**ORIGINAL ARTICLE**

**Focus group on the experience of patients and family members in the multiple sclerosis unit of a tertiary hospital**

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**KEYWORDS**
Multiple sclerosis; Quality of health care; Focus group; Caregivers; Medical assistance

**Abstract**

Introduction: Multiple sclerosis (MS) is an immunological, degenerative and chronic neurological disease that is frequently diagnosed in young adults. Medical care might be challenging as MS symptoms are heterogenic and sometimes medical-care team requirements might not meet MS patients’ needs.

Objectives: To learn the experience of patients and their caregivers of the medical care received in the Gregorio Marañón Hospital Demyelinating Unit.

Method: we designed a focus group with 26 participants incidentally recruited from the Gregorio Marañón Hospital Demyelinating Unit: 8 with low physical disability, 8 with high physical disability and 10 caregivers. Information was collected regarding three main topics: information, clinical care and medical team.

Results: High satisfaction was found among all participants with most of the medical care and with the professionals of the MS Unit. They agreed with the interventions they were offered but they considered that physical rehabilitation and psychological support must be offered, not only to MS patients but also to their caregivers and family. They also asked to emphasize transdisciplinary care.

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Conclusions: This information defined the aspects of medical care that participants perceived as quality-care and the goals the Unit needs to achieve in the future.
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PALABRAS CLAVE
Esclerosis múltiple; Evaluación de calidad asistencial; Grupo focal; Cuidadores; Asistencia médica

Grupo focal sobre la experiencia de pacientes y familiares en la unidad de esclerosis múltiple de un hospital terciario

Resumen

Introducción: La esclerosis múltiple (EM) es una enfermedad neurológica de origen autoinmune, degenerativa y crónica que aparece en adultos jóvenes. Su manejo sanitario es complejo ya que la enfermedad presenta una sintomatología muy heterogénea y las necesidades de los pacientes son distintas según la fase de la enfermedad en que se encuentren. En ocasiones las necesidades médicas pueden ser distintas a las necesidades personales de pacientes, por lo que es importante tener en consideración su opinión sobre todo el proceso.

Objetivos: Conocer la experiencia de los pacientes con EM y sus familiares en relación a la atención recibida en el Hospital General Universitario Gregorio Marañón (HGUGM).

Método: Estudio cualitativo realizado en la consulta de Enfermedades Desmielinizantes del Servicio de Neurología del HGUGM. Se organizaron tres grupos focales con un total de 26 personas provenientes de la consulta de Enfermedades Desmielinizantes del HGUGM: 8 con una discapacidad física baja, 8 con mayor discapacidad física y 10 familiares/cuidadores de personas con EM. Se identifican tres bloques temáticos a tratar: la información, la atención recibida y el equipo sanitario.

Resultados: Los resultados muestran cómo la satisfacción es alta con muchos de los servicios, así como con los profesionales. Agradecen algunas de las iniciativas de intervención, pero definen necesidades importantes en otras como la rehabilitación física y la asistencia psicológica, tanto para pacientes como para familiares/cuidadores. Identifican la transdisciplinariedad como objetivo a futuro.

Conclusiones: Con estos datos buscamos reforzar los aspectos mejor calificados y trabajar posteriormente para cubrir y adaptar los procesos ofrecidos a los pacientes con EM.
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Introduction

Multiple sclerosis (MS) is a chronic inflammatory neurological disease of autoimmune origin in the central nervous system.1,2 It entails major individual and social costs due to the accumulated disability which occurs throughout the course of the disease.3 The degree of physical dependence and its evolution has been defined (mainly that relating to the ability to walk) as having an enormous impact on the quality of life of the person with MS, and on that of their main caregiver.4

In daily clinical practice discrepancies may occur between the needs contemplated by healthcare personnel and those expressed by the patients.5 Opinions from the users of healthcare services are rarely directly collected, despite the fact that at present this is considered a quality target to be included in healthcare centre management.6 The humanization in healthcare plan states that: “participation from citizens and professionals is one of the strengths of this plan, since this has helped define and incorporate strategies and interventions from opinions and proposals expressed by the people regarding their needs, demands and expectations relating to the humanization of healthcare”7,8 Furthermore, it has been observed that the priorities and needs of these people are hugely subjective, requiring a different and adapted approach so as to know them.8

Objectives

The principal aim of this study was to determine the experiences of patients diagnosed with MS and their caregivers, with regard to the healthcare received from the Neurological Service of the Hospital General Universitario Gregorio Marañón.

