Current topic

Follow up of low birthweight children

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The volume of articles on the follow up of low birthweight children submitted for publication in recent years has grown steadily. This has occasioned editorial comment elsewhere, with pleas for a more critical approach to meet the altered circumstances resulting from changing perinatal care.^{1 2} Many of the reports have dealt with short term results in very low birthweight children from individual neonatal intensive care units, their inhabitants derived from 'here, there and everywhere',² their methods of care subtly changing over the period of time reviewed.¹ Frequent comparisons are made in these reports with the results from other units, though the populations served, the age at follow up, the years covered, and the methods of assessment used may all be very different. The results may be of importance to the individual centres. They act as an immediate check on the safety of new methods of treatment, and—at least when young children without major impairment are designated normal or healthy, and recorded as a percentage of the ever increasing number of survivors—they give encouragement to those who work so unremittingly at the early care. But they leave many questions unanswered because of their short term and unrepresentative nature, and they detract from important long term issues.

Some questions that future studies need to answer

Most low birthweight children are apparently normal at later follow up, however, the current prevalence of cerebral palsy, mental retardation, and visual and hearing impairment still has to be determined for low birthweight populations in various regions of the country. As only (very approximately) 37 000 infants weighing 2.5 kg or less, and 4000 to 5000 weighing 1.5 kg or less are liveborn annually in England and Wales, the numbers of such children with these impairments from all parts of the United Kingdom is bound to be small compared with those in the general population. But we need to know if their numbers are increasing as the numbers of very immature survivors increase. School learning difficulties also occur proportionately more fre-

quently than in normal weight controls. What is their prevalence among similarly defined populations? To what extent are they aggravated by an unfavourable home environment and parental attitude, and by bad schools? Does early diagnosis and remedial help always minimise their effect? The elicitation of 'soft' neurological signs in low birthweight children at school age has received little attention until recently.^{3 4} To what extent do they occur with learning difficulties? What will the effects of previous learning difficulties, behaviour disorders, and minor neurological impairment be on the individual's economic viability in young adult life in an intensely competitive world?

Will the impaired growth potential of some of the sickest small survivors⁵ lead to psychological problems, particularly among boys? Could similar problems occur in those who carry visible scars from the neonatal period, made by tissue extravasation of infusion fluids, arterial punctures, and so on? Will some young women have abnormal breast development as a result of scarring from hurriedly placed pneumothorax drainage tubes? We need to know if there are any long term effects of necrotizing enterocolitis, and the extent of complications of the cholestatic jaundice sometimes accompanying total parenteral nutrition.⁶ Initial reports on later effects of bronchopulmonary dysplasia on pulmonary function suggest persisting abnormality,⁷ and as low birthweight children without this disease may have subtle differences in lung mechanics compared with term controls,⁴ a truly long term view is essential. It will almost certainly need nationwide surveillance to detect other subtle or unexpected effects which may be of an iatrogenic nature because of the small numbers likely to be involved. But ultimate safety still has to be proved for such things as the greatly increased number of radiographs taken of sick infants between their preterm birth and expected date of delivery, for ultrasonography, polyvinyl leached out into tissues from indwelling catheters, xanthine treatment, phototherapy, and the sometimes astonishingly high (though apparently physiologically necessary) amounts of sodium fed to the most immature.

Who is to do follow up work?

If in the future we hope to answer some of the questions posed above, follow up work should presumably be organised on a regional basis. This would suggest that community physicians (and some family practitioners) who normally undertake the preventive care and surveillance of children would be best placed to do it.² There is now a 'comprehensive and flexible computerised programme' available in this country for childhood, extending from birth to school leaving age;⁸ its appropriate use should allow valid epidemiological study of the results obtained. Perhaps, because it is so important for both to learn of the outcome, ultimate responsibility for coordinating long term ascertainment in a region could rest jointly with the appropriate specialist in community paediatrics and child health and the consultant paediatrician in charge of the regional neonatal intensive care unit, or their appointed deputies.

