

Ethics

Conflicts of care

M Ward Platt, A Ward Platt

Could mediation help?

The UK readership of *Archives* will remember October 2004 for Charlotte Wyatt^{1,2} and Luke Winston-Jones.^{3,4} Charlotte was severely disabled following complications of extreme prematurity, and Luke with trisomy 18. In each case the clinical teams believed that active, life prolonging medical interventions would not be in the best interests of the baby. The cases were brought to the civil courts because fundamental and irreconcilable differences between the families and the clinical teams came to an impasse, leaving the respective hospitals with no alternative but to seek a judicial ruling on the management of each child. Observers from other units will either feel that they have been there too, or dread the time that they may find themselves in similar situations.

We should reflect constructively on these cases and be thankful that they remain rare. Most of the time, even in the most difficult situations, we are able to work alongside parents, maintain a bond of trust, and achieve high quality palliative care for infants where the gratuitous prolongation of life is cruel, futile, or impossible. But were the cases of Charlotte and Luke ones where such a resolution was never going to be possible? Or should we wonder whether, with hindsight, either or both of these situations could have been avoided? It would be of service to the wider community of neonatal care if, after appropriate consideration, the respective teams were able to publish their thoughts; yet the identifiability of the cases would make this impossible without the explicit permission of the families, and it is ethically arguable whether they should even be approached for such permission. We may be doomed not to be able to learn from our recent history, a part of the NHS without an organisational memory.

It would have been particularly valuable to know whether mediation or conciliation was used in either of these cases. If it was, it would appear to have been a failure in so far as the cases came to court anyway; but even if mediation is ultimately unsuccessful in achieving resolution of a problem, it can be of immense value in allowing the parties to define the issues more clearly, and it may uncover issues that have not been apparent on the surface. At an earlier stage than legal proceedings, even apparently polarised attitudes can be susceptible to skilful mediation.

Are there other similar cases around the country in which mediation or conciliation was successful in bringing together professionals and families with seriously divergent views about the management of a baby? Only the participants will know. Yet it would be so valuable for others not to have to reinvent the wheel every time a case like these arises.

Mediation and conciliation can take different forms. It is unlikely that a mediation strategy that attempted to resolve all differences in a single day (a common legal and commercial model) would be successful in a long standing clinical situation. In contrast, an approach that allowed time between meetings with the mediator so that reflection and discussion could take place, and in which the mediator could call on independent specialist clinical advice, might be an attractive option when intransigence appeared to be developing. Such a model is already used in primary care conciliations for the resolution of complaints and could easily be adapted to impasses between clinicians and parents. Mediation/conciliation does not avoid costs, but they would be vastly less than those accrued by a judicial hearing.

Will these rare events become more common? We may find that advances in medical technology collide more often with families whose beliefs are at great variance with those of their medical and nursing carers. The legal frameworks within which paediatricians work in the UK and elsewhere are always likely to lag behind medical innovations and capabilities, creating new hinterlands of uncertainty and greater possibilities for conflict. The internet allows parents access to a great deal of information, but it can be hard to be discerning about the quality of the information, and all too easy to mistake knowledge for wisdom. Our ways of working with parents must evolve to accommodate this challenge, otherwise trusting relationships will be harder to build, and conflicts become more common.

The publicity that always accompanies these cases potentially damages families, carers, and professionals, and the facts are seldom reported without distortion or spin. There is general agreement that courts are not the places where it is optimal to define clinical management, and that every avenue should be explored to obtain resolution of differences without recourse to judicial input. Mediation/conciliation remain underdeveloped approaches outside primary care: perhaps we should give more thought to their use in cases like these.