A secondary aim was to identify what areas could be improved for patients diagnosed with MS and their caregivers, so as to offer them a satisfactory healthcare service, adapted to their needs and expectations relating to varying degrees of disability.
Methodology

A qualitative study was conducted with a phenomenological approach through focus groups (FG); this approach leads to an understanding of the significance and nature of the experience with healthcare from the perspective of the people who have experienced it (patients with MS and family members). The FG is a technique which leads to flexible and open discourse and interaction between its participants, which helps us to obtain data that cannot be obtained individually.

The target population of our study are patients with a diagnosis of MS, and their family members/caregivers, who are cared for by the Unit of Demyelinating Diseases of the Hospital General Universitario Gregorio Marañón (hereinafter referred to as Unit). We selected the final sample among people with MS who were undergoing treatment or follow-up in the Unit and from among their family members/caregivers. With them, 3 FG were planned: 2 of them for patients with MS and the other with their family members/caregivers. MS patient and family member sampling was incidental.

Previous studies which used FG methodology advised that the sample size be moderate, between 6 and 10 people. This would ensure that the groups were sufficiently small for all members to be able to participate and, at the same time, sufficiently large for greater diversity of opinions to be expressed.

For grouping patients with MS the degree of physical disability was measured by the Expanded Disability Status Scale (EDSS) as a determining point for the design of the 2 patient FG. The cut-off point of the score in EDSS was 3.5, as this is an important milestone in physical disability, differentiating between patients who require support for walking from those who do not. Based on this, we created a group with an ESDD score up to 3.5 (Group 1) and another with a score of between 3.5 and 7 (Group 2), thus ensuring that their physical disability was not an impediment to attendance or participation in the session. Inclusion criteria included being of age, and having had an MS diagnosis in any of its phenotypes.

This type of grouping, on the one hand, maximises the homogeneity of the participants in the same group based on their physical disability, ensuring active, free participation in the session without constraint; and on the other, seeking to achieve sufficient heterogeneity between the members of both groups to offer different points of view on our objectives in keeping with their physical disability. However, the fact that there were other characteristics which differentiated them (gender, educational level, employment situation, ethnicity, MS phenotype) helped the group discussion to be richer and to reflect different points of view, experiences and motivations.

To select family members/caregivers (Group F) selection criteria included being of age and being the main caregiver of a person with MS. In this case, the score in EDSS of the family member was not taken into account, since there was only one family member group.

This study obtained the approval of the research ethics committee of the Hospital Gregorio Marañón, which guarantees compliance with good practice regulations and participant data protection. Signature of consent by participants confirmed their permission for the session to be recorded and they were informed that the audio would be eliminated once the session had been transcribed.

A discussion guide was created for the FG which contained specific aspects relating to the healthcare team of the Unit (Table 1). This guide contains a breakdown of issues to be addressed in the session, with a format of open questions which guide free group discussion. These issues were selected by the members of the research team through discussion and consensus, based on their everyday clinical experience of caring for patients with MS and their families.

The FG were conducted separately and were moderated by 2 members of the research team who were trained in qualitative research methods, did not know the participants and had not intervened in any aspect of their healthcare. This group took place in the hospital facilities, in a large, private room, in the afternoon and lasted 60 min. The group with family members met first, and was moderated by researcher 1. When this session terminated, the 2 groups of patients with MS took place at the same time and were moderated by researchers 1 and 2 simultaneously.

The moderator briefly explained at the beginning of the session how it worked and encouraged the participants to freely express their opinions. The discussion guide in Table 1 was used for the moderation of the FG. The moderator began by suggesting one of the themes and the group itself developed the contents of it collectively and freely, jumping from one theme to another spontaneously. The moderator did not intervene unless they observed that something in the guide was not covered and they then suggested it for continuation of the group discussion or they intervened if parallel conversations arose between the different members of the FG. It was also the moderator’s job to prevent the discussion veering off into themes not included in the Table 1 discussion guide, so as to optimise interventions and time allowed in the FG. The development of the FG was
appropriate and flowing, with each respondent participating, and contributing different viewpoints and experiences within the common theme. This methodology does not aim at saturation of collected information but does seek its subsequent transferability to equivalent contexts. The whole session was recorded in audio, and written notes on major aspects to occur during it were collected. After the sessions the content of the Table 1 discussion guide components was collected through analysis of the transcriptions of each group, separately, which will be reported in the section on results.

