Rethinking MS in Europe: Prioritising Timely, Integrated Care for People with Multiple Sclerosis

Monica Di Luca1, Claudio Bassetti2, Joke Jaarsma3, Per Soelberg Sorensen4, Maura Pugliatti5, Mario Alberto Battaglia6, Cristina Tiu7, Ludwig Kappos8, Massimo Filippi9, Hans-Peter Hartung10, Giancarlo Comi11, Jenny Freeman12, Kerstin Hellwig13, Elisabeth Kasilingam14, Pedro Carrascal15, and Vinciane Quoidbach16 –

1Department of Pharmacological and Biomolecular Sciences, University of Milan, Italy
2University of Bern Department of Neurology, Inselspital, Bern University Hospital, Bern, Switzerland
3European Federation of Neurological Associations, Brussels, Belgium
4Danish Multiple Sclerosis Center, University of Copenhagen, Rigshospitalet, Copenhagen, Denmark
5Department of Neuroscience and Rehabilitation, University of Ferrara, Ferrara, Italy
6University of Siena, Department of Life Science, Siena, Italy
7Department of Clinical Neurosciences, Carol Davila University of Medicine and Pharmacy, Bucharest, Romania
8Research Center for Clinical Neuroimmunology and Neuroscience Basel, University Hospital and University of Basel, Switzerland
9Neurology Unit, Neurorehabilitation Unit and Neurophysiology Service, IRCCS Scientific Institute San Raffaele, Milan, University of Milan, Italy
10Department of Neurology, Medical Faculty, Heinrich-Heine-University Düsseldorf, Germany; Brain and Minder Centre, University of Sydney, Australia
11Department of Neurology Università Vita Salute San Raffaele European Charcot Foundation, Italy
12University of Plymouth and Rehabilitation in Multiple Sclerosis, Peninsula Allied Health Centre, Plymouth, UK
13Katholisches Klinikum, Ruhr University, Bochum, Germany
14European Multiple Sclerosis Platform, Brussels, Belgium
15Esclerosis Múltiple España, Madrid, Spain
16European Brain Council, Brussels, Belgium

Abstract

Background: Multiple Sclerosis (MS) is a progressive neurological disease that can lead to severe disability. It is one of the most prevalent causes of disability in young adults in the world. Over 1,000,000 people are affected across Europe. Management strategies include DMTs, symptomatic treatment and lifestyle interventions—all of which must be tailored to the individual with MS in order to be effective. The European Brain Council initiated in 2018 a project RETHINKING MS, calling for change in MS care.

Method: The study’s research included data mapping, expert interviews and national roundtable discussions utilising the care pathway concept and the result of the literature search. The care pathway implies an integrated care framework. A series of clinical and patient-oriented benchmarks along the care process were developed, focusing on multidisciplinary, timely, integrated care as a key area which has been identified amongst the priorities for policy action to meet the needs of people living with MS.

Results: Findings highlight three main gaps in the management of MS across Europe. Firstly, providing multidisciplinary care is organisationally challenging. Secondly, access to specialist MS roles and programmes is limited. Thirdly, there is a lack of suitable information for people with MS. Today, it is not possible for the family physician or even many general neurologists to master the current treatment algorithm, and this calls for the establishment of multidisciplinary MS Care Units where there is an adequate infrastructure to provide proper monitoring of patients, comprehensive assessment, and detection of side effects and ability to promptly address them. A multidisciplinary MS Care Unit approach can be defined as the presence of a group of different specialists, who work together and with the MS neurologists and nurses with a formalized diagnostic workup procedure, protocols for initiation and follow-up of DMTs and management of complications.

Conclusion: Rethinking on how MS is managed in order to adequately provide care and support for all people with MS is needed. The RETHINKING MS in Europe report highlights that European and national policymakers should focus their efforts around these priorities and take specific actions. Similarly, the COVID-19 pandemic brings opportunities to re-think integrated care models across Europe.

