



ORIGINAL ARTICLE

Clinical pathways for the care of multiple sclerosis patients

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KEYWORDS

Clinical pathways;
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Abstract

Introduction: Clinical pathways are standard health care methods to coordinate clinical work, reduce inter-clinician variability, improve patient care and increase staff and patient satisfaction. The aim of this study is to develop a clinical pathway capable of organising and developing standard procedures for diagnosis, treatment and care in patients with multiple sclerosis and to coordinate all medical specialists involved in this disease.

Methods: A multidisciplinary unit for the care of MS patients was developed. All of them and quality specialists analysed some international evidence-based studies, clinical guides, international guidelines and other clinical neurological pathways in several meetings and designed several documents for the clinical pathways.

Results: A clinical pathway was created consisting of a scientific-technical framework, which arranges the care in relation to the diagnosis and treatment. The framework is accompanied by various patient-information documents on the disease, an information sheet on diagnostic procedures and a map of the process. Quality standards were established to achieve continuous improvement in patient care.

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Conclusions: A clinical pathway for the care of MS patients in a multidisciplinary unit homogenises and organises the care which the MS patient should receive from the initial symptoms to the progressive stages. This clinical pathway improves the quality of patient care, reduces the variability in work protocols and rationalises the use of the available health care resources.

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PALABRAS CLAVE

Vía clínica;
Esclerosis múltiple;
Adherencia;
Cuidados;
Gestión de procesos

Diseño de una vía clínica para la atención a los pacientes con esclerosis múltiple

Resumen

Introducción: Las vías clínicas (VC) son herramientas para coordinar el trabajo asistencial, reducir la variabilidad entre el personal sanitario y mejorar la atención y el cuidado del paciente. La esclerosis múltiple (EM) es una enfermedad neurológica crónica que afecta a pacientes jóvenes y es incapacitante. El objetivo es desarrollar una vía clínica para mejorar el diagnóstico, el tratamiento y la atención de los pacientes con EM y, asimismo, facilitar la coordinación de todos los especialistas implicados en este proceso.

Método: Siguiendo el modelo FOCUS-PDCA se organiza un equipo de trabajo integrado por diferentes profesionales implicados en la atención del paciente con EM. Se realiza una revisión bibliográfica exhaustiva y se llega a consenso; así, se diseñan los documentos de la VC con base en la evidencia científica.

Resultados: Se crea una vía clínica compuesta por los siguientes elementos: una matriz temporal con una serie de anexos para ordenar el proceso diagnóstico y el tratamiento, un impreso de información a los pacientes sobre las pruebas diagnósticas, una hoja de información sobre la enfermedad y un mapa de procesos, una encuesta de evaluación de la calidad percibida y un documento con indicadores de calidad para evaluar la VC.

Conclusiones: El desarrollo de una VC de EM facilita la atención multidisciplinaria y mejora la calidad asistencial. Esta propuesta es novedosa al enfocar la atención integral de la EM desde su inicio, tanto en aspectos diagnósticos como terapéuticos, incluyendo el ámbito ambulatorio.

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Introduction

Multiple sclerosis (MS) is a chronic demyelinating disease that affects the central nervous system (CNS), with variable evolution. It is progressive and can lead to severe disability. This disease has significant social and economic impact.

MS is more common in women than in men. It is one of the most prevalent causes of disability in young adults in the world. Its aetiology is not completely understood, although it has been associated with a genetic susceptibility linked to the major histocompatibility antigen¹; the studies to date thus indicate that multiple genetic factors^{2,3} and its interaction with the environment contribute to its pathogenesis⁴.

The clinical variability of MS requires a multidisciplinary team including neurologists, rehabilitation specialists, ophthalmologists, psychiatrists, urologists, nursing staff and social welfare resources. This complexity requires a

high degree of coordination and management of resources to obtain the best care for patients.

Clinical pathways are coordination tools that detail the daily routine activities in the care of a patient with a specific diagnosis in order to obtain greater optimisation⁵. They are welfare plans that are applied to patients with a specific process, and who present a predictable clinical course⁶. They define sequence, duration and responsibility for the activities of health personnel for a particular procedure, thereby improving the quality of assistance^{7,8} and reducing variability in clinical practice⁹. Clinical pathways were implemented for the first time in the New England Medical Centre in Boston by Zander in 1980¹⁰. These pathways present a way to adapt clinical practice guidelines or protocols to clinical practice; they are the operational version of clinical guidelines^{11,12}.

