Doctor-patient dilemmas in multiple sclerosis

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Author's abstract

This paper is based on the second Jack Pritchard Memorial Lecture given at the Queen's University of Belfast (1).

The author describes his own personal response to having multiple sclerosis (MS), and then examines the psycho-social aspects of the disease in a wider context. The distress caused by the emotional difficulties associated with MS is emphasised, and in particular the strain placed on the doctor-patient relationship at the time of diagnosis. The physician's ability to cope with the needs of MS families is explored, together with the importance of offering counselling.

Also discussed is the ethical question of whether or not the patient should be told the complete truth. Patients with MS are seen as having a potential not only for helping each other, but also for being able to share in the management of their own health care.

Personal experience

Relationships between doctors and their multiple sclerosis patients are particularly complex. Before examining more fully the issues concerned with such relationships I shall describe my personal experience of having multiple sclerosis (MS). I have decided to do this because I hope that it will enhance the significance of what I have to say later and also make clear the reason for my special interest in this subject.

Eighteen years ago, while I was studying medicine in London, I developed a sharp pain in my left eye followed by blurred vision and partial loss of sight. Thinking that I had something wrong with my eye I consulted the doctor responsible for medical students. He gave me a full neurological examination, which alarmed me, and so I went into the library to look at the textbooks. I discovered for myself that my symptoms could be the start of multiple sclerosis.

I was profoundly shocked; I felt lonely and frightened. I can remember sitting in the library with sweat pouring off my face and with my pulse beating rapidly. I saw several doctors over some weeks but

none encouraged my questions, or seemed to be aware of my emotional needs. When I asked about the possibility of developing MS I was told that as I could read the textbooks I knew as much as any doctor, and that only time would tell.

This was not reassuring; the textbooks had already indicated that within 10 to 20 years I could find myself paralysed, blind, incontinent, unable to speak properly and even demented!

A few months later I was left with only slight visual loss but the next few years were difficult emotionally. Other symptoms appeared in keeping with the diagnosis of MS, but I was scared to go to a doctor, and I hid my symptoms and feelings from others. I felt isolated and very depressed at times and I was occasionally unable to work properly.

About five years later while working in Winchester as a casualty officer I developed numbness and clumsiness in my right arm. This interfered with my work so much that I saw another consultant neurologist. He told me bluntly that I did have MS and reprimanded me for not coming sooner.

This definite diagnosis was a relief to me and I was grateful for this man's frankness, and for the chance to talk to him about my future. He told me that the outlook was uncertain but I could expect progressive disability and should make allowance for this. I had always been interested in psychiatry, and my experiences as a patient so far had convinced me that the medical profession as a whole tended to undervalue the emotional and relationship problems associated with physical illness. I therefore determined to go ahead with post-graduate training in psychiatry as soon as I could. My neurologist was not sure about this, and I remember I laughed when he mentioned that there were some very long corridors to walk down in psychiatric hospitals!

So far I have been one of the luckier ones with MS, but I have never forgotten the misery and confusion that surrounded me at the beginning of my illness. My own emotional adjustment to MS did not end with the diagnosis, and I feel I must complete my story before making more general observations. I had several MS relapses during my psychiatric training and I also experienced periods of depression; my symptoms were not easily visible to others and I continued to hide them.

Key words

Multiple sclerosis; doctor-patient relationship; truth-telling; communication; counselling.

and to bottle up my feelings.

While working as a senior registrar I became so depressed that in desperation I prescribed myself a course of anti-depressants because I could not bring myself to share my troubles with anyone else. They helped me a little but it was counselling from a medical colleague that finally enabled me to come to terms with the disease. She listened to my anxieties, and to my sad, angry and confused feelings. She helped me to understand that these feelings were natural and realistic. I realised from talking to her that it would have been abnormal not to have been emotionally upset by a very real loss of health and the threat to my security. I was able to express my feelings openly after this, to admit to having MS and to make realistic decisions about my future. For the first time I felt that I had been understood; I had received counselling from another person, who happened to be a doctor.

