Costs and benefits of neonatal intensive care

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SUMMARY A cohort of very low birthweight infants (<1500 g) born in 1979–81 from a geographically defined area was followed up, and a costing of the initial admission to the neonatal intensive care unit was made. A four point scale for the severity of disability was used and estimation of the costs of education and full time residential care was made and discounted at 5% over the appropriate period. During the three years a progressively increasing proportion of infants survived, and this was associated with an increasing proportion of disabilities among the survivors. If costs are related to outcome up to the age of 4 they get progressively less over the three year study period. After the age of 4 the costs of special education and residential care dominate, and the cost trend is reversed.

Mortality rates among low birthweight infants have shown a particularly sharp decline in the past decade and at least some of this is attributable to modern methods of neonatal intensive care.1-3 Higher survival rates are, however, also associated with increased costs and a greater incidence of impairment.

Relatively little is known about the long term costs of caring for low birthweight infants but a detailed clinical follow up has made it possible to assess survival, disability, and morbidity in a geographically defined population. Detailed costing of a neonatal intensive care unit has been combined with a study of the costs of health care up to the age of 4 and a projection of long term costs for the care of the disabled. This had allowed a comparison to be made of the costs and benefits of neonatal intensive care.

Health economists have proposed that costs and benefits may be neatly combined in the concept of the cost of a quality adjusted life year (QALY) gained.4 This is one measure of efficiency and it has been applied in the evaluation of neonatal intensive care units in Canada.5 In this study we present estimates of the cost of producing QALYs in a neonatal intensive care unit over a three year period during which there was a considerable change in clinical practice following the appointment of a consultant neonatologist.

Methods

A cohort of very low birthweight infants (VLBW) (<1500 g) born during 1979–1981 to residents in two health districts on Merseyside (Liverpool and South Sefton) who had at least one admission to the neonatal intensive care unit were studied. They were followed up, and examined when they were between 3 and 4 years old to see what disabilities they had and what use they had made of medical services. They are a subgroup of a larger cohort of which details of history, examination, and clinical assessment have been previously described.6

Disabilities

A four point scale for severity of disability was used:

1 Normal—no clinically apparent neurodevelopmental abnormality causing functional disability.
2 Mild disability—for example, myopia, language delay, mild hearing loss, or hyperactivity.
3 Moderate disability—for example, diplegia, hemiplegia, or moderate learning disability (intelligence quotient 50–69).
4 Severe disability—for example, quadriplegia, blindness, deafness (loss 70 decibels or more in either ear), hydrocephalus, uncontrolled epilepsy, or severe learning disability (intelligence quotient <50).

Those children in class 4 were assumed to have a life expectancy at the age of 5 of 40 years. Those in classes 1, 2, and 3 were assumed to have a normal life expectancy of 70 years.

Costs

Details of the clinical management of the infant’s initial admission to the neonatal intensive care unit
until the time of its first discharge were obtained. If the infant was transferred to any other specialist unit during this initial period (for example, for operation) it was included in the costing of the initial admission. The degree of care during this admission was subdivided into: intensive care—infants receiving respiratory support either by intermittent positive pressure ventilation or by constant positive airways pressure; special care—infants receiving either electronic monitoring or intravenous infusions, or both, but not requiring respiratory support; and nursing care—infants receiving special observation or care but fed orally and not requiring respiratory support or intravenous infusions.

All survivors were followed up until the age of 4 to record all admissions for inpatient care and all outpatient visits. A detailed costing of the initial admission to the neonatal intensive care unit was carried out, details of which have been previously described.7

A projection was made for disabled children of the likely costs of special education and institutional care over their expected life span. It was assumed that infants with disabilities of group 2 severity would incur no costs of this sort. Children with disabilities groups 3 or 4 severity were assumed to require special education from the age of 4 to 19 years and institutional care from the age of 19 until death. This strong assumption reflected the view that even if some of these disabled children and adults received part of their care at home, they would impose on their families costs similar in magnitude to the cost of institutional care. Costs were derived from information provided by the Liverpool Education and Social Services Departments. A deduction was made for the cost of educating a normal child.