Semantic analysis of the discourse was performed, with attention to content for subsequent grouping according to the previously specified FG themes. In the first place, the transcriptions were coded, assigning a code to each respondent, which helped to follow the discourse of the same person and guarantee their confidentiality. A researcher then analysed the data and extracted the significance of each quote, dividing them into different themes. 

This study adhered to the quality criterion required for qualitative research studies. It was based on relevance criteria, since we recommended the use of FG to collect patients’ opinions on care quality as an alternative to the use of a self-completion questionnaires or patient reported outcomes (PRO), previously used in the literature despite their possible limitations. The aim of the participant inclusion criteria and FG segmentation was to provide fair treatment of data, to therefore gain sufficiently varied, high quality data which would increase the transferability of collected information. With regard to reflexivity, the research team defined that none of the people in the Unit would participate as an FG moderator, thus avoiding any influence or bias in data collection which may have been connected to their familiarity with the participants, their closeness or their profession as researchers. To prevent these biases, 2 people who did not belong to the Unit were appointed to the research team as FG moderators.

Results

Forty seven candidates were selected incidentally to participate (patients with MS and family members) from among the patients who attended the medical practice during the 3 weeks prior to the beginning of the study (from receipt of approval from the Research Ethics Committee on 28th November until 18th December 2018). They were contacted by telephone to explain the aim of the study and to invite them to participate. Of these, a total of 26 candidates were interested, and were formally offered the information and consent form for completion. With regard to family members, the selection was made by the neurologist of the Unit, bearing in mind mainly the viability of attendance and the intention to collaborate with possible participants in the study. They were also contacted by phone and, those who were interested, were offered the information and consent form for participation.

Finally 8 participants were selected for Group 1 and 8 for Group 2, and the remaining 10 for Group F. More women than men attended the groups, both those with higher levels of disability and those with lower levels. This proportion is consistent with the prevalence of gender for this condition, which mainly affects women. The patients of Group 1 were the youngest, with university studies and most in active employment (75%), with a mean of 9 years of evolution of the disease, and most with the relapsing-remitting phenotype. In Group 2 disease evolution mean was longer (15.3 years mean), with the main phenotype being secondary progressive and in 62.5% of cases occupational disability had been arranged. The mean age of the participants in Group F was 56 years with mainly secondary educational level and half were retired (see Table 2 for demographic sample details).

With regard to themes suggested for qualitative analyses, the findings we report were obtained after analysing the 3 transcriptions separately (Groups 1, 2 and F) relating to the 3 thematic blocks specified in Table 1 on healthcare of the Unit team. We subsequently detail the 3 study categories: information, care received, and healthcare team.

Information

The participants of Group F reported that they were present when diagnosis was made and indicated that, when conveying information on the disease, the care received by the team was appropriate and conveyed tranquility to them, although this communication was reported as insufficient or worse in some cases. Both groups of patients said how the (neurological, nursing and neuropsychological) team conveyed proximity and medical punctiliousness, which was highly positively appreciated. The way in which the disease was explained to them in the diagnosis helped to allay their fears. Those in Group 2 highlighted the change for the better the Unit made regarding communication and information: there are more professionals in the Unit, they are highly specialised in MS and offer several channels of communication between patients/family members and members of the Unit. Others expressed reflections on this team skill and shared a few bad experiences in the conveyance of information. All participants commented on the fact that when diagnosis was made by the team, they were informed about web sites to consult to gain reliable information on their disease (see transcribed comments in Fig. 1).

One important aspect which both MS groups highlighted regarding participation on taking medical decisions was that the team offered them different available treatment options so that they could participate in the decision, even in cases where no alternative treatments currently existed. The information included available options and expected side effects. In Group 2 they commented that, at some time during the development of their disease, they were not offered the information they required to understand the processes they were going through (see transcriptions in Fig. 2). All the patients positively appreciated the follow-up made by the Unit, stating that it had improved greatly to offer them the possibility of going to the Neurology hospitalisation department to ask questions on any doubts arising from changes in their symptoms.

