

The outcomes of neonatal intensive care

Let's use the results of research into early intervention

Deform'd, unfinish'd, sent before my time
 Into this breathing world, scarce half made up,
 And that so lamely and unfashionable
 That dogs bark at me, as I halt by them;¹

Shakespeare identified the association between prematurity and disability 300 years before Little's classic description of spastic diplegia in 1862. Disability in surviving premature infants is still an important problem, particularly in those of extremely low birth weight.² Most of the data on the incidence of disability and the costs and benefits of neonatal intensive care units come from a few research centres. A broader picture could be obtained by a standardised nationwide approach to the collection of data. There are two separate issues. Firstly, what are the outcomes of interest and how should they be monitored? Secondly, what proportion of childhood disability is attributable to the increased survival of babies nursed in neonatal intensive care units and how is the epidemiology of disability changing as a result?

A recent report highlighted the inadequacies of the collection of data currently and proposed that both issues could be addressed by collecting and linking two minimum datasets.³ The first would be of neonatal data, including demographic, obstetric, and perinatal data for each neonate and additional items for infants who had been admitted to neonatal intensive care units. The second would entail evaluating every 2 year old for disability.

Could a minimum dataset on all 2 year olds be collected during routine child health surveillance and be stored on a community child health computer? Unfortunately, obstacles exist to this apparently simple task. Firstly, child health surveillance in the 2 year age group has never been complete,⁴ and considerable extra investment would be needed to improve it. Secondly, in epidemiological surveillance the condition, event, or procedure in question must be defined precisely. The rigorous definition of cognitive and language impairment is notoriously difficult, particularly in 2 year olds, and assessment needs considerable skill. Reasonable reliability between observers is hard to achieve but would be essential to ensure comparable results between districts. Furthermore, although computer systems manage immunisation and biochemical screening programmes successfully, measures of child development and disability are harder to adapt to the constraints of existing computer software. Thirdly, in child health surveillance there has been a move away from routine standardised checking for "defects" in

favour of a more flexible health promoting approach.⁵ Purchasers and providers would view reversal of this trend as regressive.

Most of these difficulties could be overcome, but how much would it cost to do the job properly? Collecting information on every child is expensive. Two or three extra professional and clerical staff would probably be needed in each district. The cost in England and Wales might be around £5-10 million a year. This money could be spent in ways that would benefit children and their parents more directly.

Is the second birthday the optimal age for a formal re-examination of every graduate of neonatal intensive care? In well run neonatal intensive care services with adequate follow up⁶ retinopathy of prematurity (the main visual deficit) and sensorineural hearing loss should be detected within the first three months, and most of the remaining severe impairments, such as cerebral palsy and severe intellectual deficits, can be found before the first birthday. With increasing knowledge about the predictive importance of neonatal encephalopathy and of imaging⁷ before discharge, the age at which follow up is performed can be targeted at the babies at high risk more precisely than was possible 20 years ago.

The aim of neonatal intensive care is no longer merely survival or avoidance of severe disability but rather the preservation of normal brain function. Other indicators of good care have become more important, such as the incidence of learning deficits,⁸ minor movement disorders,⁹ behaviour problems,¹⁰ and child abuse. These problems often need additional educational support¹¹ and probably have an adverse long term prognosis for employment—but they cannot be identified reliably at age 2 even by experts. The true outcomes and economic costs of intensive care, and the impact of disability, cannot be assessed unless progress is monitored at least until the early school years.

How else could better monitoring be achieved? Firstly, a consensus among neonatologists on the role and function of follow up clinics for those at high risk is needed. Secondly, each neonatal intensive care unit could employ someone trained in counselling, child development, and psychological assessment to follow up its graduates. They would provide anticipatory guidance and support to the parents¹² and collaborate with education departments in developing early intervention services for specific groups of infants.¹³ Lastly, research could be commissioned at national level, involving health, education, and social services, to improve computer systems, develop better registers of children with special

needs, and simplify the sharing of information among these three key agencies. These registers could then be used more readily than at present to monitor the contribution of graduates from neonatal intensive care to the total burden of disability.