Most clinical pathways are designed for hospital use¹³ for attention before, during and after hospitalisation and,

above all, for surgical procedures. In neurology, the references to implemented and evaluated clinical pathways are very limited and are mainly related to stroke^{14,15} and the rehabilitation of patients with various neurological diseases, for example, MS^{16,17}. In 2007, a clinical pathway was developed that organised and standardised interhospital care of amyotrophic lateral sclerosis in five hospitals in the Community of Madrid¹⁸. A clinical pathway for the treatment of acute MS outbreaks has also been published¹⁹.

The aim of this study was to develop a clinical pathway to organise and coordinate the multidisciplinary care of patients with MS at a university hospital, to apply it not only in the initial stage of diagnosis, but throughout subsequent disease monitoring within an outpatient setting. The goal was to achieve better coordination of all specialists involved in caring for such patients, to reduce variability of clinical practice among them, promote better use of health resources, thereby reducing costs, and to improve healthcare quality.

Methods

The MS clinical pathway was developed jointly by different professionals at the University Hospital, at the initiative of the Neurology Department. Following the model FOCUS-PDCA²⁰, a team was organised that is responsible for putting together care plans, objectives and opportunities for improvement, among others. This group was formed of doctors, nursing staff and social resources management involved in the care of patients with MS.

To design the clinical pathway, we carried out a bibliographical review, in which we analysed diagnostic and therapeutic guides, protocols and action guidelines issued in connection with the care of patients with MS. A literature search was carried out in different sources (MEDLINE-OVID, MEDLINE-ProQuest, MEDLINE-EIFL, EMBASE-OVID) and a consensus about key points was reached among the different professionals.

We held five meetings for the design of the clinical pathway documentation. The study group consisted of specialists in neurology, psychiatry, rehabilitation, physiotherapy, ophthalmology, urology, preventive medicine, radiology, neurophysiology, and nursing and social care staff. The different documents were designed by consensus and applying evidence-based medicine. The clinical pathway was presented to the entire Neurology Department and the professionals who worked on it and was approved by the hospital medical management.

Results

The presentation form of a clinical pathway is the time matrix, which is accompanied by a series of documents to be used by all personnel involved in patient care²¹.

This clinical pathway for care of patients with MS can be used in paper or electronic formats, and consists of the following documents:

1. Scientific-technical matrix (fig. 1). This is the clinical pathway document that collects the care plan for patients

with MS. The vertical axis records assessment and assistance, medical treatments and nursing care, attention for the patient and family and the social benefits and objectives of each visit. The horizontal axis represents time ordered by consultations: initial diagnosis phase, subsequent diagnostic consultations and follow-up visits. Various annexes are extracted from this document, identified by superscript numbers:

- Annex 1. Laboratory tests in the diagnostic phase.
- Annex 2. Laboratory tests to be assessed (diagnostic phase).
- Annex 3. Analytical monitoring.
- Annex 4. Clinical and laboratory criteria for MS diagnosis (Poser, 1983).
- Annex 5. McDonald criteria for MS diagnosis (review, 2005).
- Annex 6. Expanded disability scale score (EDSS).
- Annex 7. Functional EDSS systems.
- Annex 8. Modified fatigue impact scale (MFIs).
- Annex 9. MS quality of life questionnaire. FAMS Scale.
- Annex 10. Modified Ashworth Scale.

2. Documents on diagnostic tests, for the patient. This information consists of a number of documents that describe the tests to be performed during the period of diagnosis and monitoring, specifying their details, the preparation they require, the place and time of completion and the post-test care in a colloquial and understandable language. This information is delivered to the patient in the diagnostic phase to help them understand all the tests to be undergone.
3. Information document, for the patient and family. This document provides an overview of the disease (concept, symptoms, course, treatment), as well as general recommendations and useful information (associations, consultation schedules and contact details) (fig. 2).
4. Survey for perceived quality assessment. This is a questionnaire to be filled out anonymously. It is delivered to patients and families in follow-up visits. Through various questions it evaluates different aspects of satisfaction with the care received with respect to information about the study of the disease, tests undergone, information on associations and websites, existing social support and adjustments to daily life, symptom control, rehabilitation exercises and physiotherapy, availability of staff for taking care of requests and needs and staff friendliness. Responses are assessed using the five-category Likert scale. After that, there is a visual analogue scale from 0 to 10 for generally assessing the care provided. There is a space to note whether there has been a problem with any aspect of the quality perceived. There is also an empty space for commenting on aspects that could be improved.
5. Evaluation of the clinical pathway. This is carried out through different indicators that assess improvements in quality. In the case of the MS clinical pathway, the following are evaluated:

- Appropriateness of diagnostic tests.
- Diagnostic effectiveness.

