed or off-licence drugs[3]. Surveillance covers many different aspects of care, but most importantly surveillance that ensures appropriate neurodevelopment progress remains a key part of neonatal follow-up.

Many studies, including the UK EPICure study[4], have shown that a significant proportion of the most preterm infants are at risk of moderate to major neurological disability. It is not only preterm infants who may be adversely affected but also those of any gestation who suffer peripartum hypoxia resulting in neonatal encephalopathy. It is by discussion with parents, clinical observation, physical examination and assessment against recognised criteria that neurological and neurodevelopmental deficits may be identified at the earliest age and appropriate therapeutic input introduced.

Coordinating clinical care

For some infants, their medical problems are sufficiently complex to necessitate the input of many health professionals and even multiple clinical teams who may be based at geographically separate sites. The core local neonatal follow-up service is usually best placed to coordinate these different teams to ensure a successful programme of care. In the UK it is often difficult to arrange multidisciplinary team meetings, bearing in mind geographical separation of teams and their different working patterns. If care cannot be coordinated, this leads to parental distress, anxiety and potential loss of confidence in their healthcare teams. Poor coordination may lead to missed opportunities or unnecessary investigations.

Whilst it is not impossible for an interested primary care team to function in this role, this is generally not practical in most circumstances. For some primary care teams who may not be used to caring for infants who have graduated from neonatal intensive care, general advice regarding infant care such as weaning or growth monitoring may be challenging.

Research and audit

Although the need for research to inform clinical practice and for audit to confirm neonatal standards of care is not in question, it remains a challenge for many units, particularly those outside level 3 neonatal intensive care, to collect data or participate in research. The advent of accepted computer data packages such as SEND (Southern England Neonatal Database) will facilitate data capture and, hopefully, meaningful local audit as well as contribute to neonatal research.

Research on a local level is often driven by interested individuals. However for major clinical questions, only multi-centre trials will suffice. Although participation by units remains generally good, this becomes more problematic if data collection includes those in long term follow-up, unless under the auspices of a high profile group such as the British Paediatric Surveillance Unit (BPSU). Several reasons may account for this including the variability in clinic organisation, external pressures on clinic follow-up (particularly time available), the lack of dedicated resources to collect, collate and forward data to the nominated centre together with the relatively low profile of such research. Groups such as the EPICure Study Group have tried successfully to circumvent this by specific questionnaires and data collection by the study's own team.

Parental support and feedback

Finally, and by no means the least important, is the opportunity to support parents and receive their feedback. Support may merely involve listening to their views or concerns, but may also include tasks such as reviewing periods of intensive care in which parents can no longer recall important details. Occasionally misperceptions regarding clinical problems that may have occurred can be rectified by a joint review of the hospital notes. Despite regular formal and informal meetings during their baby's stay in the neonatal unit, parents may feel that they have remaining questions that can be answered during follow-up.

Many current popular 'baby books' on sale appear dogmatic in terms of developmental milestones, weaning and general infant care. These may not always be appropriate to the needs of the ex-preterm infant or survivor of severe neonatal disease. An explanation of why a particular baby may not be conforming to the 'norm' as dictated in the book may be extremely reassuring. Advocating an alternative and possibly more successful approach may improve the quality of life for the whole family. Occasionally, discussion with parents may unearth rather more fundamental concerns or complaints regarding care. Sensitive, open and honest explanations may avert a more formal complaint.

On a social level, it is beneficial to try to cohort peers receiving follow-up, thereby allowing families, who were together during the neonatal unit weeks, to meet up again. In an attempt to facilitate this, the author's unit's local neonatal charity 'Born Too Soon' has a presence in many of the clinics – not only for fund raising purposes but also for parental and family support via the family support worker. This important key worker also facilitates the local 'coffee mornings' for parents of infants discharged from the neonatal unit which is held away from the hospital site.

How should neonatal follow-up be delivered?

There is no easy answer to this question. Most neonatal follow-up programmes are evolutionary in nature. The author's own clinic has been chameleon-like over the decades, having been initially devised as a multi-professional 'one-stop' facility with all local neonatal graduates attending on the same afternoon. In addition to the paediatric medical staff, the clinic included an audiologist, specialist dietitian, liaison health visitor, community liaison neonatal sister and, on occasions, some of the neonatal unit nurses who had been trained in aspects of neonatal follow-up. Such a multi-professional clinic was difficult to maintain. With the advent of universal (rather than targeted) newborn hearing screening, the need for an audiologist to be present was no longer required. With the pressure on time and staffing, the input of the neonatal nursing team ceased.

Currently the neonatal follow-up programme is conducted on several weekday afternoons, partly because of patient numbers, but also in recognition of the impact of changes in working hours consequent to the 2003 consultant contract. Separate clinic sessions that are nurse-led occur during the winter season for administration of palivizumab to those infants at particular high risk for contracting respiratory syncytial virus (RSV) bronchiolitis.

Nearing the corrected age of 12 months of life, all infants at risk of neurodevelopmental problems by virtue of their prematurity, birth weight or clinical problems in the neonatal period, undergo formal developmental assessment by the neurodevelopmental/neurodisability paediatrician.

Gastro-oesophageal Reflux Feeding Clinic

Locally one of the major issues identified by therapists and medical staff during neonatal follow-up was the number of babies with persisting, and clinically important, infantile gastro-oesophageal reflux (GOR). Whilst the clinical impact of GOR in babies during their stay in the neonatal unit remains controversial[5], it appears that significant GOR is a major factor in the development of dysfunctional feeding leading to marked aversive behaviour, difficulty in swallowing, problems coping with lumpy food and general delay in weaning[6]. Therefore a specific multi-professional clinic has been developed incorporating a paediatrician, paediatric dietitian and specialist speech and language therapist. This team streams those infants with particular feeding problems associated with GOR, enabling appropriate treatment and therapeutic interventions to occur earlier than previously possible. This is with the express aim of reducing the number of 'problem feeders' presenting later, a large percentage of whom were survivors of neonatal intensive care.