Continuing attendance at hospital after discharge will obviously be necessary for some infants such as those needing treatment or continued supervision for bronchopulmonary dysplasia or hydrocephalus. Research workers there will still want to correlate later outcome with newer methods of central nervous system investigation such as ultrasonography, nuclear magnetic resonance, and positron emission tomography, together with evoked potentials and serial neurological examinations; for these may have important messages for modifications of early care in some significant way, and their prognostic value needs to be determined. But as soon as possible, supervision should be delegated to the family practitioner and to the child's local health clinic. This would ease the often considerable financial burden for the families of travelling long distances, the anxiety sometimes engendered by hospital visits, and the feeling that their children were different.

Many neonatologists have shown much ingenuity in recent years in attracting money to buy equipment for their units. Technology, however, cannot operate in a vacuum and at least as much money has somehow to be found for the continuing surveillance and support of those who survive as a result.

Defining impairment, disability, and handicap

Children with conditions such as spastic cerebral palsy that might reasonably be linked with low birthweight have usually been designated 'handicapped' in past surveys, whether capable of a nearly normal life or in need of total care. We must try now for greater precision, not only to allow easier comparison of outcome between defined popula-

tions of low birthweight children but, as important, to understand what provision needs to be made for the individual child. The terms impairment, disability, and handicap, increasingly used for classification in adult life,⁹ are no less applicable to children.¹⁰ An impairment is essentially the diagnostic medical category of the disorder. Disability will result if the impairment causes restriction or lack of ability. Handicap is the disadvantage accruing to the individual by virtue of the impairment or disability, because some aspects of normal life are denied him. As childhood and adolescence are periods of continuous growth and development, the definition of disability and handicap needs modification at various ages to allow for the changing abilities and changing role in society of the normal peer group. The provision of helpful definitions for this whole period is thus a task of some complexity, and we must hope that those known to be engaged in this work can produce clear guidelines that will allow all to speak with one voice. Meanwhile, an attempt must be made to try to determine the disordered function that any given impairment poses.

Controls: yes or no?

In real life the low birthweight child has to compete on equal terms with his normal birthweight peer and should be so measured from the beginning. Several previous large surveys, however, have established a higher prevalence of cerebral palsy, mental retardation, and visual and hearing impairment among the smaller babies. Controls are still needed though to establish the extent of less obvious neurodevelopmental disorders and associated learning difficulties, and of iatrogenic disease, particularly among the new very immature survivors. Within group controls of similar gestational age, birthweight, and socioeconomic status are most helpful in deciding benefit or disadvantage for certain forms of perinatal treatment or illness, but obviously have limitations. Siblings of normal birthweight, when they exist, have the great advantage of a nearly similar home environment, but birth order and age at testing cannot be matched. Choosing different groups of controls at different ages to compare different aspects of outcome seems valid providing they match as nearly as possible for any variables which may influence results.

Ages of examination, and methods

After their discharge from neonatal units, low birthweight infants, particularly those of very low birthweight, are at greater risk than the normal infant population from certain well defined hazards,

particularly in the first six months of life. These are sudden unexpected death, non-accidental injury, lower and upper respiratory tract infection, and inguinal hernias (which may strangulate). Thus, especially in the first months at home, readily available help from and close supervision by community paediatricians, family practitioners, and health visitors might have a preventive role for the first of these hazards¹¹ and at least allow early recognition and appropriate intervention for the remainder. The parents of recently discharged immature infants are often fearful of their new responsibilities and welcome extra support.

Most major impairment is likely to be detected without developmental screening—indeed it is often obvious while the infant is still in the neonatal unit. The main thrust of screening should be to detect, *before school entry*, those who have neurodevelopmental disabilities likely to lead to learning difficulties.¹² In their study of over 5000 Dundee children, Drillien and Drummond have shown that screening by child health clinic doctors effectively identified those less severe disabilities which had implications for education. The Dundee cohort was screened at 8 weeks by the health visitor, and at 20 weeks, 9 months, 15 months, 2 years, and 3 years by the clinic doctors or family practitioners. Preterm infants were screened at their corrected age rather than real age. The screening examinations used at the various ages are clearly set out in appendices.¹²

The question of whether or not correction should be made for preterm birth is a difficult one. It has been shown (Elliman *et al* unpublished data) that considerable discrepancy in results for preterm infants occurred with the Cardiff modification of the Denver developmental screening test¹³ according to whether real or corrected age was used. When, in the first 2 years, real age was used, the Denver test detected all those who were subsequently shown to have developmental delay on the more detailed Griffiths mental development scales^{14 15} at 3 years; using corrected age it did not.