MATRIZ DE LA VÍA CLÍNICA: UNIDAD MULTIDISCIPLINAR DE ESCLEROSIS MÚLTIPLE												
ACCIONES	CONSULTAS DE SEGUIMIENTO											
	C	F	F	F	F	F	F	F	F	F	F	F
EVALUACIÓN Y ASISTENCIA	<input type="checkbox"/> Historia Clínica.....											
	<input type="checkbox"/> Brotes.....											
	<input type="checkbox"/> Fecha.....											
	<input type="checkbox"/> EDSS.....											
	<input type="checkbox"/> Tipo.....											
	<input type="checkbox"/> Tratamiento.....											
	<input type="checkbox"/> Inicio de la progresión.....											
	<input type="checkbox"/> Exploración Neurológica.....											
	Pruebas a valorar: <input type="checkbox"/> RM Craneal.....											
	<input type="checkbox"/> T2.....											
	<input type="checkbox"/> T1.....											
	<input type="checkbox"/> Gd.....											
	<input type="checkbox"/> Atrolia.....											
	<input type="checkbox"/> RM Cervical.....											
	<input type="checkbox"/> T2.....											
	<input type="checkbox"/> T1.....											
	<input type="checkbox"/> Comparación con RM previas.....											
	Tipo de E Múltiple: <input type="checkbox"/> SDA <input type="checkbox"/> EMRR <input type="checkbox"/> EMSP <input type="checkbox"/> EMPP <input type="checkbox"/> EMPR.....											
	<input type="checkbox"/> Escala EDSS (6).....											
	<input type="checkbox"/> F. Piramidal.....											
	<input type="checkbox"/> F. Cerebelosa.....											
	<input type="checkbox"/> F. Tronco cerebral.....											
	<input type="checkbox"/> F. Sensorial.....											
	<input type="checkbox"/> F. Inter. Intersticial.....											
	<input type="checkbox"/> F. Visual.....											
	<input type="checkbox"/> F. Mental.....											
	<input type="checkbox"/> Otras.....											
	<input type="checkbox"/> MFSC.....											
	<input type="checkbox"/> S-HPT.....											
	<input type="checkbox"/> F. ASPT.....											
	<input type="checkbox"/> Marcha (7/8).....											
	<input type="checkbox"/> Fatiga: Escala Modificada del Impacto de la Fatiga (MFIS).....											
	<input type="checkbox"/> Calidad de vida: Escala FAMIS.....											
	<input type="checkbox"/> Espacialidad: Escala Modificada de Asworth.....											
	<input type="checkbox"/> De lectora cognitiva: Batería Neuropsicológica Breve (BNB).....											
TRATAMIENTOS MÉDICOS, CUIDADOS ENFERMERÍA Y APOYO SOCIALES	Valorar atención y necesidad de:											
	<input type="checkbox"/> Tratamiento sustitutivo.....											
	<input type="checkbox"/> a. Fisiología activa.....											
	<input type="checkbox"/> b. Logopedia/terapia.....											
	<input type="checkbox"/> c. Terapia ocupacional.....											
	<input type="checkbox"/> Tratamiento modificador.....											
	<input type="checkbox"/> e. INF A-1-A (Avonex).....											
	<input type="checkbox"/> f. INF A-1-B (Glatiramer).....											
	<input type="checkbox"/> g. INF A-1-C (Copaxone).....											
	<input type="checkbox"/> h. Interferón beta.....											
	<input type="checkbox"/> i. Fingolimod.....											
	<input type="checkbox"/> j. Dimetil fumarato.....											
	<input type="checkbox"/> k. Siponimod.....											
	<input type="checkbox"/> l. Ocrevus.....											
	<input type="checkbox"/> Tratamiento sintomático(12).....											
	<input type="checkbox"/> Disfagia.....											
	<input type="checkbox"/> Espasmodia.....											
	<input type="checkbox"/> Paresia de la marcha.....											
	<input type="checkbox"/> Calidad emocional.....											
	<input type="checkbox"/> Fatiga.....											
	<input type="checkbox"/> Depresión.....											
	<input type="checkbox"/> Eructos/eructos.....											
	<input type="checkbox"/> Incontinencia rectal.....											
	<input type="checkbox"/> Distorsión visual.....											
	<input type="checkbox"/> Fenómenos parosícticos.....											
	<input type="checkbox"/> Terapiacognitiva.....											
	<input type="checkbox"/> Recomendaciones generales (13).....											
	<input type="checkbox"/> Estudio clínico.....											
ATENCIÓN A PACIENTES Y FAMILIARES	Información paciente/familia.....											
	<input type="checkbox"/> Información de la enfermedad (18).....											
	<input type="checkbox"/> Tratamiento.....											
	<input type="checkbox"/> Cuidados/adaptaciones para vida diaria.....											
	<input type="checkbox"/> Derechos/ Ayudas sociales.....											
	<input type="checkbox"/> Breve cita de evaluación de la atención (21).....											
OBJETIVOS	<input type="checkbox"/> Establecer plan de atención y cuidados: las evaluaciones de calidad.....											
	<input type="checkbox"/> Informar sobre ayudas sociales y adaptaciones para la vida diaria (15).....											

