Communicating the diagnosis of multiple sclerosis
Results of a survey among Greek neurologists

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Abstract In the frame of current treatment options for multiple sclerosis (MS) and recommendations for early intervention, we investigated the practice and attitudes of neurologists towards MS-diagnosis communication in Greece. We constructed and sent out a 22-item questionnaire to neurologists practising in different employment settings and geographic regions in Greece. Overall, 217 (37.41 %) of 580 neurologists replied. The vast majority (94.9 %) informs the patient of a definite MS diagnosis, and 73.6 % do so immediately, but only 41.7 % use the term multiple sclerosis. Furthermore, neurologists strongly agreed that timing of diagnosis communication depends to a large extent on the individual patient’s personality (62.5 %) and mental state (52.3 %). Most neurologists (78.7 %) inform relatives about the diagnosis, but only in the presence of the patient. In cases where disclosure was delayed, 59.5 % noted that they did not observe any changes as regards the trust or confidence of their patients towards them. Most neurologists also noted that education level (72 %) and mental state (51.9 %), at the time of disclosure influenced patients who did not fully understand the meaning of their diagnosis. This survey provided some useful new findings with respect to MS diagnosis communication; however, the questions of how and possibly how much to communicate warrant further cross-cultural investigation.

Key words demyelinating disease · multiple sclerosis · diagnosis communication · neurologists · disclosure

Introduction

A change of attitude towards disclosing the diagnosis of medical conditions has been witnessed in the past few decades, from an attitude of medical paternalism to one that respects patient autonomy [1]. However, there is not much knowledge on the current practice among physicians about communicating the diagnosis of chronic neurological diseases.

Disclosure of chronic or incurable diseases can be particularly difficult and require an understanding of the patient’s ability to comprehend the complexity associated with the disclosed disease. Weighing the potential costs and benefits of disclosing must be evaluated in terms of options for how and when to disclose. Multiple sclerosis (MS), a neurological condition marked by its incurability, unpredictability and predilection for young adults is one such disease, and the disclosure of MS to patients is among the primary challenges facing the physician neurologist who has to deliver the diagnosis.

The revised diagnostic criteria for MS allow for a definite diagnosis in earlier stages of the disease after a so-called isolated syndrome [2]. Disease modifying treatments for early MS have further narrowed the time frame between diagnosis and treatment decision-mak-
ing [3, 4]. Although most patients with chronic neuro-
ological diseases appear to develop close relationships
and trust their physicians as they continue to consult
them during the course of their disease, the narrowed
time framework between diagnosis and treatment deci-
sion-making in MS may require a disclosure of the diag-
nosis before the neurologist and patient have developed
such a relationship. Furthermore, a number of neurolo-
gists still hesitate to pursue a diagnosis of MS at the pre-
presentation of the first symptoms, as they consider an early
diagnosis of limited benefit to their patients in terms of
early treatment and long-term prognosis [5, 6].

We are aware of only one previous survey that investi-
gated the practice of neurologists in communicating
MS diagnosis [7]. In that survey, 90% of neurologists
communicated the diagnosis, although only half the pa-
tients reported this as a significant aid in helping them
to clarify issues related to the disease. Although most
patients (69%) opted for information about a possible
MS diagnosis, only 24% of the physicians believed that
they should provide a full communication of a possible
MS diagnosis. Neurologists further agreed that the tim-
ing of disclosing the diagnosis should depend on the
individual patient, and 28% did not use the term mul-
tiple sclerosis when disclosing the neurological condi-
tion to their patients.

Recently, a qualitative study [3] utilizing focus group
meetings examined the personal experiences of com-
municating the diagnosis of MS, in both MS patients and
health professionals. The study noted great variability in
the manner the diagnosis was disclosed or received. Par-
ticipants agreed that MS diagnosis should be disclosed
to the patient as soon as possible, and that adequate time
should be devoted. Furthermore, MS patients reported
that poor levels of support and information were some-
times provided. Both MS patients and health profession-
als, however, agreed that diagnosis communication re-
quires further improvement as regards the appropriate
setting, individuality in information provision and con-
tinuity of care.

In an earlier study [8], conducted by our group on a
large sample of Greek MS patients regarding their expe-
rience towards receiving the diagnosis, 91% favored
learning the diagnosis immediately, but only 44% had
this experience. In fact, 29% had been informed within
1–3 years of their diagnosis and 27% later. Interestingly,
a significant minority preferred for a delayed delivery of
diagnosis and 23.2% revealed that concealing the diag-
nosis would not lead to loss of confidence in their doc-
tor. Another similar study noted that MS patients prefer
an early disclosure of their diagnosis [5].

Our previous study [8], although the largest of its
kind in terms of number of MS patients recruited, was
limited to answering the question of when Greek MS pa-
tients prefer disclosure of their diagnosis. Furthermore,
studies examining the practice and attitudes of neurolo-
gists in communicating MS diagnosis are missing. Thus,
in the present study we investigated the practice and at-
titudes of physician neurologists towards MS diagnosis
communication in Greece. This issue needs to be ad-
dressed in the frame of current treatment options for
MS as well as recommendations for early intervention
and in the prospect of potential new MS therapies in the
near future.

### Material and methods

#### Sample and questionnaire

We constructed a 22-item questionnaire (see Appendix 1) with a focus
on Greek neurologist’s views regarding diagnostic and communica-
tion issues in MS. The construction of the questionnaire involved a
pilot validation phase. More specifically, we piloted an initial ques-
tionnaire composed of 30 questions by having 25 specialized neurolo-
gists (academic and non-academic affiliated, employed in neurology
departments, private practice and medical Social Insurance Organiza-
tions) comment on each question with respect to its clarity, rele-
vancy and representativeness. Based on these comments we excluded
3 questions of the 30 initially included. We then conducted an item
analyses using Cronbach’s alpha in order to check if questions in a set
were internally consistent, and collapsed sets of questions with low
consistency into fewer questions. Following the item analyses we
ended up with the final 22 questions included in the survey. Six of
these questions focused on basic sociodemographic characteristic,
and the other 16 questions focused on years and site of employment
as a neurologist, disclosure of MS diagnosis, inclusion of relatives
when disclosing the diagnosis, usage of the term MS explicitly or of
other terms in informing patients about MS and comments regarding
delivery of the diagnosis. The questionnaire was then sent out to 580
of the total 620 registered specialist neurologists practicing in differ-
ent employment settings and geographic regions in Greece during the
timeframe of the study. We were unable to obtain details regarding
employment status and setting for 40 of the 620 registered specialist
neurologists; therefore, questionnaires were not sent out to these phy-
sicans. As regards the status of the remaining 580 registered special-
ist neurologists, 72 were employed as academic affiliated neurologists
in university neurological clinics, 65 as non-academic affiliated neu-rologists in other departments of public hospitals in the Greek Na-
tional Health System and the remaining 483 in private practice and
medical Social Insurance Organizations. We did not send out a re-

#### Descriptive data

A total of 217 (37.41%) completed questionnaires from
the total 580 sent out were returned. Of the 217 neurolo-
gists who returned completed questionnaires, 165 (76%) were men and 52 (24%) women (mean age: 51.21 years,
range 33–71). Seventy eight (36.1%) were employed pri-