Keywords: Multiple sclerosis • COVID-19 • Neurological disease • Environmental

Introduction

Multiple Sclerosis (MS) is a progressive neurological disease that can lead to severe disability. It is one of the most prevalent causes of disability in young adults in the world [1]. According to the new MS Barometer(2020), over 1,000,000 people are affected across Europe [2]. The underlying causes are unknown, but MS is thought to be triggered by complex interactions between genetic and environmental factors. The personal and economic impacts of MS grow significantly as the condition progresses and disability worsens. It has been estimated that in Europe the total costs of MS to society, including indirect and
Changing paradigms in the management of multiple sclerosis

The European Brain Council (EBC), an organisation promoting research in Europe on health and disorders of the brain to improve the quality of life of those living with such disorders, collaborated in 2018-2019 with experts from across Europe to build an interdisciplinary consensus around practical and sustainable policy responses to MS management at the European level. This new project, calling for change in how MS care and support is organised, formed the basis of the core report, RETHINKING MS in Europe: Prioritizing timely integrated services for people with multiple sclerosis [11].

Study Results

The Report highlights three main gaps in the management of MS across Europe. Firstly, providing multidisciplinary care is organisationally challenging. It can be difficult to provide high-quality multidisciplinary care, particularly in low-resource settings. Capacity can be a challenge in many MS clinics due to low numbers of specialists, large caseloads and high requirements for DMT monitoring. Secondly, access to specialist MS roles and programmes is limited. In many countries, people with MS are predominantly treated in smaller clinics in the community, resulting in variable access to a full multidisciplinary team. Geographical and financial inequalities can affect access to specialist services and facilities. Thirdly, there is a lack of suitable information for people with MS. Many people with MS and their carers do not feel that they receive suitable information, advice and education from healthcare professionals on the disease, progression and care needs. The lack of timely information can cause confusion and stress, and impact the person’s ability to make decisions about treatment.

Technical expertise and the MS care unit

Today, it is not possible for the family physician or even many general neurologists to master the current treatment algorithm, and this calls for the establishment of multidisciplinary MS Care Units. According to the recent ECTRIMS-EAN guidelines for treatment of MS, the entire spectrum of DMTs should only be prescribed in centres where there is an adequate infrastructure to provide proper monitoring of patients, comprehensive assessment, and detection of side effects and ability to promptly address them [12]. A multidisciplinary MS Care Unit approach can be defined as the presence of a group of different specialists, who work together and with the MS neurologists and nurses with a formalized diagnostic workup procedure, protocols for initiation and follow-up of DMTs and management of complications. The MS Care Unit should offer availability of a specific single contact neurologist and nurse, who can provide information, support and advice to the individual MS patients. This is imperative as a recent study on the effect of organizational features on patient satisfaction with care in Italian MS centres clearly showed that patient satisfaction was inversely associated with hospital size, probably because larger hospital may have failed in building an individualized relationship between patients and the MS neurologist and nurse and tailoring the communication of information [13].

The core of the MS Care Unit should, in addition to MS neurologists and nurses, typically comprise neuropsychologists, clinical psychologists, physiotherapists, occupational therapists and secretaries, and will work together with a group of different specialists on formalized diagnostic workup procedures, protocols for initiation and follow-up of disease-modifying therapies. It is obvious that the terms of performance of different MS Care Units will vary across regions and need to be balanced with clinical practice according to local conditions (Figure 1). Although the main objective for establishment of MS Care Units...
will be to offer the single MS patient seamless and correct management of the disease to increase patient satisfaction and quality of life, it may even be cost-effective for the society by maintaining the working ability and reducing the costs of home help and custodial care by keeping people with MS resourceful. It will also increase knowledge sharing and strengthen national research environment, ultimately creating a network for the study and development of new treatments [14].
National policy priorities and way forward

The priorities identified in Denmark, Italy, Romania and Spain stem from experts’ consensus within those countries; however, they are also likely to be relevant to other regions in Europe. In the case of Denmark, it is proposed to address the above challenges that highly specialised, multidisciplinary MS centres be established in each of Denmark’s five regions. In Italy, the National Plan for Chronicity clarifies ambitions to provide person-centred and multidisciplinary approaches for all people with chronic diseases with the extension of the care pathway on MS throughout the country. In Romania as in Spain, integration of care and interoperability of healthcare services are high on the political agenda. Rethinking on how MS is managed in order to adequately provide care and support for all people with MS is needed. The RETHINKING MS in Europe report highlights that European and national policymakers should focus their efforts around these priorities and take specific actions. Similarly, the COVID-19 pandemic brings opportunities to re-think integrated care models across Europe.

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