(*) La vía clínica no reemplaza al juicio clínico del médico, que ha de adaptar las recomendaciones al caso particular del paciente que atiende.

Figure 1 Scientific-technical matrix of the clinical pathway for multiple sclerosis.

- Information on diagnostic tests.
- Evaluation of functional capacity using the EDSS scale.
- Information on disease and monitoring.
- Information on social support and patient/family associations.
- Perceptions of the care received by patients/ families.
- MS outbreaks (standard evolution).
- MS hospital admissions (effectiveness in reducing the length of hospital stays).
- Quality of life.

6. Process Mapping. The process flow chart provides a general overview of the management system for the diagnosis, treatment and monitoring of a patient with MS (fig. 3).

Discussion

Clinical pathways represent a very useful tool in the continuous improvement of the quality of care and also

facilitate the integration of clinical practice guidelines, protocols and algorithms²². Their advantages are based on the integration of the activities of all professionals, optimisation of appropriate and necessary activities, timeliness and coordination and collaboration of all professionals involved²³.

Multiple sclerosis patients are young, with a chronic and disabling evolution. This disease is characterised by a variable course and a wide range of symptoms (blurred vision, impaired sensitivity, abnormal gait, urinary alterations, depression and cognitive impairment, among others) that require the involvement not only of the neurologist, but also of many other specialists. The nurse and the neurologist monitor the subcutaneous or intramuscular immunomodulatory treatments used in this disease. Moreover, as these patients are young, the role of the social worker is very important in helping them to stay active in the labour market. Therefore, the care of these patients can only be carried out with a multidisciplinary approach.

Clinical pathways are often used in very common diseases, and in those with a high risk or high cost, but are also used