Care

With regard to the treatment received in hospital emergency departments, when they suffered from an outbreak or worsening of symptoms, they all agreed that, in gen-
Table 2  Demographic data.

<table>
<thead>
<tr>
<th>Group</th>
<th>Gender</th>
<th>Mean age</th>
<th>Education level percentage</th>
<th>EDSS media</th>
<th>Phenotype percentage</th>
<th>Employment percentage</th>
<th>Years of evolution, mean</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>2 men</td>
<td>37</td>
<td>Primary</td>
<td>12.5</td>
<td>RR</td>
<td>Active</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>6 women</td>
<td></td>
<td>Secondary University graduates</td>
<td>25</td>
<td>SP</td>
<td>Disabled</td>
<td>12.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>62.5</td>
<td>CIS</td>
<td>Unemployed</td>
<td>12.5</td>
</tr>
<tr>
<td>2</td>
<td>2 men</td>
<td>55,5</td>
<td>Primary</td>
<td>12.5</td>
<td>RR</td>
<td>Disabled</td>
<td>62.5</td>
</tr>
<tr>
<td></td>
<td>6 women</td>
<td></td>
<td>Secondary University graduates</td>
<td>25</td>
<td>SP</td>
<td>Retired</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>62.5</td>
<td>PP</td>
<td>Unemployed</td>
<td>12.5</td>
</tr>
<tr>
<td>F</td>
<td>6 men</td>
<td>55,9</td>
<td>Primary</td>
<td>12.5</td>
<td>NA</td>
<td>Active</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>4 women</td>
<td></td>
<td>Secondary University graduates</td>
<td>25</td>
<td>Retired</td>
<td>Disabled</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>62.5</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Cuidador 1: Nos explicó lo que había. Nos lo explicó con una tranquilidad y con un ese... vamos, nos calmó completamente... Intentó quitarnos los miedos, que no pensáramos en ciertas cosas...

Cuidador 2: fue maravilloso, desde luego, el trato.

Cuidador 4: ...Piengo que habría que hacer una mejor acogida a los recién diagnosticados. Es decir, la bomba que la conocemos todos, la bomba que supone para el familiar esto es poco menos que destructiva. O estás muy bien formado, con la cabeza muy firme, o sino puede llegar a destruir una familia.

Paciente 9: “Sin embargo, conmigo fueron muy dulces.”

Paciente 1: “Yo lo quería lanzar sobre la mesa el punto positivo de la muy buena evolución que ha llevado el hospital con la comunicación al paciente, todo ese proceso de primer contacto en general. Estoy muy contenta como ha evolucionado el tratamiento hacia los pacientes: ... de lo que voy viendo, de cómo se informa, cómo se contacta, cómo se notifica, cómo se habla. En aquel momento, era como si me hubiese dado una espada de Damocles encima de la cabeza y “prepárate que ya es tu fin”...”

Paciente 3: “Hay que entender que en la carrera les enseñan a hacer medicina, no a comunicar. Son habilidades personales que tiene cada uno y ahí dejo... que hagan cursos de comunicación si les hace falta, pero tenemos que tenerlo muy en cuenta.”

Paciente 6: “Pero no confundámos el comunicar con el hablar mucho o poco.”

Paciente 4: “...me dice “¿Quién te ha mandado esta medicación?” Me lo dijo con un tono, como si fuese yo quien hubiese ido a la farmacia y hubiese dicho “Quiero tomar esto”. [...] A mí me dolía ese comentario del doctor y me sentí totalmente como “¿Tú quién te crees que soy”.

Figure 1  Transcriptions on the ability of the team to convey information.
eral, it was appropriate. Group F reported that they had had a bad experience at some time the patients reported that at times there was poor communication between the medical staff and the Unit specialists. Another follow-up procedure commented upon was that of email and phone contact by the Unit. Here opinions differed between family members/caregivers and patients. Group F said they had called on many occasions and sent emails and had not received any response and they determined that the lack of staff was the cause. However, the perception in the patient group differed, and they spoke positively about the telephone service of the Unit (see transcriptions in Fig. 3).
Healthcare team

Group 2 patients were highly favourable in their opinion regarding the humane treatment from the staff of the Neurology Service, including doctors, assistant nurses or ancillary staff, but identified the lack of human resources as an impediment for improvement. They also acknowledged that the initiative of the Unit in having training workshops for patients and family members was highly useful.