Understanding MS

I have spent some time describing my own experience because this has been basic to my understanding of other people with MS, and the problems that they have had to cope with. Once I had accepted the disease more fully I joined the MS Society. I felt that I could help people who were having difficulties with their own acceptance, and with other associated emotional or relationship problems. I also wanted to share my experience with medical colleagues, many of whom seemed to be ignorant of the psychological side of MS. At the same time I wished to help myself by doing something positive about the situation: to turn base metal into gold. By then I had undergone a personal analysis and training in psychotherapy. I had also begun to work with children and families at a child guidance centre where I discovered many parallels between families that I saw there, and families containing a member with multiple sclerosis.

Over the past few years my wife, Penny, and I have talked to many people with MS who had a whole range of emotional, relationship, and sexual problems. Where possible we have also seen them with their partners. The majority came to us soon after the diagnosis had been made or discovered, or when MS was suspected. We have seen them at our home, and they have been referred by physicians, social workers, community nurses, by MS welfare officers and by other MS persons.

As a result of this voluntary work we have been made aware of much criticism, from MS families as well as from volunteer helpers, directed at our colleagues in the medical profession. Many people with MS are bitter about the way they feel they have been treated by doctors. Our own observations (2) are confirmed by a recent survey (3) which found that a large number of patients had not been told by their family doctors that they had MS and most resented this.

Through my own experience of having MS I am well able to understand their feelings. Being myself a person with MS as well as a doctor, I belong to both

groups and I do not pretend to be objective or detached in my outlook. On the contrary, I am emotionally involved and the views expressed here are the consequence of living with my own MS and the result of helping others through counselling, as well as my work as a doctor. In this dual role I have benefited from hearing confidences from people with MS not usually shared with doctors. I have also been able to listen to the ideas and anxieties that colleagues have expressed about their MS patients.

MS often leads to a long and complicated illness, and there are many different occasions when help and understanding from a physician are crucial. Particularly stressful for families are the occurrences of frightening relapses and complications. The advent of incontinence, or bedsores, or the need to depend on aids for the first time, can all precipitate emotional and relationship difficulties as well as physical ones. When sexual problems occur, whether for physical or psychological reasons, or from a mixture of the two, then skilled counselling from the physician is essential as well as a knowledge of the disease and its many manifestations. Families also need time, support and information when pregnancy is an issue, or when long or short-term residential care are being considered.

Telling the truth

A most important time, when the physician's skill is often tested to the limit, is the time of diagnosis. Poor communication of a definite or suspected diagnosis is responsible for as much distress, misunderstanding and ill feeling as at any other period in the relationship between doctor and patient.

The diagnosis of multiple sclerosis may be difficult to make depending as it does on a pattern of symptoms and signs occurring over a period of time. There are still no reliable diagnostic tests for MS and the disease is often suspected before it can be confirmed by subsequent events. Yet an early diagnosis is desirable to exclude treatable conditions (such as spinal tumours) and to meet the needs of research into the disease. Equally important are the emotional needs of the person with MS and his or her family, who are faced with a frightening experience to which they must adjust before they can plan for the future. Honesty from the doctor will enhance the doctor-patient relationship, and will eventually lead to a greater trust in him by his patient. Advances in detecting MS by using a nuclear magnetic resonance scanner may eventually speed up the time that it takes to diagnose this disease. A Lancet editorial (4) optimistically suggests that an accurate diagnosis should soon be possible in most patients during their presenting clinical episode.

A great deal of controversy surrounds the issue of 'telling the patient' and many people with MS have claimed they were not told the truth in a straightforward manner. Some have found out by accident, whilst others have had to resort to subterfuge such as steaming open doctors' letters, or reading

hospital notes upside down. Sometimes the patient's spouse has been informed of the diagnosis but instructed not to tell his or her partner. This inevitably places a great strain on family relationships.