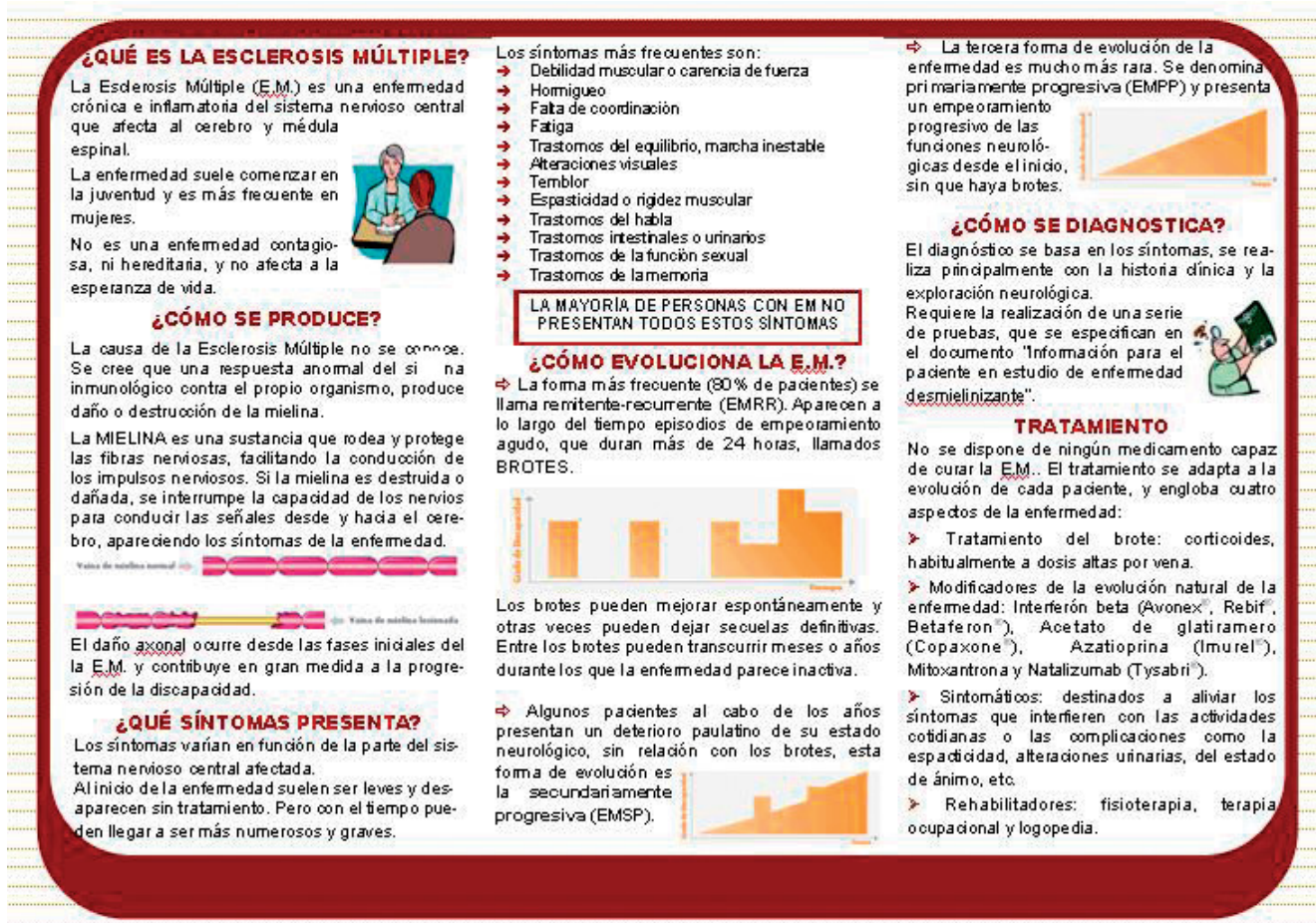


Figure 2 Information document for patients with multiple sclerosis.

when the collaboration of many professionals is necessary²⁴.

The development of a clinical pathway for MS patients in our hospital arose from the need to coordinate the multidisciplinary care these patients require, as well as the health costs arising from it. Using the clinical pathway will make it possible to achieve high quality multidisciplinary care by various motivated professionals within the appropriate timeframe. It may also reduce the costs involved in a chronic disease, through an improved use of resources (in addition, used by specialised professionals), and will standardise the processes of diagnosis and treatment.

The elaboration of this CP is innovative because standardised pathways for acute processes of MS were found, such as treatment with intravenous corticosteroids in outbreaks of the disease¹⁹ or in rehabilitation¹⁶ in our review of the literature; however, there were no pathways focused on comprehensive care of this disease that took diagnostic and therapeutic aspects into account from their inception. In addition, published pathways were designed for an outpatient scenario rather than for a hospital environment.

The clinical pathways implemented in other processes²⁵⁻²⁸ generally report satisfactory results. They obtain homogeneous, high quality assistance, based on evidence-based medicine, and significantly reduce hospital stay and waiting lists and, secondarily, healthcare costs. They allow the diagnosis and treatment to be standardised, always giving priority to common sense and clinical experience. It is important to keep in mind that a CP does not replace the decision of a professional²³.

Using CPs also influences better training of professionals, facilitating teamwork^{28,29}.

Our clinical pathway indicates the steps to follow, first in the initial phase of diagnosis, and then in the monitoring phase of drug treatment and rehabilitation. It explains the tests to be conducted, possible treatments and when and what kind of information should be given. It sets a chronological order for the intervention of the various specialists.

Clinical pathways make it possible to set up an evaluation system of care, based on established criteria, indicators and standards²³. We have established ten indicators that will help us to assess the effectiveness of this clinical pathway annually and that will allow us to know the areas needing improvement and the degree of patient satisfaction.

