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PATIENTS WITH MULTIPLE SCLEROSIS PREFER EARLY DIAGNOSIS

Abstract

The new diagnostic criteria for multiple sclerosis (MS) allow for a definite diagnosis in earlier stages of disease. Yet, clinicians may be hesitant to pursue a diagnosis of MS at the presentation of first symptoms as they consider the benefit for the patients limited. We studied satisfaction with the timing of diagnosis in patients recently diagnosed with MS and found that 70% of the patients were satisfied with the timing, whereas 24% favoured an earlier, and 6% a later disclosure. Patients who preferred an earlier diagnosis had a significantly longer interval between their first visit to the neurologist and the disclosure of diagnosis ($p < 0.001$). The probability of satisfaction did not substantially decrease in the year following the first visit to the neurologist, meaning the neurologist has ample opportunity for a thorough evaluation of the early clinical course.

Introduction

The introduction of MRI in the diagnostic criteria for multiple sclerosis (MS) allow for a definite diagnosis of MS in an early phase of the disease.[1] The benefits of an early diagnosis are subject for debate, because the effectiveness of early treatment for the long term prognosis is not certain[2] and the possibilities for prediction of prognosis are limited.[3] In addition, early diagnosis of MS could bring along a higher frequency of misdiagnoses.[4] For these clinical reasons, physicians may hesitate to discuss the possibility of MS at the presentation of first symptoms and may defer further diagnostic investigations to prevent psychological harm to patients.[5,6] It is not known whether patients themselves prefer an early diagnosis. We examined satisfaction with the timing of diagnosis in recently diagnosed MS patients and related their preferences to the duration of their diagnostic work-up.

Methods

The study sample consisted of 95 recently diagnosed MS patients, who participated in an ongoing follow-up study of early MS. Mean age of the patients was 38.7 years (SD 9.4), 71% were female, 91% were diagnosed as definite MS, mean time *since* diagnosis was 1.7 years (SD 0.8) and the median score on the Expanded Disability Status Scale (EDSS) was 2.5 (range 0.0 - 7.0). In a short questionnaire, patients were asked to summarise their MS-related medical history including the date of first visit to a general practitioner (GP), date of first visit to a neurologist and date of diagnosis. These dates divide the diagnostic period into two phases: duration of the diagnostic workup within the primary health care and at the neurological clinics. Further, patients were asked whether they were satisfied with the timing of their diagnosis or whether they would have preferred – if possible – to be diagnosed earlier or later. Patients were asked to elucidate their preferences in their own words.

Results

Seventy percent of the patients were satisfied with the timing of diagnosis, whereas 24% preferred an earlier and 6% a later diagnosis. Patients who were satisfied had a shorter time interval between their first visit to a GP and their diagnosis (median 5 months, inter-quartile range [IQR 2-17]) compared to those who preferred an earlier (31 months [9-87]) or later diagnosis (25 months [3-74], Kruskal-Wallis test $p < 0.001$). Further analyses demonstrated that these differences were particularly significant for the duration at the neurological clinics ($p < 0.001$) and not at the GP ($p = 0.59$); median duration at the neurological clinics was 1 month [1-5] in those who were satisfied compared to 9 months [3-45] in patients preferring an earlier and 4 months [2-7] in patients preferring a later diagnosis. Figure 1 shows that the predicted probability of satisfaction was lower when the time between the first consultation with the neurologist and the diagnosis was longer. Of all patients who were diagnosed within 6 months after the first visit with the neurologist , 82% (54/66) were satisfied with the timing of diagnosis, compared to 41% (12/29) of the patients whose diagnostic workup took more than six months. These results remained significant after adjustment for EDSS, time since diagnosis, age and sex (p = 0.03).

The main reasons for favouring an earlier diagnosis were the high burden of uncertainty (n = 8), lack of understanding of family and friends (n = 4) and the possibility of having missed options for early treatment (n = 4). Patients who preferred a later diagnosis favoured diagnostic uncertainty over a definite diagnosis (n = 3) or did not experience any further symptoms (n = 2).