Even when the diagnosis is certain a doctor's reluctance to tell may be justified on the grounds that the patient cannot cope with the diagnosis. Yet time after time people with MS speak of relief at knowing their diagnosis. Naturally, many are shocked and distressed, but at least they know the truth and can begin to come to terms with it. The truth is rarely worse than the unknown. An American study published in 1982 (5) found that a great deal of conflict often arose between MS patients and physicians during the pre-diagnosis period. Many patients began to take an active role in establishing their own diagnosis and conflicts extended to relationships with family and friends; but naming the disease led to a reduction in stress and the investigators urged physicians to consider these emotional factors when deciding whether or not to inform patients of a tentative diagnosis of MS.

How much to tell: an ethical dilemma

Some physicians consider that it is not always in the best interests of multiple sclerosis patients to be told the truth at an early stage, or even to be told the truth at all. They argue that the doctor's first duty is the relief of suffering and that to tell the truth could cause unnecessary anguish rather than be conducive to peace of mind.

In support of this it is pointed out that a patient presenting early in the course of the disease, having had only two or three MS symptoms, could be free from further clinical episodes for many years or even for a life-time. Other justifications for deceiving patients about their prognosis are that it is impossible to predict the future with certainty, and that patients are not able to understand the complexities involved.

Not knowing whether a patient really wants to face the truth can be a reason for being cautious about how much to tell. But dishonesty justified on these grounds can sometimes result from the doctor's own discomfort when discussing emotionally painful issues. In such circumstances the doctor's unconscious anxieties could be the real cause for not being truthful, rather than a genuine regard for the patient's needs.

A few people with MS have told me they resented being given their diagnosis early because they had altered family and career plans unnecessarily in the light of subsequent events. In these cases the failure could have been in *how* they were told rather than *how much*.

Alternatively a gloomy picture of the future may have been given by doctors with an over-pessimistic view of the disease based on treating severely disabled patients in hospital. But many people with MS live normal lives and may have little or no disability even after many years.

In my experience the vast majority of MS patients have wanted to know the nature of their disease as early as possible. They have been keen to discover all they could about the disease to enable them to make their own decisions about the future. Many have felt they had a right to know about their illness and to participate in their own treatment.

A moral question for the physician is whether to do what he or she thinks is right when this differs from the patient's wishes. It is difficult for the doctor to be sure that he accurately knows what the patient really wants. Although there are no simple answers to these questions they emphasise a need for the doctor not just to understand the patient, but also to be aware of his or her own feelings and attitudes. The physician must be prepared to consider what the truth could mean for a particular patient, and it is surely right to respect a patient's need to make his or her own decisions. The doctor's prime task must be to serve the patient and the patient's family and to provide them with the information and support they require to adapt to the demands of an uncertain future.

Emotional reaction

Once the diagnosis of MS is known a period of adjustment will follow. In many ways this process is like bereavement; the patient has to mourn lost health and adjust to a new identity, to a different picture of him or herself and of the future. He or she will feel shocked, angry and depressed, and may try to deny what has happened. This is a normal reaction and it should neither be discouraged nor over-indulged. Counselling at this time may help people to work through confused and painful feelings and to accept their limitations.

A particularly distressing feature of MS is the fact that the course of the disease varies greatly from patient to patient; people in the early stages live with alarming uncertainty about their future. Added to this is the remarkable variability of symptoms within one individual; not only does the patient have to cope with major relapses and remissions but he or she must also learn to live with ups and downs from day to day, and even from hour to hour.

Many MS symptoms are subjective and invisible to other people. This is especially so with fatigue, a common problem in MS, made worse by exertion and hot weather. It may fluctuate markedly and can cause a great deal of misunderstanding. This symptom can be extremely disabling but it seems to be inadequately recognised as a handicap by many doctors.

Physicians need to understand that the way in which a person reacts to MS does not necessarily relate to the severity of the disease. A person who is only mildly affected can be psychologically devastated, whilst someone else who is severely handicapped might cope well. Many factors play a part in determining an individual's response: these include the effect of the disability on the person's way of life, his or her

personality, and the amount of support received from family as well as from health care workers.

Adjustment can sometimes be more difficult when symptoms are mild; the patient is unsure whether to perceive him or herself as normal or handicapped. When physical signs are obvious it may be easier to accept a new identity, but people may then have to cope with the stigma of disability. They may try to deny their handicap; some refuse to use a stick, preferring to stagger about dangerously; neighbours or passers-by may suspect them of being intoxicated.