An international perspective

Elsewhere solutions to the model of neonatal care may be very different. In the USA, Utah's state-wide neonatal follow-up programme aims to target specific groups of neonatal survivors based upon birth weight, severity of clinical intervention and the presence of neonatal encephalopathy. The service aims to provide periodic follow-up for two-and-a-half years utilising an impressive number of health professionals whilst ensuring this is complementary to local follow-up provision. Similar practices occur elsewhere in North America with, on average, a three year follow-up time. Although such networked solutions appear attractive and would certainly facilitate both data for research and audit purposes, there is little evidence to support this model over a looser model described as 'community follow-up' that utilises telephone contact and primary care surveillance[7]. This was considered both a more cost-effective model and less disruptive to the individual families. Such approaches have been further described and deemed both successful in terms of infant neurodevelopmental outcomes and cost-effectiveness to the health economy[8].

So who should provide neonatal follow-up?

Hospitals?

For some paediatricians, providing neonatal follow-up is not a high priority. In the past such services, like many others, were heavily dependent upon the use of paediatric trainees. Nowadays the unavoidable tension between service and training rightly precludes unsupervised outpatient care including neonatal follow-up. However, although it is recognised that it is important for neonatal trainees to gain both exposure to and experience in neonatal follow-up, there are no specific training requirements over and beyond numerical attendances and basic competencies, unlike formal training programmes advertised abroad.

Trained neonatal nurses have been employed to undertake some of the follow-up role[9]. Currently in the UK neonatal nurses remain a scarce resource and many units are unable to attain the British Association for Perinatal Medicine (BAPM) standards for the level of staffing their units, without contemplating utilising nurses in neonatal follow-up roles. It is therefore unlikely that utilising neonatal nurses or advanced neonatal nurse practitioners in this role will be a feasible alternative.

Primary care?

Can primary care undertake this role? Whilst health surveillance may be considered to lie within the remit of primary care, it is unlikely that any particular health professional will have the requisite skills to undertake this role in the current primary care configuration of the NHS. In his recent publication 'Healthcare for London: A Framework for Action'[10], Professor Sir Ara Darzi suggests a seismic change in how clinical care should be provided. In particular, based upon both financial estimates and a perceived appropriateness for the needs of those living in London, the report suggests vertical integration between primary and secondary clinical care. According to the report, traditional outpatient care should be transferred out into the community to polyclinics that will house general practitioners, other health professionals and visiting, possibly peripatetic, specialists. Within this framework, paediatricians may find themselves both delivering and supervising others in providing neonatal follow-up.

The movement of neonatal follow-up into the 'community' may also solve some of the issues arising from the impact of performance management constraints such as a reduction in the number of clinic follow-up appointments permissible within commissioning intentions. Whilst it is perfectly reasonable to ensure that inappropriate frequency of review is eradicated, it will be unfortunate if neonatal follow-up is inappropriately curtailed, posing both a clinical risk and a risk to research and audit, for solely monetary or political reasons.

Tertiary centres?

Can tertiary level 3 centre-based networks undertake this work? This is certainly attractive if the profile of neonatal follow-up among trainees is to be raised. Such arrangements already exist to a degree with periodic review at the level 3 unit in parallel with local follow-up. A network need not lose the benefits of local follow-up in terms of ease of travel for families and the local interplay of often geographically localised therapists. However more formalisation of networked neonatal follow-up might prevent unnecessary repeat of clinical investigations and avoid unfortunate friction or confusion that can occur between distant and unfamiliar clinical teams.

What is the future?

In the current medico-political climate, and at a time when the future of paediatric services seems under scrutiny, it is difficult to predict how to juxtapose our desires to provide optimal neonatal follow-up with the reality of possible service reconfiguration. Certainly networking is the current mantra and therefore it seems logical to extend this theme to neonatal follow-up. A nationally agreed schedule for follow-up would underpin such arrangements that might also borrow from the more successful of low-key follow-up initiatives from abroad, including regular scheduled telephone contacts with parents and carers. The development of the electronic care record service may facilitate such a system, whilst periodic assessment by a trained multi-professional team in a one-stop process might appear to be a good use of resources. It is unlikely that every hospital will be able to either host or staff a neonatal follow-up clinic-based programme. This may well occur due to reconfiguration of hospitals or a transfer of work to polyclinics. More likely the continuing problems in recruiting staff and the competing demands on both trained and trainee staff will prevent every hospital from continuing its service in isolation.

Conclusion

For those who survive a stormy neonatal period, ongoing care and surveillance for complications is mandatory. Early intervention supports improved outcomes in many instances. The requirement is not in doubt, although how to deliver such programmes and by whom, remain uncertain as major changes in the delivery of health care are debated. We owe it to the infants and their families under our care to determine the optimal way of ensuring their future safety.

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Born Too Soon™ is a registered charity attached to the Kingston Hospital Neonatal Unit. We were set up in 1985 by parents such as myself and staff in order to offer information and support to families whose baby/babies are being cared for on the neonatal unit. I am on the unit on a daily basis to offer support to families.

Born Too Soon also purchases equipment for the unit. We set up a parents' support group outside the hospital at Welcare House, 53-55 Canbury Park Road, Kingston, which meets every Wednesday 1.00-4.00pm. We hold a graduates' party every year for our special babies who have been cared for on the unit. Next year's party is being held on Sunday 2nd February, 2008, between 12.00 Noon and 4.00pm. All the parents whose babies have been cared for on the unit in the previous year receive an invitation. We usually have up to 400 families attending.

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