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WHAT SHOULD I TELL A PATIENT AFTER AN ISOLATED EPISODE OF DEMYELINATION?

Geraint Fuller

Gloucestershire Royal Hospital, Gloucester, UK.

Email: Geraint@fullerg.demon.co.uk

INTRODUCTION

There is nowadays a widespread belief that it is right for patients to be actively involved in decisions about their care (Coulter 1999). Much time is given to informed consent before surgery. The balance of risks and benefits is discussed with the patient before proceeding to an operation. Discussion prior to a surgical intervention is more formalized than for medical intervention, such as drug treatment, because an operation is a unidirectional intervention, once it is done it cannot be undone. What other intervention is unidirectional in the same way as surgery? Giving information shares this property, once you have told a patient something you cannot undo that, you can expand on the information, put it in context, but you cannot retrieve the information.

A large part of what we as neurologists do is to give patients information. We make diagnoses, which we explain to patients, we devise investigation and management plans, again discussed with the patient, and we give a prognosis. Most neurologists do this using a system that has evolved during their own clinical practice. There will be a number of factors that influence how this is done. These include the nature of the clinical problem, the patient's background and knowledge and expectations. The neurologist decides what he or she feels is appropriate for the patient to know about their condition

and aims to communicate that effectively. There is however, no straightforward way for the provision of information to be handled in the same way as a surgical operation. You cannot gain the patient's informed consent before giving the information, because in doing so you inevitably give the information. 'I would prefer you hadn't told me that', is an observation that cannot be remedied.

There has been a trend for telling patients more and more about their illnesses, to allow them to be increasingly involved in decisions about their own care. This is in contrast to the relatively recent past when the concern about giving unwelcome information was addressed by withholding information.

In the past there were patients who were not told about a definite diagnosis, for example of multiple sclerosis (MS). This policy of nondisclosure was justified as a way of protecting the patient from anxiety and concern about possible deterioration. There has been an increasing recognition of the need for explanation, even if sometimes with qualification. To quote from McAlpine *et al.* (1965):

'Formerly every effort was made to keep the patient with multiple sclerosis in ignorance of the diagnosis, and it would be generally agreed that this policy should be continued *in the case of the young unmarried adult* ... as a general rule, it is better to give a rational explanation of symptoms to allay anxiety and ensure intelligent co-operation in treatment.'

The italics in that quotation are mine and reflect an area where practice has moved on. Most contemporary neurologists would be more comfortable with Matthews' observations in Practical Neurology (Matthews 1963):

'Once the diagnosis is reasonably secure, the question arises as to what to tell the patient. Some balance must be held out between inducing despair by baldly stating the diagnosis and probable outcome after slight symptoms, or, by reticence, making the patient feel that her doctors are ignorant or afraid to tell her the worst ... after two or more relapses, or with progressive symptoms when there is no room for doubt, the patient must be told.'

However, there are still areas where neurologists are reticent in giving information. In this paper we will explore one such area, the risk of recurrence after a single episode of demyelination. There are four patients whose clinical details are given in the box.

THE PATIENTS

Patient 1

A 32-year-old-female estate agent is referred by the ophthalmologists after recovering from an episode of optic neuritis. She has never had any other neurological symptoms and examination reveals a left-sided relative afferent pupillary defect with a pale optic disc. An MR scan organized by the ophthalmologists shows multiple (> 10) periventricular white matter lesions. The report, a copy of which was sent to the GP, concludes that the changes are 'typical of MS'. During the consultation the patient gives no indication that she has any knowledge of the potential implications of the episode of optic neuritis.

Patient 2

A 36-year-old male butcher had an episode of numbness, which came on over about 6 days, that spread from his feet to his waist, and included the saddle area. He was seen then and found to have minimal weakness of hip flexion, brisk reflexes in the legs and flexor plantars. There was a sensory level to pinprick at T10. An MR scan of his spine showed a single intrinsic high signal lesion in the thoracic cord at T6. No MR scan of the brain was performed. He returned 6 weeks later fully recovered. He had never had any previous neurological episodes. He gave no indication that he has any knowledge of the potential implications of the spinal cord syndrome. He was concerned that it may hamper him in his plans to set up his own business.

Patient 3

A 28-year-old mother of two has recovered from an episode of dizziness and double vision. This developed over a 6 day period and she was admitted under the general physicians. They found her to have a right internuclear ophthalmoplegia and an ataxic gait. An MR scan of the brain found six periventricular white matter lesions. She reported that she had never had any previous neurological episodes. You confirm the signs described above. Her sister is a nurse and her husband is a computer programmer.

Patient 4

A 44-year-old-woman, a factory worker, has recovered from an episode of right sided optic neuritis without sequelae. An MR brain scan was normal. She has never had any previous episodes. She gave no indication of any knowledge that this may have any other implications.

THE QUESTIONS

What should you tell each of these patients about the risk of further episodes and about the possibility of the development of MS?

Do you need any further information?

How should you go about telling them?

Flashback ...