Other people with MS will not adjust their life-style and may attempt impossible tasks to prove to themselves that they are still 'normal'. At the opposite extreme are patients who take to a wheelchair although they can still walk reasonably well. In such cases there is often an over-protective relative, and the relationship can become a 'hostile dependent' one in which anger and guilt are mingled.

People with MS have to find a happy medium between complete denial on the one hand and giving in on the other. Only by doing this can they discover their strengths. The best encouragement for someone with MS is to be valued and wanted by others. We all need to contribute in some way, however small, and the patient should be given respect and responsibility by his medical advisers wherever possible.

Doctors

But what about the doctors? We need to understand them too! In these modern days of 'high-tech' medicine, doctors may feel trained to cure rather than to care for their patients. It seems that medical students are selected primarily for their ability to pass examinations rather than for their more human qualities. Medical training perpetuates this bias and doctors can come to see their role as that of technical experts in the diagnosis and treatment of disease. They may prefer to see quick and positive results and may only feel that they have succeeded as physicians if a patient gets better. While being useful in some well defined medical conditions such as pneumonia, for instance, this approach can leave a doctor feeling less confident when faced with the vague and recurrent symptoms of long-term illness, and more particularly he or she may find it difficult to cope with the emotional side of disease.

Technical expertise and medical knowledge, though essential, are not enough. A doctor must combine these with communication and counselling skills to be wholly effective. A balance between bedside manner and technical competence is needed today just as it was at the end of the sixteenth century when Francis Bacon wrote: 'Physicians are some of them so pleasing and conformable to the humour of the patient, as they press not the true cure of the disease; and some others are so regular in proceeding according to art for the disease, as they respect not sufficiently the condition of the patient. Take one of middle temper; . . .' (6).

The doctor must also be able to cope with his or her own feelings of inadequacy or frustration when faced with an MS patient, and must not take personally the anger and bitterness projected onto him by the patient. Most importantly doctors need to realise that they can help their patients best by giving them time and interest, and by 'just listening' on occasions. A patient can gain a great deal of relief from sharing his fears and confused feelings, and by being accepted as a fellow human being.

A person once diagnosed as having MS must live with a disease which is both humiliating and depressing. He or she has to cope with loss of health and security as well as changed roles in the family and at work, which can be devastating to self respect. Many people feel angry and may look for someone to blame. Often, eager to find an explanation and cure, patients turn to 'quack' remedies or diets. In both of these circumstances a patient's doctor will be the natural scapegoat and may be rejected or treated unfairly. Unfortunately at this point some doctors take the patient's reaction personally, and may feel unable to cope with the relationship in a positive way. The outcome of this can be that the doctor does not wish to see this patient more than he has to, or that he passes him or her on to somebody else.

As well as coming to terms with loss of health the person with MS has to cope with the vague initial symptoms of the disease, which are subjective but very real. These symptoms are often difficult to describe without appearing to be 'neurotic' or 'a hypochondriac'. Such labels are sometimes used by doctors but they serve only to undermine the trust and goodwill in the relationship between the patient and doctor. Visual or sensory symptoms, and in particular multiple sclerosis fatigue, are hard for patients and close relatives to understand. It is important that doctors give reassurance and explanation in order to justify the sick role taken on by the person who has multiple sclerosis. Because of the difficulties involved in communicating subjective symptoms, some patients may deny or hide them; others may exaggerate the symptoms, often in an emotional way, and so perpetuate the doctor's suspicion that they are purely psychological. Both of these strategies will most probably lead to a further breakdown in communication.

Counselling the family

Can communication between doctor and patient be improved? Telling someone a disturbing diagnosis or prognosis is not just a question of the transfer of information but of establishing an appropriate relationship. It is difficult to take in more than a little information in the clinical atmosphere of a consulting room at a time of emotional shock. Patients often forget what they have been told under these conditions and may sometimes deny that they have been given a diagnosis at all!

