

Thinking of talking?

Managed care is a concept assuming ever increasing importance in the consciousness of the practising neurologist.¹ In the United States it is linked inextricably with cost control. To date, the emphasis has been on the use of resources, including the neurologist's time; but within a consultation, how cost-effectively and efficiently is time used to give families what they want from us, as opposed to what we set out to give them from our medical agenda?²

In Europe the emphasis has been more on models of care rather than managed care. The defined referral pattern is complemented by clinical guidelines, a process which American physicians find more acceptable.³ Here again the management steps, each with its evidence base, centre on investigation and treatment. Little attention is paid to what families regard as of paramount importance, that is, a clear understanding of the illness involved and the purpose of the investigation and treatment plan which is to follow.

The evidence base for what we do varies widely in quality. There are neurological conditions, notably epilepsy, which lend themselves to the randomized control trial, and pooled data through the Cochrane collaboration allows clinical decision making to be refined, at least to a degree. However, many clinical situations do not lend themselves to the clear cut algorithm and the process and path to follow is less well defined.

In these circumstances, above all, families need to be kept informed. The chance of bewilderment needs to be minimized, the biology of illness along with investigation and treatment plans need to be explained so that people can adjust to a process and understanding, if not precise definition and cure. This makes communication one of the most important things neurologists do: communication through talking, communication through literature, and communication through other media including web-based information.

This fact then begs the question whether consultation content needs definition, or should the whole process of interaction with families be left to intuition (i.e. previous experience and knowledge). In his editorial this time last year Stuart Green asked the question, 'How much to tell?'⁴ The linked dilemmas are 'How to tell?', 'How best to tell?', and, of course, 'By what means?'

Guidelines have been developed on how to give the news of well defined disability, such as Down syndrome. They are widely known, if not always followed. It is not clear, however, to what extent these principles can be generalized to other conditions and paradigms, for example, an evolving condition such as cerebral palsy. Nonetheless SCOPE in its widely publicised 'Right From The Start'⁵ campaign emphasized how well-defined principles should be followed in all potentially disabling conditions whilst refining the detail.

In a recent study on epilepsy⁶ it was evident that children with epilepsy did not have the knowledge of their condition

enjoyed by other groups of children with asthma and diabetes – despite the clinicians involved thinking that the issue had been addressed. The time has come to look at consultation content in far more detail, e.g. which issues are raised in which condition and in what order, which written information is provided to complement what is said in the clinic along with valid and reliable methods of process assessment? There is currently much information written for children in very attractive formats but rarely is any attention paid to the reading age of its content and therefore its comprehensibility.

There is a suggestion that levels of anxiety and depression following receiving information of disability can be reduced if the process is executed well. It is likely that this in time will lead to better adjustment and more effective use of health, education, and social service resources.

In the United Kingdom the collective name for the process that is to underwrite the future quality of care is clinical governance. Linked to this in the next few years will be the same sort of appraisal system, seen in other professions for some time now, which will ensure a continuing right to practise. Governance guidelines should regard communication as a medical intervention recognizing its great power to do good as well as harm. We should develop an evidence base for content and then as we develop our appraisal systems look closely at who is doing it well and who needs help.

John Dryden as part of the exploration of his ideas on anarchy and order wrote:

*But far more numerous was the herd of such
who think too little and who talk too much*

This is perhaps the time when we ought to bring the two together and start to think about how we should talk. In that way the foundation of all we do can be underpinned and the families we set out to help will really get their money's worth.

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