Leading article

A touch of cerebral palsy

A mother came into my clinic with her ex-premature baby who had been through the mill of neonatal intensive care but appeared to be doing very well. After we had finished the consultation and I had praised her and her baby for the excellent progress they both were making, she asked me what I thought of another doctor’s opinion, that her daughter had “a touch of cerebral palsy”. The physiotherapist and I agreed that her daughter did not have cerebral palsy, and I reassured her, but asked whether she hadn’t been distressed at the diagnosis. “No” she replied “because you had always warned me of the risk”. Oh that breaking the news of cerebral palsy and explaining it to parents was so simple!

In a paper in last month’s Archives of Disease in Childhood, Baird and colleagues discuss the thorny problem of how to disclose the diagnosis of cerebral palsy and how we might improve practice.1 In their study, dissatisfaction with the structure and manner of disclosure of diagnosis was reported by 20% and 23% of 107 mothers, respectively and 43% expressed dissatisfaction with the information given at that time. In particular, lower satisfaction was found among the mothers of more premature children, mothers with more severely disabled children and worse depression scores, and not surprisingly, those taking legal action.

Does this study have implications for neonatologists and what are they?

Improving current practice

Baird and colleagues develop guidelines for disclosure of diagnosis which are sensible and to a large extent derived from the work of Cunningham and colleagues over the disclosure of a diagnosis of Down’s syndrome; tell both parents together with their child and a third party if possible, in a private place without interruptions; offer parents a chance to be alone; be clear, direct, and honest; and give accurate information with structured rapid follow up. These principles are difficult to fault and are often practised well in the neonatal intensive care setting where breaking difficult news to parents is part of routine practice, contrary to the assumption of Baird et al. The use of tape recordings of discussions may be of value to the family and to the staff looking after them, and a way of ensuring that everyone knows what is said to a couple. These practices are well described and can be audited.

In a busy outpatient clinic, where you are unexpectedly and genuinely concerned about a child who has clear cerebral palsy and wish to make a referral for support, setting the scene can be very difficult. Parents expect honest answers and not to be “fobbed off”. It is rarely ideal but rapid follow up and an appointment outside the clinic setting can usually be arranged, giving some time to arrange the other critical follow up strategies. Waiting until the next clinic slot is not usually a satisfactory option. Guidance that communication skills, developmental assessment, and a period attached to a follow up programme or child development centre are important parts of training for a neonatologist. Too often this experience is not gained in a structured manner. Too often it is the trainee who identifies the disability and breaks the news (or gives the game away!). Baird and colleagues rightly suggest that learning how to approach disclosure is not best done on the job but by using formal training sessions. This has support in the plethora of training scenarios that are developing in critical care. As the Royal College of Paediatrics and Child Health develops its new competency based syllabus the knowledge, skills, and experience of breaking such news to parents will continue to be an integral part; training scheme coordinators must develop training strategies in these areas.

Forewarned is forearmed

Why was the mother described in the first paragraph so accepting of the trite description of cerebral palsy? I suspect it was because we had opened discussion about disability, because of prematurity and the complications we had observed during the neonatal admission, and that she understood that the surveillance we were providing was directed to detection of disability, and not confirmation of normality as is often the case.

Parents are generally poorly informed about risks and outcomes for their premature child, despite the immense support given throughout neonatal intensive care. There is a great reliance on the presence or absence of structural brain lesions in how parents are counselled—that reliance may be misplaced.8 Increasingly we are seeing cerebral palsy in children with “normal” ultrasound scans, often in the most immature. There is also increasing evidence that severe developmental delay is a common and important disability,9 and complex patterns of cerebral palsy are very...
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common in the most immature. Prediction is complicated by the fact that a proportion of infants will develop transient patterns of neurological abnormality that may require intervention but resolve over the second year. Parents use hope and denial as defence mechanisms in the unexpected crisis following premature birth; leading them through to realistic expectations is an important function of the counselling that occurs in neonatal intensive care. National data are now available for disability rates at 30 months of age in extremely preterm infants. Many regions also collect data on disability that can be used to inform parents. Hospitals providing neonatal intensive care should collect information on outcomes to inform their practice. Using data such as these, the neonatologist has a duty to inform and explain outcomes to parents as part of the counselling process that accompanies intensive care. Parents deserve to be aware of the potential outcomes for their child using contemporary and unbiased information. Many will explore internet sites relating to prematurity and they need to be able to put the information they access into a proper context and also feel comfortable doing so. A touch of cerebral palsy should be a thing of the past.

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