The advice given by Professor Matthews in *Practical Neurology* in 1963 was:

'In practice I do not tell the patient after one attack, however apparently typical. Possibilities of error exist and there may be a prolonged remission. In most circumstances it is best to warn a responsible relative of the possibility of relapse ...'

BACKGROUND INFORMATION: WHAT IS THE RISK OF FURTHER EPISODES?

There are several studies that have looked at the risk of developing MS following clinically isolated syndromes. Some have looked at whether MRI abnormalities and other variables alter the risk. Prospective studies are relatively few and have a number of problems. Most studies have come from tertiary referral centres and are not population-based. Follow up is often incomplete and of relatively short duration, particularly in the MRI studies. Table 1 summarizes some of these studies. In the most recent (O'Riordan *et al.* 1998), if it is assumed that none of those lost to follow-up went on to develop MS, then 56% (45/80) of those with abnormal MR scans developed MS and 6% (3/49) of those with normal scans developed MS. These figures represent the minimum estimate from that study. The study also found a correlation between the number of lesions at baseline with the expanded disability status score at 5 and 10 years. However, the initial scan in those with no clinical relapse at 10 years (0–26 lesions) had significant overlap with those with benign MS (0–74), relapsing remitting MS (2–31), and secondary progressive MS (2–29).

DISCUSSION

The discussion will be held between a paternalistic doctor (Dr P) and a doctor who believes in patient involvement in all aspects of their care (Dr I). They will outline how they would conduct the interview with the patients described above and justify their approach.

Dr P

'Primum non nocere', 'first do no harm', is the guiding principle of medicine. Interventions, including giving of information, should not leave the patient worse off than before. When discussing the pros and cons of operative or drug treatment it is relatively straightforward to involve the patient in the decision, discussing the relative risks and benefits of any proposed intervention. Sometimes, thanks to the nature of the evidence

Reference	Follow up	Patient number	Spinal cord syndrome	Brainstem syndrome	Optic neuritis
Sandberg-Wollheim <i>et al.</i> (1990)		15 years	86		45%*
Morrissey <i>et al.</i> (1993)**	5 years	89	11/28 (39%)	8/17 (47%)	24/44 (54%)
O’Riordan <i>et al.</i> (1998)**	10 years	81 followed from 129 in total			
		Normal MR brain scan	2/8 (25%)	0/5	1/14 (7%)
		Abnormal MR brain scan	10/15 (67%)	10/11 (91%)	25/28 (89%)
		Total	12/23 (52%)	10/16 (62%)	26/42 (62%)

*Actuarial estimate.
**Same cohort, different follow up.

Table 1 Some long-term prospective studies considering the risk of developing clinically definite Multi-ple Sclerosis after a clinically isolated syndrome.

that guides clinical decisions, there can be fairly confident statements of the risk of intervention and of conservative treatment. One good example is the discussion of the possibility of a carotid endarterectomy with a patient who has had a recent carotid territory transient ischaemic attack and a high grade carotid stenosis. In other areas there is a less clear cut assessment of risk and benefit, for example a patient with cervical spondylotic myelopathy. However, in these clinical situations, the discussion benefits the patient, and regardless of the decision, these discussions will not leave the patient worse off.

This contrasts with the situation under discussion here. A patient with an isolated clinical episode may have no more episodes. He or she may have further episodes and develop benign, or disabling MS. None of these outcomes is changed by a full knowledge of that risk after the first episode. The patient is simply burdened by an uncertainty and fear for the future. This may produce significant psychological problems. MS is a particularly frightening disease because it is incurable, with limited disease modifying treatments, unpredictable and most alarming of all, disabling. Thus it is held in particular dread. We have all seen the dis-

stress provoked in a patient with an abnormal scan (such as patient 1) when told by a well-intentioned non-neurologist that they have MS (James 1997; Young 1997). In addition, it is quite common to see patients who have recently been diagnosed as ‘MS’ after a second clinical episode, with a multitude of minor neurological symptoms that are almost certainly not related to any MS but to the patient’s anxiety and increased vigilance. In a patient with an isolated clinical episode one would then have to decide whether these symptoms really were recurrent further episodes, a further cause of anxiety for the patient and a source of potential diagnostic error.

There are thus several areas of concern. Firstly, that telling the patient about the risk of

MS may have an adverse psychological effect. A substantial proportion of patients will not develop further problems and that group would suffer the same psychological distress needlessly. Secondly, this information may increase the patient’s vigilance, distort symptomatology and contribute to diagnostic error. Poser reported that 35% of patients referred to him for a second

opinion had other neurological problems (Poser 1997). He attributed the high error rate to an increased emphasis on neuro-imaging in making the diagnosis rather than depending on the history and examination. Finally, attempts to make more specific risk assessment for the patient are unhelpful for an individual patient. The risk of going on to develop MS increases with an abnormal scan. However, there are patients with abnormal scans who do not

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progress, some with markedly abnormal scans. So while a patient is relatively more likely to develop MS there are those with highly abnormal scans who will not have had a recurrence at 10 years. If patients with abnormal scans had been advised of the risk, a smaller number of patients would have been informed unnecessarily, but there still would be some.

How should we tackle these clinical interviews?

