Multiple Sclerosis

Ian Robinson

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Editors' preface

The aim of this series is to integrate the personal accounts of individuals who experience illness with the growing sociological and psychological literature. Ian Robinson vividly portrays the reality of multiple sclerosis by drawing on a rich body of research material.

Individuals with multiple sclerosis describe the lengthy and often distressing phase prior to the formal diagnosis. Varying symptoms remain unexplained and when eventually contact is made with the doctor the continuing uncertainty often leads to further frustration. The course of multiple sclerosis varies considerably from one individual to another and the future for any individual is often unpredictable. The uncertainty that this evokes is graphically conveyed by the author. Patients respond with a variety of coping strategies, the complexity of which is well illustrated.

A further issue that individuals have to contend with is the absence of any treatment of established efficacy. This throws individuals on to their own resources and impels them to seek other forms of accommodation and solutions. The courage and hope that some individuals are able to bring to bear illustrate some of the positive themes Ian Robinson has found in patients' accounts.

The book also examines how disability may lead to dependence on others and how voluntary and self-help groups can provide a powerful sense of identity and control over the illness. Ian Robinson examines the debates on the contribution such organizations make in this area.

Those who look to the social sciences to illuminate and inform ideas about health and illness will find in this volume a revealing and moving analysis of one major illness.

Preface

The main source on which this book is based is a collection of over 400 life stories of people with multiple sclerosis and members of their families from Australia, Canada, and the USA as well as the United Kingdom. The life stories have provided invaluable insights into how people manage life with multiple sclerosis, and richly supplement other evidence about the meaning, impact, and experience of living with the disease. In the book all names of individuals have been changed to preserve confidentiality, as has other information which might identify those concerned.

The life stories form part of a large collection of quantitative and qualitative information on the epidemiological, personal, and social aspects of multiple sclerosis which is held at Brunel, the University of West London. It is at this university that a research unit into these aspects of the disease has been established and funded by Action for Research into Multiple Sclerosis (ARMS). The initiative of the Chief Executive of ARMS, John Simkins, which resulted in the founding of the unit, and the continuing support of ARMS and its members for its research projects, is gratefully acknowledged.

I would also particularly like to acknowledge the support and encouragement of Judith Monks and Anna Wynne, as well as for their careful reading of an earlier version of the text, from which I have benefited considerably. I owe a debt of gratitude to many others, especially Julia Segal, on whose knowledge and experience I have drawn. Jenny Charteris has been of immense administrative help in organizing the preparation of the manuscript. The editors of this series have exercised a patient and facilitating role which has expedited the completion of this book. For my wife Jane and son Alistair the preparation of the manuscript has involved considerable sacrifices and I thank them for their forbearance.

Finally I would like to express gratitude to the many people with multiple sclerosis, and members of their families, who have been

prepared to contribute to this research. In a real sense without their contributions this book could not have been written. I hope that they will feel that I have done justice to their personal accounts and will feel that they have enabled others to learn from their experiences.

Chapter one
Understanding multiple sclerosis

Multiple sclerosis is a disease of unknown aetiology, variable onset, problematic diagnosis, unpredictable prognosis, and no effective treatment. Many features of the disease are therefore the subject of intense speculation and controversy. The debate about the nature of multiple sclerosis conditions its clinical diagnosis and management, as well as research into all aspects of the disease. The experience of people with multiple sclerosis is thus mediated not only through the uncertainties, problems, and difficulties of their personal and social world, but also through the spectrum of medical uncertainty and dispute about key aspects of the disease. In this chapter there is an introductory discussion of some of these uncertainties and disputes.

Describing multiple sclerosis

One of the standard definitions of the disease is provided by Walton, who describes it as

> A disease of unknown aetiology characterised pathologically by the widespread occurrence in the nervous system of patches of demyelination followed by gliosis. In many cases the early manifestations of the disease are followed by conspicuous improvement, so that remissions and relapses are a striking feature of the disorder, the course of which may be thus prolonged for many years. The early symptoms are often those of focal lesions of the central nervous system, while the later clinical picture is one of progressive dissemination tending to produce the classic features of ataxic paraplegia.
>
> (Walton 1977:544)

This definition is a succinct medical description of multiple sclerosis, and it also indicates the likely variability and

uncertainty in relation to the condition. From a patient's point of view such a description may understate the range and nature of the symptoms and experiences to which the disease may give rise, in its early as well as its later stages. The experience of the onset of the disease is more fully considered in Chapter 2, but it is important to indicate that both the clinical and personal interpretation of the initial symptoms can be at variance with the subsequent diagnosis of multiple sclerosis.

A more graphic indication of the variability of the disease is given in this further description by Schumacher and his colleagues.

> Multiple sclerosis is a disorder characterised in cross-section by symptoms and signs of neurologic dysfunction indicating multiple and separate lesions in the central nervous system. Symptoms appear longitudinally in the form of acutely or slowly developing episodes scattered over a period of time. Individual attacks may assume a variety of patterns. The overall course is made up of multiple attacks or of erratic or steady progression over prolonged periods, usually many years…. Regardless of the course assumed by an attack, subsequent recurrence or steady progression usually leads ultimately to chronic and permanent disability.
>
> (Schumacher *et al.* 1965:553)

This account of multiple sclerosis emphasizes both the symptomatic variation and the different courses that the disease may take.

