Chronic pain

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

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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 meningitis* 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-analysis[7] 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 particular[9] 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*