The Stycar tests are best for screening vision. Details of the simple equipment necessary, where it can be obtained, the conduct of the tests by the examining doctor at various ages, and the deductions that can be made from them are given by Baird and Gordon.¹⁶ Stycar tests are available too for testing hearing, and their use is also described.¹⁶ The particular proneness of low birthweight babies to otitis media means that a normal first hearing test should never be taken as meaning that later testing is unnecessary. Testing of vision should also continue through childhood and adolescence as defects may develop later or established visual impairment worsen. Scales for the assessment of behaviour

disorders have been devised for 3 year old children by Richman and Graham;¹⁷ and the Rutter scales, which involve school teachers as well as parents, are very useful for older children.¹⁸

More detailed neurological examination becomes possible from about 6 years of age. Touwen has described a standardised examination which aims to detect those with 'soft' neurological signs or minor neurological dysfunction.¹⁹ A few simple tests, which might act as a screen to see if more detailed testing is necessary, are given by Baird and Gordon.¹⁶ Various tests of intelligence which may be used after school entry are of course the prerogative of psychologists and only they have the necessary skills with children to administer and interpret them. The physical examination of the low birthweight child at follow up at various ages does not differ from that of normal children. Particular care should be taken, however, to examine the ears and fundi in the early months, to record the blood pressure, to note any untoward scarring, and to record measurements of height, weight, and head circumference.

Failure of follow up

Families of low birthweight children, often socially and economically badly off, have a nomadic tendency to cross regional and national boundaries quite often, and even continental ones occasionally. This and their penchant for changing their names have meant a variable fall out from follow up studies, sometimes so great that it negates any conclusions drawn. The computerisation of child health records should presumably make tracing their whereabouts, previously a long and difficult task, much easier. Non-attendance at child health clinics is common by those who would most benefit from being there.²⁰ When very low birthweight children are persistent non-attenders arrangements should be made for them to be seen at home. Expensive and time consuming though it may be for those doing the home visiting, it should also be remembered that when the real needs of even a disadvantaged inner city population are being met in local child health clinics by the provision of skilled and sympathetic attention, attendance will approach 100%.²¹ Since the Dundee¹² and various American²² studies have shown that intervention is effective in mitigating school failures in these populations, the importance of seeking out those who need them cannot be overemphasised.

Referral for specialist advice

The responsibilities of those undertaking follow up

work do not cease with the diagnosis or suspicion of abnormality and the collation of results. Referral for treatment, for specialised diagnostic tests, or for expert advice may be needed, with the involvement of surgeons, ophthalmologists, audiologists, speech therapists, school teachers, social workers, psychologists, and psychiatrists. An area handicap team may need to take over the care of any severely disabled children. In many areas facilities for treatment of children who are profoundly deaf or speech retarded, or both, are inadequate. The support received by many families of severely disabled children is lamentable.

Conclusions

Much time and effort is now devoted to keeping very immature infants alive. At least as much effort is needed to follow the survivors if this achievement is not to fall into disrepute. Apart from determining the extent of major impairment among defined populations of low or very low birthweight children, there is a pressing need to ascertain the extent of preschool neurodevelopmental delay. This may increase with decreasing birthweight and gestation. Community and hospital paediatricians may have to campaign to see that places in play groups and nursery classes are made available for these children, and mothers given appropriate help and instruction. This is particularly important when environmental and social conditions are poor. Familiarity with and expertise in administering the screening tests which have been so successfully used elsewhere is probably not yet widespread among child health clinic doctors, and is certainly not among hospital paediatricians. Concerted effort to achieve this on a regional basis on behalf of the small numbers of low birthweight children would soon benefit the whole preschool child population. As appropriate intervention for those with neurodevelopmental delay is now known to be of proved advantage, this has implications for all children, but especially those at present caught up in a web of deprivation.