Diagnosing multiple sclerosis

The diagnosis, assessment, and classification of multiple sclerosis is undertaken on the basis of clinical examinations supported by an increasing range of technical investigations. The role of these investigations in the diagnosis of the disease is a matter of continuing debate. In a condition as complex as multiple sclerosis, where reported or observable symptoms may be at variance with the results of laboratory tests—or such tests themselves may be indeterminate—the overriding importance of clinical judgement has been emphasized (Poser 1984:233). In this context the status of the formal neurological examination, following established diagnostic criteria, remains of paramount significance.

A neurological examination for multiple sclerosis involves a consideration of current signs and symptoms, as well as an investigation of the clinical history. One of the problems in making a definitive diagnosis of the disease is that many of the early symptoms can individually or severally be as indicative of other conditions as they can be of multiple sclerosis. In order to make a distinction between cases of the disease with an established diagnosis, and those in which the diagnosis is unclear, or provisional, McAlpine, Lumsden, and Acheson (1972) proposed three diagnostic categories—definite, probable, and possible. These three categories have come to be widely accepted as a basis on which assessments of potential cases of multiple sclerosis are considered.

For the category 'definite' multiple sclerosis a variety of diagnostic criteria have been used in the assessment of the disease. One of the most widely deployed has been that of Schumacher *et al.* (1965). According to these criteria there must be

1 evidence of objective neurological abnormality
2 evidence of involvement of two or more separate parts of the central nervous system (CNS)
3 a predominant white matter basis to the CNS disease
4 slow progression of signs and symptoms, or two or more exacerbations separated by at least one month
5 an age range of 10 to 50 inclusive at the onset of symptoms
6 no better alternative explanation by a clinical neurologist.

These criteria were constructed before the advent of a number of additional laboratory techniques, which have now become available. None the less the clinically oriented approach of Schumacher and his colleagues has come to be accepted even in more recent criteria (Poser *et al.* 1983). As both sets of criteria indicate, a combination of signs and symptoms characterize the disease, a number of which may become apparent only through observation over time. In an attempt to foreshorten diagnostic uncertainty, and to provide definitive evidence as to its existence in an individual, the pathology of the disease has been intensively studied. Some components of the pathological jigsaw of the disease are well established, although the clinical manifestation of these pathological signs may be subject to considerable variation.

The pathology of multiple sclerosis—reading the signs

An apparently typical pathological feature of multiple sclerosis is the existence of sclerotic plaques or lesions mainly in the white matter of the brain and spinal cord—from which the name of the disease derives. These plaques are caused by the demyelination of nerve fibres. The exact size, nature, and location of the sclerotic plaques is now open to more precise determination with the development of techniques such as computerized tomography (CT) and more recently nuclear magnetic resonance (NMR) imaging. These imaging techniques are beginning to reveal information which may call into question existing assumptions about the nature of the disease. In particular patients with single symptoms, on whom imaging has been undertaken at an apparently early stage of their disease, reveal the presence of multiple lesions—without corresponding clinical symptoms (Ormerod *et al.* 1986; Miller *et al.* 1987). This finding may suggest that the clinical diagnosis of the disease, as being based on disseminations occurring over time with associated clinically observable symptoms, needs reconsideration. So-called 'silent plaques' may have no clearly identified symptomatic effects, and even other actively changing lesions may have no demonstrable symptoms associated with them. At one extreme is the situation where multiple sclerosis has been diagnosed after death in apparently asymptomatic cases, through the existence of lesions on pathological examination (Gilbert and Sadler 1983).

Other pathological signs used to assess the presence of the disease may be subject to equally problematic interpretation. Since the discovery of abnormalities in the cerebro-spinal fluid (CSF) of those with multiple sclerosis, an examination of CSF for indicative oligoclonal bands and other features has become a common procedure. However there are clinically confirmed cases of the disease where these features are not present, and other conditions which may exhibit virtually identical CSF changes.

The involvement of optical symptoms in many cases of multiple sclerosis has led to particular concern with the detection and measurement of the pathology of the optic nerve. Optic neuritis and its consequences, traditionally associated with multiple sclerosis and a number of other conditions, have, until fairly recently, been detected through general clinical examination of the eye. However the difficulty of consistently identifying all cases where optical involvement was suspected has led to the development of new procedures. Perhaps the most widely used

techniques in connection with the diagnosis of multiple sclerosis are currently tests of visually evoked potentials (VEP). These tests measure the electrical conductivity of the visual system of the brain, and have been found to produce values for most cases with multiple sclerosis which differ significantly from those of the normal population. The reliability of VEPs as a convincing indicator of multiple sclerosis has been questioned by some, who have argued that a variety of conditions and circumstances may produce values which mimic those found with the disease (Poser 1984:243). However, for many clinicians VEPs remain the most useful of the generally available diagnostic aids.

Other pathological work has concentrated on immunological aspects of multiple sclerosis, and the detection of abnormal elements in the blood chemistry of people with the disease. It is likely to be some time before tests based on this research are widely deployed to aid diagnosis in clinical practice.