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Rationing intensive care

Preventing critical illness is better, and cheaper, than cure

Lassen's now classic description of the polio epidemic in Copenhagen in 1952 has many messages for modern intensive care. He showed that deaths from respiratory failure fell from 87% to 40% with the change from cuirasse ventilation (the iron lung), with an unprotected airway, to manual positive pressure ventilation through a cuffed tracheostomy tube using medical students as the power source.¹ He was the first to describe the geographical concentration of scarce resources for the intensive care of critically ill patients and the first to show the benefits and expense of the continuous presence of an attendant at each patient's bedside. Lassen was also the first to show that skilled support of organ systems may defer death rather than prevent it: despite the fall in mortality more of those who died did so later in their illness.

Forty years later the case mix in intensive care has changed substantially, although the challenges identified in Lassen's report have not. For example, none of the new and very expensive treatments for sepsis has impressively affected survival. The mortality from multiple organ failure remains high.² The financial (and emotional) costs of care are also high: it costs twice as much to die in intensive care as it does to survive,³ and in a recent British study the 15% of 3600 patients who died after admission to the intensive care unit consumed 38% of the unit's budget.⁴

Indeed, the problems facing intensive care are probably greater in Britain than in any comparable developed country. Britain has one of the smallest health care budgets (in 1992 around 6.2% of its gross national product) and also allocates less of it to intensive care (1-2% of the hospital budget).⁵ For the United States the figures are 15% and 20% respectively.⁶ International comparisons show that outcomes of intensive care adjusted for severity of illness are as good in Britain as elsewhere but that the patients are more severely ill^{7,8}; presumably in Britain the less severely ill patients receive their care on ordinary wards. This is unlikely to be appropriate: the Intensive Care Society's national acute physiology and chronic health evaluation (APACHE II) study showed that mortality on wards after discharge from intensive care varied from 6% to 16%.⁹

Two recent audits of intensive care at regional¹⁰ and national¹¹ levels in Britain show high rates of refused or deferred emergency admissions because of constraints on resources, frequent transfers of critically ill patients between hospitals in the search for intensive care beds, and a serious shortage of facilities for intermediate care. In a six week

period in the west midlands, of 245 patients referred for emergency admission to 12 intensive care units, 23% were refused admission, 7.5% had their admissions deferred, and 8% were transferred to other hospitals; other major conurbations will probably share these problems.¹⁰ The survey released by the Department of Health last month shows similar refusal rates nationally.¹²

What happens to those patients who are refused admission? As delay in resuscitation and admission to intensive care adversely affects outcome^{13,14} and non-specialist transport has a high complication rate,¹⁵ Britain's underfunding of intensive care probably results in avoidable illness and death. In summary, much of a small budget may be being wasted on patients too sick to benefit, while opportunities to prevent deterioration in other patients are being lost.

The most commonly proposed solution has been to identify patients admitted to intensive care units whose chances of survival are so small that continued treatment is futile and should be withdrawn. Indeed, the range of scoring systems available to guide clinical judgment is far greater for intensive care than for any other discipline. The proposed application of these systems has resulted in emotive stories about doctors "pulling the plug" on sick patients, which have distracted attention from two important issues. Firstly, probability and prediction are different. Scoring systems do not decide the outcome in individual patients; they provide information about the probability of various outcomes for groups of patients. Doctors know more about specific patients than any scoring system ever can, but scoring systems incorporate more knowledge about groups of patients than any clinician could hope to acquire; the two are complementary. Secondly, attempts to avoid wrongly predicting death in patients who will in fact survive reduces the sensitivity of such systems. Consequently, the many patients who ultimately die are not identified early on and therefore consume resources that cannot be reclaimed. Does an alternative to limiting treatment exist that is ethically acceptable and more cost effective?

One possibility is for intensive care staff to adopt a more proactive approach to life threatening illness, and to identify patients at risk before organ failure becomes established. Theoretically, preventing deterioration should be more cost effective than trying to salvage patients in extremis. An aging and increasingly dependent hospital population suggests that such an approach may be necessary. Chronic poor health is an important determinant both of decisions to limit treatment in