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Managing chronic pain in children: the challenge of delivering chronic care in a "modernising" healthcare system

C Eccleston

Commentary on the paper by Lindley *et al* (see page 335)

An alliance between the healthcare professional, the patient, and the family is at the heart of effective and humane childhood medicine. When patients complain about doctors, and doctors complain about patients, this essential therapeutic alliance has been ruptured or even destroyed. Reason is usurped by fear and concordance gives way to paternalism. It should be remembered that patients often complain about doctors for the same reasons that doctors find some patients difficult to help: when patients don't get better and they are distressed by it.¹

Drs Lindley, Glaser, and Milla have provided an interesting descriptive account of a selection of the behaviour of a small number of parents with children referred to a single paediatric gastroenterologist at a tertiary referral centre, bringing to our attention issues that should be debated further.² I have brief comments on only two of these issues; other correspondents may wish to raise more. The first relates to the importance of reflexive and quality controlled research, the second relates to the current problems of treating chronic pain in a "modernising" NHS healthcare system.

In this report parents are described in terms of their unwillingness to accept advice, their persistence in seeking further professional opinion and investigation, their use of formal and informal complaints procedures, and their reticence to accept psychological referral. The authors judge some of the complaints to be manipulative. No data are reported on parental mental or physical health, or on any description of family status, or any history of treatments within the NHS. Progress in our understanding of why such unhelpful parental behaviour occurs will be achieved by the specific design of studies with parents as the recruited participants so that the antecedents of complaint and resistance to advice can be fully understood. It will be important, for example, to focus on the realities of the clinical encounter and

assess the potential mismatch between the pre-interview expectations of patients, parents, and physicians, and the post-interview memory and understandings of patients and parents.³ In addition, how and why chronic pain patients come to feel blamed by the healthcare professionals offering care is of considerable research interest but has yet to be investigated in childhood pain.⁴ There should be no doubt that power dynamics and expectations of care are shifting within the NHS, and the specialist paediatric clinic is perhaps one of the most complex domains within which to understand how "partnership" can be achieved.⁵

Modernisation of the NHS, as the present UK government fashions it, has some broad stroke policies that are having uncomfortable effects on everyday practice. This article wrestles with a cultural shift, the implications of which, the authors are correct to highlight, have yet to be fully realised. Patient expectations of health and healthcare are being driven up; we are encouraged to believe that what is important in healthcare are organisational indicators such as "waiting times" and "global satisfaction". These targets, and the mechanisms for achieving them, such as "complaints procedures", are borrowed from the retail and entertainment business sectors and played out in a centrally governed healthcare system. That there is not a perfect fit should be a surprise to no one, even to those who implemented them. There is nothing, of course, intrinsically wrong with not having to wait and with being satisfied. The problem is that good medicine does not always seek to quickly satisfy. Healthcare professionals working with untreatable pain routinely have to negotiate with patients and families to shift their goals from immediate cure to chronic self-management of persistent or recurrent illness. Accepting that pain cannot be cured, or that illness is to be a fact of childhood and family life is a complex and difficult process that is not easy to achieve.⁶ Until we have fully

understood how to reform everyday hospital procedures to maximise the possibility that patients will be safely given and hear difficult messages, individual doctors will continue to find themselves unheard and complained about.

Many children and adolescents suffer chronic pain that has widespread detrimental effects on themselves and other family members.⁷⁻¹⁰ Parental anxiety and the impact of parenting a distressed and disabled child in pain are often high. This stress is thought to be a major determinant in the style of coping adopted, whether that be the investment of all resources into searching for a cure, or working to change family habits, routines, and parenting styles. Methods for directly targeting parental anxiety and parenting stress are emerging to be potentially crucial in facilitating child improvements.¹¹ We should be honest and admit that we know embarrassingly little about how families develop illness promoting or illness defeating coping strategies, and only a little more about how to help.¹² Until we know more, we should put greater collective effort into building multidisciplinary chronic pain teams in our regional centres. A core task of these teams will be to maintain an alliance between healthcare professionals, patients, and families as they struggle to make sense of the contradictions made prominent when the realities of accepting a life of pain and illness clash violently with our expectations of "modernised" healthcare.