Diagnosing and managing MS is not just about informing the patient of the facts, but about being sensitive to his or her emotional needs and reacting appropriately to them. It is often best for a patient and close relative to be seen together for as long as they need to ask questions and to express their feelings. Opportunities must be provided for them to return for more information and support as they require them, and time is necessary for people to work through their feelings of shock, fear, anger and sadness at each stage of the disease. Some people need to deny part of the truth until they can cope with it all, and skill is needed to assess how much someone really wants to know at any one time. The truth should not be forced on people anymore than it should be withheld completely.

A question often discussed by people with MS is whether the neurologist or the general practitioner (GP) is the best person to inform patients that they have MS. Each case is unique and will depend on the circumstances surrounding it.

It is often appropriate for a neurologist to tell someone that he or she has MS, or to discuss suspicions that this might be so, and I know that many see this as their particular responsibility. But this will only be satisfactory if the neurologist has enough time to offer the patient and family the chance to be seen on several occasions. I stress again that only such an approach will allow them to question the neurologist, work through their feelings and obtain the necessary emotional support as well as information.

In many cases it will be the GP who has the time and skills necessary especially if, as the family doctor, he or she has already established a trusting relationship with the patient.

Whatever is decided by the doctors concerned it is essential that general practitioners and neurologists work closely together, and are absolutely clear about their individual responsibilities. Unfortunately this is not always the case and patients may find themselves cast adrift 'between the devil and the deep blue sea'.

When one member of a family has multiple sclerosis the whole family will be affected; children can be very sensitive to anxiety and may become disruptive and attention-seeking if their needs are ignored. Facts should be explained to them and if they are involved in major family decisions they will not feel excluded and resentful.

The process of grieving that surrounds loss of health and future security may last a long time. Patients and relatives will need to be permitted to express their natural feelings and this can be painful for those working or living with them. If this process is blocked then there is a risk that personal and relationship difficulties will occur, requiring psychiatric help at a later stage.

'Telling the truth' to the patient and relatives is basically a counselling exercise, requiring an understanding of psychological processes, self awareness and relationship skills. But the doctor does not always have sufficient time or even the required

counselling skills. Often a nurse or a social worker will be able to help on these occasions and may be in a better position to provide the regular follow-up that is so necessary when a diagnosis of MS has been made. For this to happen there must be a shared understanding of each other's roles by medical and non-medical personnel as well as mutual trust and respect.

Encouraging self-help

Many MS persons and their partners find it helpful to meet others who have successfully come to terms with similar experiences. Self-help groups have grown in the last few years and there is a strong potential for involving others with MS, as well as volunteers, in the provision of emotional support. Workers in the United States of America (7) have described the group counselling of MS patients in a hospital setting, whilst 'Crack MS' self-help groups in the United Kingdom now form an important part of the MS Society's work in the community.

It must not be forgotten that patients have a responsibility to communicate with the doctor. Doctors are not mind-readers and they cannot guess what is worrying their patients unless patients ask questions and state their fears. Sometimes a patient with long-standing MS can become an expert in the disease and may become disillusioned with a doctor who has only limited experience. This puts a strain on the relationship but it is unfair to expect a GP to know everything about MS when he or she may only have one or two patients with the disease in the practice. MS welfare officers can also become frustrated with a local doctor for similar reasons.

Some doctors are prepared to admit their ignorance of MS and to acknowledge the expertise of MS patients. One lady told me that her GP's reaction to a consultant neurologist's confirmation of the diagnosis of MS was to share the letter with her, and to say 'I don't really know much about MS; let's find out what we can together'. And that is exactly what they have since been doing, with great benefit to each of them I feel sure. Similarly, another doctor, when dealing with complications of multiple sclerosis, said to his patient 'You're the expert: tell me what you know about this problem and I'll do my best to help'.

We can contrast these encouraging responses with the reply given to a patient who asked whether it might be useful to meet someone else with MS. The doctor, in this case a consultant neurologist, answered 'Don't be so silly! The next thing that you will be doing is writing to the MS Society for leaflets'. Unhelpful responses like this are all too common, and I hear reports of this kind quite regularly.