Conclusions

Our study shows that 70% of the MS patients were satisfied with the timing of their diagnosis and 24% had preferred an earlier diagnosis – if this had been possible. The probability of patients' satisfaction particularly decreased with a longer duration of the work-up after their first visit to the neurologist. The duration of the

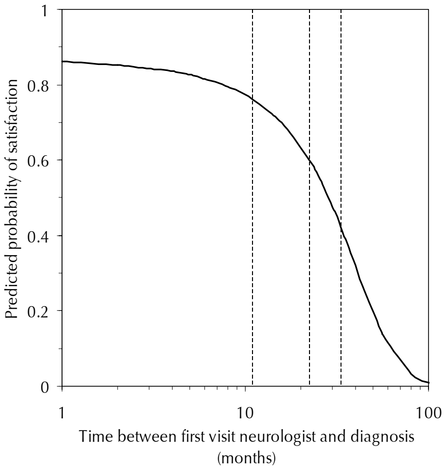

Figure 1 Predicted probability of patient satisfaction by duration of diagnostic work-up at the neurological clinics

Predicted values were obtained from logistic regression analyses with duration as independent variable. Vertical lines indicate 1-, 2- and 3-year period. Time is presented on a logarithmic scale.

neurological work-up may be important to the patient because a referral to a medical specialist indicates that the severity of their symptoms apparently warrants further examination at the hospital. From that moment, patients may start worrying about the origin of their complaints.

A potential shortcoming of the study is that patients evaluated satisfaction with the timing of diagnosis *after* they were diagnosed. Preferably one would study these preferences at the presentation of first symptoms, when patients are not yet informed about the possibility of MS. It is questionable whether studying the satisfaction with a future diagnosis of MS in patients who did not yet receive their diagnosis is feasible and ethical. Our retrospective approach may have biased the conclusions in two ways. First, patients may be more inclined to be dissatisfied because they are in general dissatisfied with the fact they were diagnosed with MS. It is difficult to see that this explains the significant association between satisfaction and duration of the diagnostic workup that we observed. More likely, this would also have led to higher levels of dissatisfaction in those with a short diagnostic workup. Moreover, the lack of a relationship between satisfaction and duration of the workup by the GP argues against the view this bias had occurred. Second, bias may have occurred due to the fact that the study population only included patients who were sooner or later diagnosed with MS, but not subjects with suspected symptoms who were never diagnosed. Most likely these patients will be comfortable with the fact that they were not informed about their (possible) diagnosis of MS. The clinical dilemma is that this group cannot be identified at the presentation of first symptoms but only with hindsight. An important question to be answered in future studies is how many patients do not progress. However, another point of consideration will be to examine the influence of the rapid developments at the Internet. When patients with major MS related symptoms such as optic neuritis search at the Internet for more information, they will easily learn about the possibility of MS (see also Appendix B).[7] Not discussing the possibility with the patient in neurological practice may lead to unanticipated findings of patients at the Internet. Needless to say there also is a high risk that patients will (mis)diagnose themselves.

A last issue to be discussed is that a long duration may be indicative of a difficult diagnostic workup, which may in turn explain the dissatisfaction of patients. The retrospective study design does not provide information whether earlier disclosure of the diagnosis in our patients with a long workup had been possible. There could have been medical reasons for the prolonged diagnostic period, such as discrepancies between clinical findings, MRI and CSF test results. In these instances, time itself may be the decisive factor. However, a point of consideration in this scenario is the fact that patients may be dissatisfied with such lengthy procedures because they did not understand why the workup took that long. This implies a need for more explanation on the diagnostic procedures by the neurologist.

Since the majority of MS patients was satisfied with a disclosure of diagnosis within 6 months, our data suggest that there appears to be no reason to delay diagnostic procedures. It is important to note that satisfaction did not substantially decrease in the months following the first visit to the neurologist, leaving ample time for a prudent diagnostic work-up. In line with the present findings, we argue that further diagnostic testing at the presentation of first symptoms may benefit to all patients either because the disease is diagnosed early in those who do suffer from MS or is ruled out in those who do not suffer MS. Finally, satisfaction with the timing of diagnosis will obviously not be determined by time alone, but is most likely influenced by adequate and transparent diagnostic procedures that are clearly communicated with patients. The knowledge that their symptoms are taken seriously and efforts are made to find out the causes of symptoms may outweigh the effect of time in determining patients' satisfaction.

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