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Meningitis

Improving the outcome of pneumococcal meningitis

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Commentary on the paper by McIntyre *et al* (see page 391)

Bacterial meningitis continues as a major cause of morbidity and mortality among children throughout the world. McIntyre *et al* report on a six year experience in Australia with 122 cases of pneumococcal meningitis; 89% of cases occurred in children less than 5 years of age.¹ Fifteen (13%) children died and 23 (22%) suffered severe neurological outcomes including paresis, hydrocephalus with shunting, visual loss, and marked intellectual impairment. Only 55% recovered without any identified sequelae. How can we improve the outcome of pneumococcal meningitis?

Early antibiotic treatment appears appealing as a fundamental for improving outcome, yet not all cases treated early have a good outcome. The report of McIntyre *et al* shows once again that children presenting “in extremis” (shock, respiratory failure, etc) are frequently beyond the full benefits of intervention regardless of whether their course was one with rapid onset or more slowly progressive after a prodromal illness. However, the authors report that delay in admission to the hospital is likely to contribute to poor outcome. Yet, once at the hospital, the time to antibiotic administration (either 4–12 hours or later) was not associated with enhanced morbidity in survivors. These observations support the practice of complete evaluation including blood and cerebrospinal fluid (CSF) cultures, when not contraindicated, prior to initiation of therapy as there is no evidence that short delays resulting from transport and/or performance of a lumbar puncture or computed tomography (to rule out increased intracranial pressure) results in increased morbidity.

Lebel and McCracken reported excess morbidity among children whose cerebral spinal fluid culture remained positive for the causative pathogen 18 to 36 hours after initiating therapy compared to children with more rapid sterilisation.² Short term complications such as seizures and subdural effusion were observed in a greater proportion of cases with delayed sterilisation, as well as greater likelihood of neurological disabilities and moderate or profound hearing loss. Although patient age, severity at presentation, and bacterial pathogens all contribute to morbidity in bacterial meningitis, there is no debate about the benefit of early sterilisation. Current antimicrobial strategies usually result in rapid sterilisation of *Neisseria meningitidis* in the CSF (within 4–6 hours), while *Streptococcus pneumoniae* requires as long as 48 hours when children are treated with third generation cephalosporins.³ Is it possible that, in part, the morbidity of pneumococcal meningitis is related to slower sterilisation of the central nervous system by currently recommended therapy (cefotaxime plus vancomycin)?

Even with rapid sterilisation and administration of potent antimicrobial agents, the inflammatory reaction within the central nervous system and its effects on cerebral blood flow as well as direct action of bacterial toxins on the nervous system can still cause severe morbidity.⁴ In 1990, Mustafa *et al* reported that children with detectable markers of inflammation (cytokines) within the CSF had a higher prevalence of neurological sequelae.⁵ These insights led to a renewed interest in corticosteroids as adjunctive therapy for bacterial meningitis because of the potential to

modulate cytokines, thus reducing the inflammatory response and decreasing intracranial pressure. Early studies of dexamethasone supported a reduction in sensorineural hearing loss with early administration; however, the effect appeared pathogen specific (*Haemophilus influenzae* type b) and limited to hearing loss.^{6,7} The current report of McIntyre *et al* adds one more perspective to the controversy over whether, in fact, dexamethasone administered to children with pneumococcal meningitis improves the outcome. To support this conclusion, McIntyre *et al* reference a meta-analysis⁷ and a randomised clinical trial (RCT) in children that showed trends favouring the dexamethasone treated group for sensorineural hearing loss (at 3 months).⁸ There are several reasons to question whether these citations resolve the ongoing controversy. In McIntyre *et al*'s meta-analysis of dexamethasone as adjunctive therapy in bacterial meningitis, the authors concluded that the evidence was only suggestive for a benefit in pneumococcal disease.⁷ In addition, one study in particular⁹ had an unusually high mortality (28%), and hearing loss was not assessed in younger children. The study included patients from 3 months to 60 years of age and did not specify if the observed effects of dexamethasone occurred in adults or children (or both). Even the authors of the meta-analysis concluded that this study “differed from others” and that statistical evidence of protection from early dexamethasone (for pneumococcal meningitis) is lost if this study is excluded. The RCT cited included children older than 2 years of age and the differences in mortality, neurological outcome, and moderate to severe hearing loss (between 27 patients who received dexamethasone and 26 who received placebo) were “statistically insignificant” at the 6 week follow up.⁸ Statistical significance was achieved only at the 3 month follow up for hearing loss when one child in the dexamethasone treated group was found to have significantly improved hearing compared to the earlier measurement. For several clinical studies that failed to show improved outcomes with dexamethasone,^{6,10,11} McIntyre *et al*