In summary there are continuing developments in the detection and measurement of pathological aspects of multiple sclerosis, particularly relating to those areas which may aid early diagnosis. However a definitive diagnostic indicator of the disease has yet to be found. With such a wide variety of pathological signs, some of which may prove to be apparently contradictory, and others of which may prove to have little or no direct association with observable symptoms, the importance of an overall clinical assessment of the status of an individual case is emphasized. The interpretation of individual symptoms over time, in conjunction with measurement of signs, is particularly important.

Interpreting symptoms in multiple sclerosis

Diagnostic criteria employed in the assessment of multiple sclerosis, such as those of Schumacher *et al.,* emphasize the importance of clinically investigating both signs and symptoms. If the examination of signs is an art—supported by a variety of tests —the interpretation of symptoms in the disease is even more dependent on clinical skill and judgement. The patterning of symptoms, particularly over time, is a crucial component of the diagnosis.

Given the requirement in certain diagnostic criteria for the existence of symptoms in a particular temporal pattern, it can be seen that a definite diagnosis of the disease may not be made at a first medical assessment. Thus a patient seeking medical advice for the first time with visual symptoms, or with disorders of sensation or muscular weakness—all common initial symptoms

associated with multiple sclerosis (Matthews *et al.* 1985)—may receive no indication of the possible diagnosis of the disease at that stage. It is the persistence or recurrence of symptoms, as much as their presence at any one time, which is a determining factor in focusing on multiple sclerosis as a potential diagnosis.

The course of and prognosis for multiple sclerosis

The variability of the course of multiple sclerosis is one of its key characteristics. With the possibility of the distinctive lesions of multiple sclerosis occurring at many points in the central nervous system in a relatively unpredictable way, the appearance of the effects of the disease and their timing is particularly problematic to anticipate. Thus a clear and reliable indication as to how the disease will progress in any one case is difficult to achieve. The course of multiple sclerosis may vary from being relatively or completely benign throughout life, to being rapidly progressive and leading to death within a period of months—although it should be noted that this speedy and fatal variant of the disease is statistically rare.

Despite problems associated with the assessment of the course of multiple sclerosis, there are classifications of different temporal patterns of the disease. In an attempt to provide a clinical and research guide to the most common courses that the disease takes, a twofold classification is often employed. Cases may thus be divided into those whose course is progressive, and those whose course is characterized by relapses and remissions.

In summary the course and prognosis of the disease is still a question of debate. There are a number of factors which appear to act as partial prognostic indicators. However even the most significant of these falls far short of indicating decisively how the general course of the disease develops, let alone providing clear guidance in any individual case (Compston 1987b). Further research thus continues to attempt to elucidate the complex course of the disease.

The distribution of multiple sclerosis

Multiple sclerosis is characterized by a particular demographic and geographic distribution. This distribution has assumed a very considerable importance in attempts to understand the disease. In the absence of any clear and agreed view as to the cause of multiple sclerosis, the clues provided by this epidemiological

evidence have been used to explore a number of the theories discussed in the next section.

Perhaps the most striking feature of the geographical distribution of multiple sclerosis is high correlation of the prevalence of the disease with temperate latitudes. In Kurtzke's comprehensive review (1980) of all the population prevalence studies up to 1979, the highest prevalence rates are in the latitudes 43° to 65° north in Europe; 37° to 52° north in the Americas; and 34° to 44° south in Australasia. Moderate then low frequency prevalence rates occur both north and south of these latitudes as the Poles and the Equator are approached. The difference between high and low prevalence rates is substantial. In the high prevalence latitudes rates range from 30 to over 80 per 100,000 and in the moderate frequency latitudes from 5 to 25 per 100,000 (Kurtzke 1980:63–7). There are even lower prevalence rates for other latitudes. However, as the medical and particularly the neurological services in a number of the countries concerned in these very low prevalence areas are relatively undeveloped, some caution must be exercised in interpreting the findings. None the less the pattern of geographical distribution of multiple sclerosis is sufficiently consistent and uniform to warrant special consideration in research to understand the disease.

Another demographic feature of the prevalence of multiple sclerosis, not unrelated to geographical distribution of the disease, has been the finding that populations, other than those which are caucasian in origin, have a lower prevalence rate. This finding has prompted a number of studies related to the possibility of increased or decreased risk of the disease following immigration to high or low prevalence areas. Although such studies are methodologically difficult to undertake, the general finding has been that immigrants tend to retain much of the risk of their birthplace. Other surveys have indicated that immigration before the age of 15 tends to result in the acquisition of the risk of the area to which the immigrant has moved (Alter, Leibowitz, and Speer 1966). However, there must be extreme caution used in interpreting these findings for the relevant factors are extremely complex to identify, research, and evaluate.

Other aspects of the demographic distribution of multiple sclerosis are as interesting and important as its geographical distribution. The age of onset, as indicated in many clinical studies, is predominantly between the ages of 20 and 50, although there are both earlier and later recorded cases. However, it must be remembered that the exact age of onset is often difficult to determine, particularly in those cases where symptoms have