With regard to the initiative of the multiple sclerosis informative conferences for family members and patients, several participants from Group F were unaware of them, but those who did know them, recommended them highly. They stated that they felt supported by the healthcare staff with them and stressed the huge efforts the professionals made for them. Some participants from Group 1 commented that, regardless of the informative aspect, what they appreciated was the added value of sharing experiences with several people who shared their same situation, since several people had difficulties about speaking of their disease outside the hospital. They also stated that the conferences took place in a favourable environment and dealt with questions which were not initially part of the service schedule. In Group 2 they even made suggestions for future themes to be included in the conferences (see transcription in Fig. 4).

All participants identified several aspects relating to the healthcare team were care could be improved. Among these were psychological support and a greater multidisciplinarity. Regarding the former, Group F demanded psychological support on diagnosis and during follow-up for them and for the patients with MS. Several participants of Group 1 commented that they would have liked to have previously met the neuropsychologist, because they considered that this would have had a positive impact on how to face up to their disease.

Regarding multidisciplinarity, in Group F participants commented that they should be more effectively referred to the different specialists when a specific problem arose, but they could not see any existing forethought or teamworking by the different healthcare teams. They also commented that the Unit required more staff to really fulfil this multi-disciplinary format. In Group 1 and 2 they stated they did not agree with the waiting times for neurological reviews, or for complementary tests. Within multidisciplinary care, they also requested the existence of a long-term, high quality medical rehabilitation service, without referral to primary care where clinicians are not specialised to treat this disease specifically. Also that they should not have to spend money on this service (see transcriptions in Fig. 5).

Discussion

Conducting this FG with patients and familiarly members of people diagnosed with MS has allowed us to become aware of the knowledge, sensations and experiences of the actual users of the service offered by the Unit of Demyelinating Diseases of our Hospital. This type of direct user information on the healthcare service is increasingly valuable from the point of view of the new care focus which has changed direction from being "disease-care centred" to "personalized-care centred".28

Internationally, the importance of offering healthcare quality has reached a consensus and one of the main challenges is not just achieving it but being able to measure it to ensure its continuity over time.21 Patient questionnaires are proposed (PRO) as a way of measuring the patient’s circumstance and obtaining their opinion,23 but, although useful, the main limitations of these questionnaires is the low content validity.25 For this reason it is necessary to methodologically extend information collected directly from the patient with better designed PRO.25 FG development may help with collecting valuable information for the design and validation of these PRO, given their subjective and experiential nature. Our results show that there are expediences relating to care and information which acquire great importance, and which therefore may be a starting point for new measurements of this issue.

Having included 2 different groups according to their degree of physical disability (Group 1 up to 3.5 in the EDSS and Group 2 with over 3.5 in EDSS) we were able to gain specific information regarding the opinion of each group on several questions encompassed by the procedure. It is important to objectify how participants with higher disabilities stated how several care aspects in the Unit had improved compared with the situation 10 years previously. The positive aspects they commented upon were related to the increase in therapeutic options and the current style of the medical team in offering information and taking decisions. Group 2 positively assessed the inclusion of new professionals into the Unit and suggested there was an uncovered need for rehabilitation support in the long term for these patients. Compared with group 2, group 1 was mainly interested in the management of acute events, visits to emergency departments, issues relating to the start of treatments and the best form of diagnosis communication by the neurologist. This is in line with that of other studies which mention the diversity of care requirements and their relationship to the degree of disability, rather than the length of disease evolution.26

Many studies have analysed the caregiver’s burden when caring for people with MS,29 identifying the relationship between the health status of the patient with MS and their quality of life. However, the family member does not normally give their opinion on information needs during the diagnostic process or medical decisions, and these were defined as important to them.30 Our findings coincide with the study by Bogosian et al., supporting the fact that there may be an existing need which is not satisfied by the healthcare team and is of great important to the family member/caregiver of the person with MS.

