What's in a name?

Editorial

In their text Stanley, Blair, and Alberman[1] consider the question of whether the term 'cerebral palsy' should be retained . They write: 'Because of the heterogeneity of the condition, and our increasing understanding of some of its causes and related syndromes, we need to consider whether a case can be made for the retention of this umbrella term'. Reasons for not retaining it are probably obvious. It is not a disease entity and the 'diseases' which cause it are many and varied, although there is a tendency to remove individuals from it when they acquire a pathology such as the genetic ones. What the authors draw attention to is how the use of the key words 'cerebral palsy' indicate a whole range of reference to conditions which collect around a severe disability. Even though we can identify so-called mild forms of cerebral palsy, we are usually thinking of the motor disorder. The recent publication on hemiplegias[2] is full of reminders that although the motor disorder may be mild, the accompanying manifestations often mean that the child with hemiplegia has serious problems. But those manifestations may give one further cause to wonder about the name cerebral palsy.

If the child displays behavioural problems and these extend to autism, as has been reported[3], what label should have primacy for the child? Autism is another umbrella word and there are probably as good grounds for arguing against the continuation of that label as there are for a arguing against the continuation of cerebral palsy as a label.

In this issue of the Journal several different aspects of cerebral palsy are presented. Professor Jan and his colleagues in Vancouver have contributed so much over the years to our understanding of visual disorders in childhood that one would imagine in their unit that child neurology could be approached with an umbrella diagnosis perhaps of visual disorders! Certainly the team have elucidated many visual problems and they continue to do so with their account of visual impairment in dyskinetic CP, which they ascribe to dyskinetic movement disorder in the eye. A theme which emerges is the complexity and difficulty in the assessment of vision in this group of children, even with the most skilled observers. Of course it is not only in dyskinetic CP that one is concerned about vision but also in many of the tetraplegias where involvement of the optic radiation in white matter disorders can be recognized. Decisions about the visual function of these children are often extremely difficult and I can immediately think of more than one child who has benefited from very experienced paediatric opthalmic advice. I can also think of other children who have not had the fortune to meet an expert in the field and whose visual problems have not been identified or their examination delayed for too long.

In reading Pennington and McConachie's contribution we examine the whole process of communication (not forgetting the significance of vision in communication). In some ways it was reassuring for them to discover that the most straightforward explanation of communication difficulties for these children and those surrounding them was poor speech intelligibility. They emphasize the insignificance of this not only for the child but for those who are part of the dyad communicating.

The third group of CP raised in a paper by Roijen and colleagues in this Journal is the issue of continence. Again, an area of function that can be neglected in the disabled child. Perhaps the sad reminder is the significant number of children who remain incontinent throughout life. However, they equally emphasize that following experienced treatment, improvement is possible. But it is to be noted that such improvement was reported from a unit highly experienced in dealing with neuropathic bladder[4].

Vision, communication, continence: three distinct problems in a CP population in this Journal dealing, of course, with childhood. But Andersson and colleagues deal with a population of adults with cerebral palsy and they pull us back to the main criterion for inclusion in CP, namely the motor disorder. Mobility problems continue throughout the lifespan and staff need to be aware of these and other problems of ageing. Their study emphasizes again the importance of planning for the needs of young and older adults with this condition.

The protean manifestations continuing throughout life are sadly a feature of CP which is emphasized in this issue of the Journal and the implications for service provision are clear. If we are to provide a good service for children with CP and many other neurologically disabling diseases, we need a wide range of experts available to teams to provide a good service.

For parents, policy makers, and the public, the label of cerebral palsy defines groupings of children who are desperately in need of a service, and this seems an adequate ground (for the moment), for continuing with the unsatisfactory academically grouping of these children under the umbrella term 'cerebral palsy'.

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References

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