The aim is to convey the information I am certain about and offer the patient the chance to ask more while not giving explicit information that might not be welcomed.

The patients need to be told of their diagnosis, optic neuritis (patient 1 and 4), myelitis (patient 2) and brain stem syndrome (patient 3). I would tell them that these reflected areas of inflammation, which we could expect to recover, usually over a few months. I would explain that for most patients we did not know the cause of the inflammation. I would suggest that if they had any further problems then a cause for the inflammation might become apparent. I would attempt to do this in such a way that would allow the inquisitive to ask about the condition further. For example, they might ask what cause might be found if they had further episodes. If they did, I would tell them that there were a range of inflammatory conditions that could do this but that MS was the most common of them. I would aim to allow them to discuss MS further if they wanted to but would not press further information unless they asked. If they asked about the risk of going on to develop MS then I would probably quote the broad figure of about 50% at 10 years for all patients after a single event. In the patient with a normal scan (patient 4), I would say that the scan indicated that she had a lower risk, perhaps only 10% of going on to MS in 10 years. I would anticipate that patient 2 would ask in detail about the future given his concern about his business so I would expect a full discussion with him. I would justify using

these figures on the basis that incomplete follow up in the studies makes the higher figures uncertain.

Dr I

'Paternalism or partnership?', the title of a recent British Medical Journal editorial (Coulter 1999) pithily characterises the nature of the debate here. The subtitle, 'patients have grown up – and there's no going back' summarizes the editorial conclusion. The days where doctors could control patient access to information have passed. We must face this and alter our behaviour to allow us to help the patient's best use this information.

Dr P, in his discussion, emphasises the distress provoked in a patient by becoming aware of the possibility that he or she may develop MS. This needs to be balanced against the patient discovering it themselves, by accessing medical texts or increasingly via the Internet, or more distressingly via other routes, for example if they are refused insurance, are misinformed by another doctor (such as the GP of patient 1 reading the MR scan report) or on requesting copies of their notes. This method of discovery is worse because it occurs in a situation where the size of any risk and the significance cannot immediately be discussed with a neurologist. Furthermore, by this time the neurologist may have lost the patient's confidence through not informing him explicitly about the potential risk.

How easy is it to get this information? I searched the Internet using a standard search engine (Altavista) for the phrase 'optic neuritis'. In the first four results (of several thousand) were two patient information sites, one not mentioning the risk of MS but referring to possible 'other causes', the second quoting a 40% risk of going on to develop MS. While Internet access is not universal many patients who do not have access will have friends or relatives who will search on their behalf. Patient 3 has a husband who is a computer programmer and he almost

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certainly would search the Internet for information about his wife's condition.

The size of the risk of developing MS is surely one that merits explicit discussion. In discussing complications of surgery or adverse effects of drugs we would usually explicitly discuss events that occurred in more than 5% of patients. Certainly any treatment that had a risk associated with it of 50% would be fully discussed. A patient with a 50% risk of recurrence of a tumour after treatment would have this issue discussed with them. Why is the discussion of the likelihood of recurrence and of development of MS different?

The butcher (patient 2) has another reason for a full discussion. He is considering setting up his own business. For him the knowledge of the risk of developing MS will be a factor in the decision about whether this is in his, and his family's, best interests. He may decide that the security of his current job and its benefits are preferable to the uncertainty of his own business if he has a 50% risk of going on to develop MS. Following discussion you might reasonably decide that you should do a brain MR scan, as that might further inform his decision by either increasing or decreasing the risk. The other patients may need to make important decisions that would also be different if they knew of the risk. These decisions may not be under consideration at the time of your discussion with the patient, so it seems reasonable to equip them with the information to tackle the decisions when they arise.

The aim of the discussion with the patients is to fully inform them of their situation. As some of the ideas are quite complicated, it may need more than one consultation.

I would explain their respective diagnoses in the same way as Dr P, and explain that these related to episodes of inflammation and would expect them to recover in a few months. I would indicate that for them we could not be certain about the cause but that a proportion (about 50% in five years for patients 1 and 2; about 40% in five years for patient 3 and less than 10% in 10 years for patient 4) would have a further episode that would probably lead to a diagnosis of MS. I would briefly discuss the nature of MS, emphasising that the diagnosis could only be made when there were multiple episodes and not after a single episode and discuss the variability of its prognosis, ranging from benign to disabling. I would indicate that the longer the patient went

without recurrence the smaller the risk of developing MS would become.

From the quotations from the early 1960s given above, it is clear that giving the diagnosis of clinically definite MS was inconsistent. Why should McAlpine not have given the diagnosis to young unmarried adults (McAlpine 1965)? The increasing dissemination of information and increased sophistication of patient understanding of health matters will make this discussion seem as strange in 40 years time.

CONCLUSION

The information provided to patients following a clinically isolated neurological episode varies. The two discussants have aimed to reflect what could be considered the range of opinion at the moment. There is a trend to provide more information to patients and this seems likely to continue and will probably include this group of patients. Given the concern that this may be harmful, and that there is uncertainty over what is best for the patient, there is a case for a formal trial to compare different strategies of giving information in this situation.

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