Limitations

Although we designed several participant groups to assist representativeness, the qualitative FG methodology has certain limitations relating to sample size, which undermine representativeness and generalisation. Although the principal aim of qualitative methodology is not external validity, we believe that the heterogeneity of the groups and the themes selected referring to healthcare for both patients with MS and caregiver and their needs may contain common elements that could serve as a benchmark for other similar
Paciente 9: El resto, la verdad es que en positivo quizás diría, ahora que estoy ingresada, el trato de enfermería es espectacular, pero quizás debería haber más enfermeros y más auxiliares. Creo, desde mi punto de vista porque ellos no siquiera tratan con todo el amor del mundo, pero les ves que van que no llegan, que van agobiados porque no llegan y que incluso vienen y te dicen: “Oye, mira, perdóname, de verdad...”.

Paciente 13: Yo no puedo poner ninguna queja al hospital, me siento satisfecho y afortunado. No pido más, porque no se puede pedir más.

Paciente 11: Todo el equipo me parece que se vuelca mucho con el enfermo y la familia del enfermo, y te tienen como arropado. Y es agradable.

Cuidador 7: “...lo de las charlas me parece alucinante”.

Cuidador 4: “… las charlas estas que han dado de formación, a nosotros particularmente nos ha valido mucho. El tema de tener tiempo para hablar, bromear, dialogar, con ellas directamente... eso nos ha valido de mucho porque puedes plantear muchos dudas, ver lo que dice el resto de la gente, todos su experiencia personal de cómo les va la vida... y todo eso ha salido de sus espaldas...”.

Paciente 2: Quería dar las gracias al hospital por tener todo lo que están haciendo ahora, la neuropsicóloga y los profesionales, con la parte de las charlas. Porque yo no hablo con nadie de esto.

Paciente 2: “[...] Y lo importante es que en la última preguntaron si tenéis alguna inquietud o algo que os llame la atención o algo sobre lo que queráis que se hable. Un señor comentó, por ejemplo, que quería que se comentase esclerosis múltiple y las relaciones sexuales. Entonces dices, a lo mejor le interesa a mucha gente y todavía no se ha hablado de eso.”

Figure 4 Transcriptions on the perceived quality of Neurology Department staff.

research studies in our contest. Another limitation of FG are the possible associated biases, such as those relating to the moderator (their experience and ability to coordinate), the existence of deviations during group discussion to themes not included in the guideline, or even the dominating of the group discussion by some participants over others who do not participate so frequently.

Lastly, we should comment upon aspects of quality which did not completely satisfy this study. From the most technique viewpoint, we would describe the incidental sampling used as suboptimum, because it was unable to provide an increase in relevance and generalism of results. Also, the design of the groups and thematic blocks did not probe into the issues to be discussed to finally reach detailed consensual analysis of each content. In contrast, this format sought diversification of opinions and variability of data, and therefore did not fulfil the information saturation criterion. From a more global viewpoint, no quality criteria were fulfilled, such as the validation of responder or member checking, as verification or validation of information in each of the groups with the study participants was not made. The criterion of data triangulation too, since no alternative data collection method was available which would allow us to confirm the information obtained in this study.

**Conclusion**

The experience of patients with MS and that of their families/caregivers collected in these FG highlights positive aspects of care received, and also demands for improvement. The humane treatment and the way in which they are considered when diagnosed, the management of their symptoms and information on treatments are aspects which are highly appreciated both by patients and by their family members in general. They conveyed the importance attached to the increase in specialised staff in MS in the Unit, since they understand that this has repercussions on the value of what they offer, both in care (the opening of the Day Hospital of Neurology and the direct lines of communication with the team through phone and email) and education (with the teaching workshop days).

It is interesting how the neuropsychological care is positively assessed both by patients and by their family members. This resources is not universal, although all guidelines to recommendations relating to care of people with MS recommend them at an early stage and during the course of the disease.31

However, the points of improvement detected by patients and family members relate to long-term care aspects (such
as physiotherapy and psychological support) which they demand should be covered by the national health service because at present it is privately financed. Care from the Emergency Department service is not forthcoming since the groups explained how complicated it sometimes was to consult the neurology department.

**Conflict of interests**

The authors have no conflict of interests to declare.

**References**