After school entry it is possible to be more precise about the presence or absence of minor neurological dysfunction in low birthweight children; and those with learning difficulties must be sought out and given remedial help. A truly long term view, and one needing nationwide surveillance preferably extending to the next generation, would be necessary to detect possible and at present unsuspected effects of certain perinatal and neonatal investigations and treatments.

References

- Mitchell RG. Perinatal follow-up. *Dev Med Child Neurol* 1980;22:1-2.
- Bax M. Following up the small baby. *Dev Med Child Neurol* 1983;25:415-6.
- Hertzog ME. Neurological 'soft' signs in low-birthweight children. *Dev Med Child Neurol* 1981;23:778-91.
- Noble-Jamieson CM, Lukeman D, Silverman M, Davies PA. Low birth weight children at school age: neurological, psychological, and pulmonary function. *Semin Perinatol* 1982;6:266-73.
- Hack M, Merkatz IR, Gordon D, Jones PK, Fanaroff AA. The prognostic significance of postnatal growth in very low-birth weight infants. *Am J Obstet Gynecol* 1982;143:693-9.
- Roslyn JJ, Berquist WE, Pitt HA, et al. Increased risk of gallstones in children receiving total parenteral nutrition. *Pediatrics* 1983;71:784-9.
- Smyth JA, Tabachnik E, Duncan WJ, Reilly BJ, Levison H. Pulmonary function and bronchial hyperactivity in long-term survivors of bronchopulmonary dysplasia. *Pediatrics* 1981;68:336-40.
- Walker CHM. Computing in child health: significant progress. *Br Med J* 1983;287:1400-1.
- World Health Organization. *International classification of impairments, disabilities, and handicaps. A manual of classification relating to the consequences of disease*. Geneva: World Health Organization, 1980.
- Butler NR, Haslum M, Golding J, Stewart-Brown S. Recent findings from the 1970 child health and education study: preliminary communication. *J R Soc Med* 1982;75:781-4.
- Carpenter RG, Gardner A, Jepson M, et al. The health visitors of Sheffield. Prevention of unexpected infant death. Evaluation of the first seven years of the Sheffield intervention programme. *Lancet* 1983;i:723-7.
- Drillien C, Drummond M. *Development screening and the child with special needs. A population study of 5000 children*. Clinics in Developmental Medicine no 86. London: SIMP (Heinemann Medical), 1983.
- Bryant GM, Davies KJ, Newcombe RG. The Denver developmental screening test. Achievement of test items in the first year of life by Denver and Cardiff infants. *Dev Med Child Neurol* 1974;16:475-84.
- Griffiths R. *The abilities of babies*. London: University of London Press, 1954.
- Griffiths R. *The abilities of young children*. London: Clinical Development Research Centre, 1970.
- Baird HW, Gordon EC. *Neurological evaluation of infants and children*. Clinics in Developmental Medicine nos 84/85. London: SIMP (Heinemann Medical), 1983.
- Richman N, Graham PJ. A behavioural screening questionnaire for use with three-year-old children. Preliminary findings. *J Child Psychol Psychiatry* 1971;12:5-33.
- Ritter M, Tizard J, Whitmore K. *Education, health and behaviour*. London: Longman, 1970.
- Touwen BCL. *Examination of the child with minor neurological dysfunction*. 2nd ed. Clinics in Developmental Medicine no 71. London: SIMP (Heinemann Medical), 1979.
- Zinkin PM, Cox CA. Child health clinics and inverse care laws: evidence from longitudinal study of 1878 pre-school children. *Br Med J* 1976;ii:411-3.
- Hart H, Bax M, Jenkins S. Use of the child health clinic. *Arch Dis Child* 1981;56:440-5.
- Darlington RB, Royce JM, Snipper AS, Murray HW, Lazar I. Preschool programs and later school competence of children from low-income families. *Science* 1980;208:202-4.

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