Doctors should respect their patients and not undermine their confidence and power. Like Kostoglotov in Solzhenitsyn's 'Cancer Ward' patients need to feel able to say to their doctors 'Can't we get away from this tone of voice? You sound like a grown up talking to a child. Why not talk as an adult to an

adult? . . . You start from a completely false position. No sooner does a patient come to you than you begin to do all his thinking for him. After that, the thinking's done by your standing orders, your five minute conferences, your programmes, your plan and the honour of your medical department. And once again I become a grain of sand, just like I was in the camp. Once again nothing depends on me' (8).

Like Kostoglotov all of us with MS must begin to question and actually to manage those whom we ask to give us medical help. In another book *Patienthood* by Siegler and Osmond we find the following. 'The doctor-patient relationship resembles that of the elephant and the mahout (the elephant driver). Elephants have many virtues: they are an excellent means of transportation in difficult country, and they can use their great strength to move heavy obstacles. They are not cheap to feed, but everyone knows that. All things being equal, one is lucky to have a good, strong, kindly elephant at one's disposal. However, for all their good nature, elephants are dangerous simply because of their size. They may sit, stand or roll over on you quite inadvertently. . . Elephants are like doctors in that the very qualities which make them so useful – their power, strength, and sagacity – also make them dangerous. Patients are like mahouts, in that they need the elephants and can get essential services out of them, but they must learn how to manage them and how to avoid being trampled upon. They must also avoid stampeding them inadvertently' (9).

So patients as well as doctors need to fulfill their part in the relationship if it is to function at its best!

Working together

In conclusion I shall outline ways in which we can help dispel some of the misunderstanding between the doctor and his MS patient. Firstly we must clearly define to the medical profession the special psychological needs of people with MS. In particular we should express our dissatisfaction with the low priority given to counselling skills at all levels of medical education. MS patients can be difficult to deal with, but it is ultimately the doctor's responsibility to overcome problems, and to understand that they are often due to a patient's response to a frightening and confusing disease. Indeed, sometimes the disease itself can cause direct psychological symptoms which may include memory loss, irritability, mood swings and, in severe cases, dementia.

Several medical students have told me of their dissatisfaction with a training curriculum which includes so little, if any, training in counselling skills. At one university the students are considering organising such training for themselves – a sad reflection on current medical education but good news about the attitudes of some of our future doctors at least!

Secondly the MS Society can compensate for the current lack of counselling by training welfare officers to acquire their own counselling skills and so cope bet-

ter with their clients' psychological problems. Giving advice or providing aids and holidays, whilst important, is certainly not enough. The MS Society could also train those who are disabled as counsellors and further encourage the development of self-help groups as in the 'Crack MS' movement. This is already happening in some places in the UK mostly due to the direct inspiration of and pressure from MS persons themselves.

Thirdly, we can all encourage patients to stand up to their doctors and make their needs clearly known, and then support them when they do so. We can encourage them to ask more questions and to complain if they are not satisfied with the service they are getting. Perhaps there could be more meetings between professionals and volunteer helpers. The Multiple Sclerosis Society has an important role to play in this area and I should like to see local branches taking more responsibility for liaison with the medical profession. In the end poor communication results from the fact that some doctors find it hard to talk or listen to MS patients while patients often find it hard to listen to and question their doctors. We all have a role to play, not just as critics or watchdogs which is far too easy, but constructively, as catalysts and as mediators. It is encouraging that some doctors are now taking counselling skills more seriously, but the medical profession has a long way to go in its understanding of the fears and feelings surrounding what is still a frightening and mysterious disease.

References and notes

- (1) Jack Pritchard was Professor of Anatomy at the Queen's University of Belfast until his death in 1979. He also served as Chairman of the Northern Ireland Branch of the Multiple Sclerosis Society of Great Britain and Northern Ireland, taking an active interest in its work for people with multiple sclerosis and their families. The Jack Pritchard Memorial Lecture takes place every two years and is sponsored by the Queen's University and the Northern Ireland Branch of the Multiple Sclerosis Society.
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