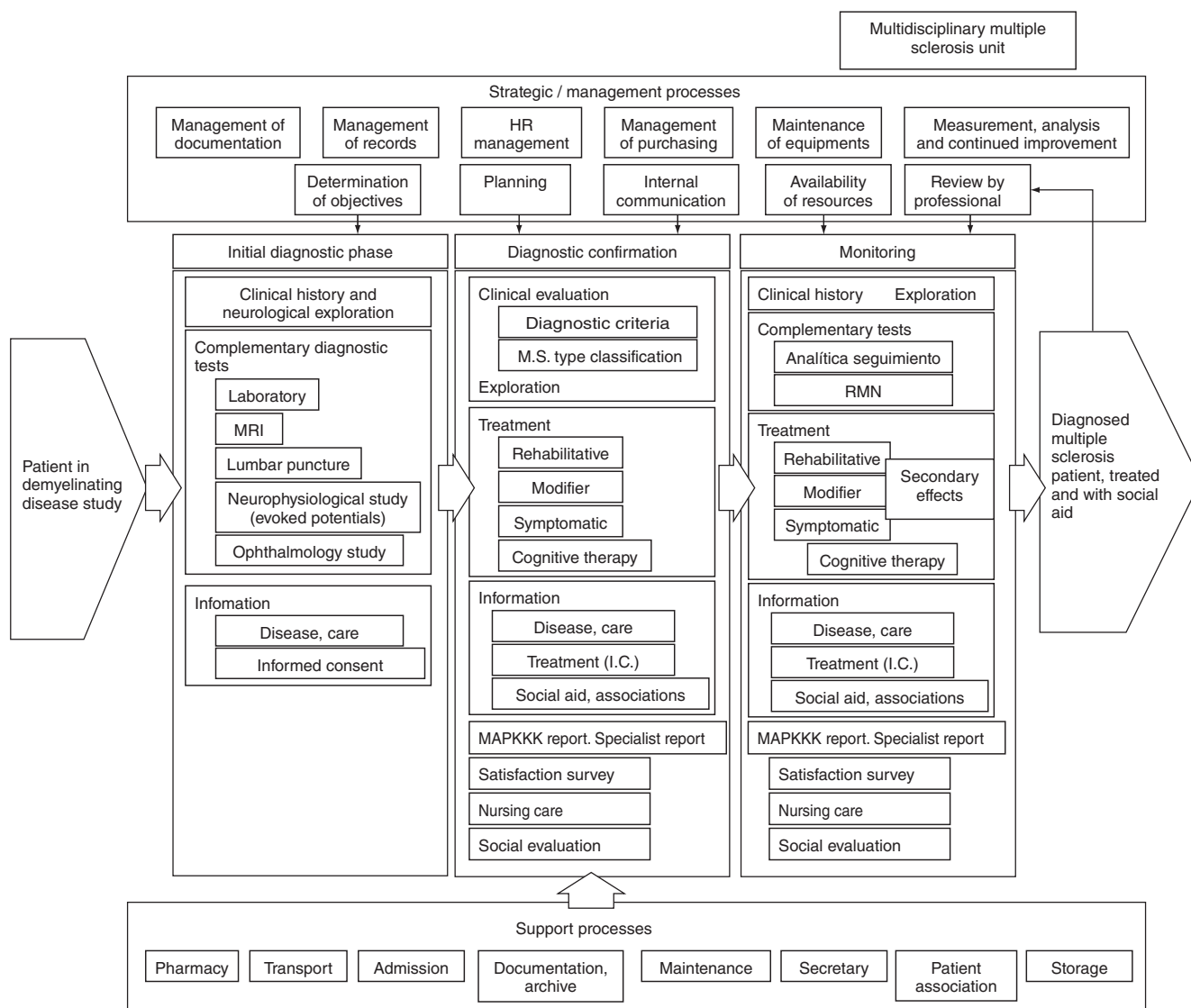


Figure 3 Process mapping flow chart.

We expect that, after long-term use, this CP will lead to continuous improvement in the care and quality of health perceived by the patient. It should also produce improvement in the empathy of the physician-patient relationship, by offering more and better information about the patient's condition and the care plan to be followed.

Finally, we believe that the MS CP constitutes a useful healthcare management tool, especially in the coordination of different professionals. It achieves comprehensive, multidisciplinary care throughout the course of the disease based on scientific-technical quality, decreases variability and rationalises the use of health resources.

Conflict of interests

The authors declare no conflict of interests.

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