suggest the lack of multivariate analysis as the reason for failing to show the benefit. Unfortunately, their current study will not resolve the conflicting views among those who believe and those who do not that dexamethasone is effective as adjunctive therapy.¹² What approach should the clinician use?

Concerns about the use of dexamethasone focus on four issues: the need for administration either prior to or concurrent with antibiotic therapy; penetration of antimicrobials in the CSF in the presence of decreased inflammation; potential for dexamethasone to mask signs such as fever that would identify the non-responsive patient; and potential for adverse events. First, there is general agreement that if effective, there is a narrow window for administration of steroids that either proceeds or is concurrent with the initial administration of antimicrobials. Second, the CSF concentrations of vancomycin, ceftriaxone, and rifampin in adults may be reduced when administered with dexamethasone. Although vancomycin appears to penetrate into CSF more reliably in children, and both ceftriaxone and cefotaxime achieve CSF concentrations that result in bactericidal activity against susceptible pneumococci, direct comparisons of CSF concentrations and rapidity of sterilisation in dexamethasone treated and untreated children have not been reported.^{13–15} Furthermore, the potential for diminished CNS penetration of vancomycin in patients receiving adjunctive corticosteroids led to US and UK recommendations, in adults, that rifampin be preferred to vancomycin to achieve optimal antimicrobial activity in the CSF for cephalosporin resistant *Streptococcus pneumoniae*.^{16, 17} Third, clinical signs or symptoms may be decreased in the presence of dexamethasone and the clinician will need to both be vigilant for subtle clinical clues of inadequate response as well as be willing to document that sterilisation of the CSF has occurred when clinical concerns warrant such an approach. Furthermore, two recent studies (using different animal models) showed increased hippocampal neuronal apoptosis and reduced learning capacity and spatial memory when dexamethasone was added to treatment of experimental pneumococcal meningitis.^{18, 19} Lastly, some gastrointestinal bleeding has been observed in up to 1–2% of children with bacterial meningitis administered dexamethasone. The current US recommendations advocate the use of dexamethasone for infants and children with

meningitis due to *Haemophilus influenzae* but only advise consideration for children with pneumococcal meningitis in infants older than 6 weeks of age, reflecting the belief that current studies have not established a clear benefit.²⁰

Early diagnosis and administration of antimicrobial therapy that is rapidly bactericidal in the central nervous system is the first principle for optimising the outcome of pneumococcal meningitis. Optimising cerebral blood flow by attention to fluid administration and strategies for reducing intracranial inflammation are attractive adjuncts; however, the optimal strategy for achieving these goals is unclear. Viewing dexamethasone as a first generation approach that reduces markers of CNS inflammation and likely ameliorates some of the morbidity of pneumococcal infection in some children places its use in perspective. Adjunctive approaches employing hypothermia, nitrous oxide inhibitors, or anti-inflammatory molecules such as IL-10 or anti-tumour necrosis factor- α antibody are under evaluation in experimental models. Thus, broad recommendations regarding dexamethasone treatment should be made with caution. Further research of mechanisms of CNS damage and strategies for abating the inflammatory response as well as its direct toxic effects are needed.

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