A further adjustment was made for differences in the quality of life. The children were allocated a quality of life coefficient according to the severity of their disability. A child that died scored zero and a normal child was assigned a score of one. The remaining groups were scored at 0-75, 0-50, or 0-25 according to whether they had been assessed as mildly, moderately, or severely disabled. Expected life spans were multiplied by the coefficients to give an estimate of the QALYs that each infant might expect. For instance, 40 years of life for a severely disabled person were taken as equivalent to 10 years of normal life. This crude method of adjusting for the quality of life would not be acceptable in a study which included larger numbers of disabled infants. In this study because the numbers were small the findings were shown not to be sensitive to the choice of coefficients.

All costs were expressed in accordance with National Health Service pay and prices in 1984. Costs and benefits that are spread over many years have to be reduced to a common base to allow comparisons to be made. Following the normal procedure they have been discounted at 5%. Discounted costs can be thought of as the capital sum that, invested at 5% in 1984, would produce a stream of income sufficient to purchase care for the cohort over its lifetime.

**Results**

Of 157 infants in the cohort five were lost to follow up. The data apply to the 152 children for whom follow up records were available.

A progressively increasing proportion of infants survived in the three years of the cohort but this was associated with an increasing incidence of disability among the survivors. These outcomes with adjustments for life expectancy and the quality of life are shown in table 1.

Table 2 shows costs of neonatal intensive care divided into initial and later hospital costs, and the lifetime costs of special education and residential care. The cost of care for those who died is included. In the 1979 cohort only one child had a disability that was of group 2 severity, and by assumption he did not incur any further costs for special education or

<table>
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<tr>
<th>Table 1</th>
<th>Outcomes for 152 VLBW infants 1979–81</th>
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<tbody>
<tr>
<td></td>
<td>1979</td>
</tr>
<tr>
<td>No of infants</td>
<td>43</td>
</tr>
<tr>
<td>No of survivors (%)</td>
<td>19 (44)</td>
</tr>
<tr>
<td>No of disabled survivors</td>
<td>1</td>
</tr>
<tr>
<td>No of quality adjusted lives</td>
<td>18-75</td>
</tr>
<tr>
<td>No of QALYs</td>
<td>1313</td>
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<tr>
<td>No of QALYs discounted</td>
<td>363-6</td>
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<tr>
<th>Table 2</th>
<th>Long term costs (£) of neonatal intensive care at 1984 prices for 152 VLBW infants. 1984 prices discounted at 5%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1979</td>
</tr>
<tr>
<td>Initial hospital admission</td>
<td>254 815</td>
</tr>
<tr>
<td>Later hospital admission and outpatient attendance to age 4</td>
<td>23 015</td>
</tr>
<tr>
<td>Subtotal: hospital costs to age 4 (early hospital costs)</td>
<td>277 830</td>
</tr>
<tr>
<td>Lifetime special education costs</td>
<td>0</td>
</tr>
<tr>
<td>Lifetime residential care costs</td>
<td>0</td>
</tr>
<tr>
<td>Total costs to death</td>
<td>277 830</td>
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residential care. In 1980 and 1981 there was a higher incidence of disability, particularly severe (group 4) disability, which accounted for the considerably greater total costs to death.

The cost of initial hospital admission for each infant treated showed a relatively small variation over the three-year study period. The progressively increasing total costs were incurred mainly as a result of the disabilities present in the survivors, but later hospital costs also rose sharply.

The measures of outcome are related to cost in table 3. Up to the age of 4 cost per survivor (cost of all infants divided by the number of survivors), cost per quality adjusted life, and cost per QALY declined in 1980 and 1981. This was a consequence of reduced mortality. The effect of the increased incidence of disability is seen in the behaviour of lifetime costs. They increased by all three outcome measures by amounts ranging between 41% and 78% between 1979 and 1980–81.

Discussion

The three-year study covered a period during which there was considerable change in clinical practice in the regional neonatal intensive care unit after the appointment of a consultant neonatologist in January 1980. This is reflected in the outcome of the infants treated. There was a pronounced increase in the number of infants who survived, but also an increase in the number of disabled children. As the children were followed up to the age of 4, the increased cost of disability among the survivors became evident. The projection of costs from the age of 4 to death depends on assumptions of life expectancy, the degree of care that will be required, and the appropriate discount rate. Any variation in these assumptions will have a potentially profound effect on lifetime costs. A further area of concern in interpreting the results relates to random variation. Because the proportion of disabled survivors is small and because the disabled have a disproportionate effect on the cost of care, the confidence intervals of the cost estimates are wide.

The findings give an account of the work of a neonatal intensive care unit over a three-year period and show the impact of continuing improvements in
techiniques. They do not, however, by themselves represent an evaluation of neonatal intensive care that would allow an estimate of the number of QALYs gained and the cost at which they were purchased. By no means all the QALYs that were produced can be described as gains attributable to neonatal intensive care because 35% of the cohort survived without ventilation. Furthermore, a full evaluation would entail comparison with a control group of similar infants treated by other means. A randomised controlled trial would be methodologically ideal but ethically unsupportable. Therefore researchers have attempted to construct control groups from infants treated before the advent of modern neonatal intensive care techniques. The problems of retrospective pricing and clinical assessment make this the weak link in most 'before and after' studies, but even this technique with all its imperfections is increasingly difficult to apply. The dispersion of neonatal intensive care makes it unlikely that any control group can be found in the United Kingdom that is entirely unaffected by neonatal intensive care techniques.

One way of avoiding the difficulty of obtaining a control group is to assume that all those survivors who were ventilated would have died had they not been ventilated. This would be an unsafe assumption for cohorts of heavier infants but it is not unreasonable for infants from the very lowest birthweight ranges. We suppose that the 45 survivors of the 1980 and 1981 cohorts who were ventilated can be claimed as gains for neonatal intensive care. The 24 infants who survived without ventilation represent 35% of the population. This is roughly consistent with the proportion of VLBW infants that is known to have survived before the introduction of modern neonatal intensive care. If neonatal intensive care can claim 65% of the survivors in 1980–81, it was also responsible for nine of the 11 with disabilities, and a high proportion of the long-term costs of care. Calculations on a sample restricted to infants who received ventilation gave the following approximate figures: cost per survivor £29 000; cost per quality adjusted life £33 000 and cost per quality adjusted life year £1770.

It will be for others to decide whether lives and life years gained at these prices represent good value for money or whether medical resources might be better used. A single study is not an adequate basis for any such decision. Neonatal intensive care is one of the most rapidly advancing specialties in medicine, so the balance between costs and benefits is almost certainly changing. Furthermore, neonatal intensive care is one of the few treatment regimens that has been systematically evaluated, at least in
some centres. Similar studies do not exist for most common treatment regimens so it is not possible to compare the costs of neonatal intensive care with other important diagnostic groups.

It is also possible to question the validity of the concept of the QALY as a basis for comparing treatments. The cost per QALY gained is a measure of efficiency. It relates outputs to inputs and says nothing about what is fair or equitable. Even if it were agreed that medical resources should be allocated efficiently rather than equitably, problems still remain with the QALY as a measure of efficiency.

The QALY is intended as a measure for discriminating among different groups of patients. As such it is a bold attempt to weigh up the costs and the benefits of neonatal intensive care against, for example, heart transplantation, or hip replacement. It also offers possibilities for improving health service efficiency by comparing units that provide similar services. In our previous report on the cost of neonatal intensive care a comparison between two units was made.\(^7\) This was not a methodologically sound comparison, but there was a strong suggestion that radically different clinical policies were being pursued. The cost of a QALY gained will differ between neonatal intensive care units as a result of differences in cost efficiency and clinical policy. Comparisons of the cost per QALY among different units could be seen as a means of disseminating best practices more widely or, alternatively, as a threat to clinical independence.

QALYs are intended to provide a systematic measure for discriminating among different diagnostic groups but many will object because they depend on the placing of subjective values on human disability. There is no sound reason for deciding whose opinion should be considered—for example, parents, clinicians, tax payers, or politicians. Boyle \textit{et al} asked the opinions of parents who expressed the view that a negative value should be attached to some severely disabled lives.\(^5\) This would be anathema to many who would include the failure to consult the patient in their list of objections.

Although it is only recently that QALYs have been used in the evaluation of health care, the ethical concepts underlying them have been debated for a considerable time.\(^9\) QALYs are an example of the consequentialist approach that justifies actions in terms of the greatest good for the greatest number or, in the context of this study, the maximum output for a given input. Utility is presumed to be derived only from outcomes and not from the process by which these outcomes are achieved. In many areas of medicine, especially those in which outcomes are predictable, the processes by which they are reached are of considerable importance. This is plain enough in the treatment of terminal illness. It also applies to neonatal intensive care units, where a measure of efficiency based solely on medical outcomes may understate the value of its outputs.

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