

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

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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

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Received 01 November, 2020; **Accepted** 08 November, 2020; **Published** 18 November, 2020

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

direct medical and non-medical costs, stand at 15.5 billion euro per annum [3]. Health systems face significant challenges in responding to patients' complex care needs and guaranteeing equal access to treatment. This has been amplified by the COVID-19 pandemic.

In MS, the immune system mistakenly attacks and damages the myelin sheath around the axons of nerves in the brain, spinal cord and optic nerve. The resulting inflammation, damage and destruction is increasingly irreversible and leads to brain atrophy and a host of symptoms including reduced motor control, cognitive impairment, visual disturbances, depression and anxiety. Owing to the heterogeneous nature of MS, the clinical course is unpredictable and highly variable. MS affects every person differently. There are three main forms of MS; most common (80-90% cases) is the Relapsing Remitting Form (RRMS) where acute symptom attacks are interspersed with remission periods when the symptoms abate due to Central Nervous System (CNS) repair and the use of neurological reserves. Many people with RRMS go on to develop Secondary Progressive MS (SPMS). Less common than RRMS is Primary Progressive MS (PPMS) in which the persons with MS has no or very few periods of remission and disability usually develops more rapidly than for RRMS [4].

The finite capacity of neurological reserve and repair mechanisms in the CNS contribute to the importance of early diagnosis. If MS-related brain damage is undetected MS may go untreated leading to exhaustion of brain reserve and an early progression into the SPMS state. Early treatment with Disease Modifying Therapies (DMTs) will work towards preserving brain tissue. Over and above pharmacological treatment initiation, early diagnosis means that appropriate steps can be taken to improve brain health, including exercise, smoking cessation, weight loss and control of co-morbidities such as hypertension. Early diagnosis is essential as it can help preserve brain tissue, maintain neurological and cognitive reserve as well as physical function, and reduce potential disability, thereby supporting people to stay in work and reducing the negative societal impact [5]. According to recent NICE Guidelines, 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 [6].

Despite the evolution of the diagnostic and treatment paradigm for MS, there is still evidence that both within- and between-country variation remains in management approaches: there are growing barriers to the provision of adequate treatment options and access to timely integrated health care services [7]. On the one hand, DMTs have become increasingly multifaceted and comprise a wide range of drugs with different mechanisms of action and adverse effects that need meticulous monitoring [8,9]. The quick access to a large set of investigations, including Magnetic Resonance Imaging (MRI), multimodal evoked potentials, optical coherence tomography, immunological tests and antibody tests, requires an advanced level of organisation. Even symptomatic therapy has become more extensive, involving a wide range of treatments. On the other hand, the young age of onset and neurodegenerative nature mean that it places also unique challenges on health care. The chronically ill patients and subjects with co-morbidities, are in special need of continuous and patient-centred care. Lately, the COVID-19 situation has also shown that the reduced availability of normal services, fear of contracting the virus by continuing to access essential healthcare, scarcity of information, and anxiety about using immunosuppressants have all placed a severe toll [10].

Considering the magnitude of the problem, relevant solutions exist, including the organised MS Care Unit and a seamless, multidisciplinary approach to improve the patient care pathway.

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]. RETHINKING MS, released during the Brain Awareness Week in March 2020, featured a sequence of research which led to a suite of four country profiles-Rethinking MS in Denmark, Italy, Romania and Spain-and took an in-depth look at the different MS-related policy and regulations, health services delivery. These countries were selected in consultation with an established Expert Advisory Group (EAG) to represent a broad range of national contexts from across the continent.

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. Its analysis encompasses the whole care process, from prodromal, early diagnosis to disease management and patient empowerment. It defines sequence and responsibility for the activities for health personnel for a particular procedure, thereby aiming to improve the quality of assistance and to reduce variability in clinical practice. A series of clinical and patient-oriented benchmarks along the care process were developed, focusing on multidisciplinary, 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.

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 recentECTRIMS-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

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.

Acknowledgements

The European Brain Council (EBC) RETHINKING MS Project was developed with the support of The Health Policy Partnership (HPP). The RETHINKING MS in Europe Report was endorsed by the European Academy of Neurology (EAN), the European Charcot Foundation, the European Federation of Neurological Associations (EFNA), the European Multiple Sclerosis Platform (EMSP), and The European network for best practice and research in MS Rehabilitation (RIMS).

References

1. Wallin, MT, Culpepper WJ, Nichols E, and Bhutta ZA, et al. "Global, Regional, and

National Burden of Multiple Sclerosis 1990–2016: A Systematic Analysis for the Global Burden of Disease Study 2016." *Lancet Neurol* 18 (2019): 269-285.

2. <http://www.emsp.org/projects/ms-barometer/>.
3. Kobelt, G, Thompson A, Berg J, and Gannedahl M, et al. "New Insights into the Burden and Costs of Multiple Sclerosis in Europe." *Mult Scler* 23 (2017): 1123-1136.
4. Lublin, FD, Reingold SC, Cohen JA, et al. Defining the Clinical Course of Multiple Sclerosis: The 2013 Revisions." *Neurology* 83 (2014): 278-286.
5. Giovannoni, G, Butzkueven H, Dhib-Jalbut S, and Hobart J, et al. Brain Health: Time Matters in Multiple Sclerosis. *Mult Scler Relat Disord* 9 (2016): S5-S48.
6. <https://pathways.nice.org.uk/pathways/multiple-sclerosis>.
7. Fernandez, O, Delvecchio M, Edan G, and Fredrikson S, et al. "Survey of Diagnostic and Treatment Practices for Multiple Sclerosis in Europe." *Eur J Neurol* 24 (2017): 516-522.
8. Comi, G, Radaelli M, Soelberg Sorensen P. "Evolving Concepts in the Treatment of Relapsing Multiple Sclerosis." *Lancet* 389 (2017): 1347-1356.
9. Soelberg, SP. "Safety Concerns and Risk Management of Multiple Sclerosis Therapies." *Acta Neurol Scand* 136 (2017): 168-186.
10. <https://www.msociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies/covid-19-coronavirus-and-ms>.
11. <http://www.braincouncil.eu/rethinkingms/>.
12. Montalban, X, Gold R, Thompson AJ and Romero SO, et al. "ECTRIMS/EAN Guideline on the Pharmacological Treatment of People with Multiple Sclerosis." *Eur J Neurol* 25 (2018): 215-237.
13. Mattarozzi, K, Baldin E, Zenesini C, and Solari A, et al. "Effect of Organizational Features on Patient Satisfaction with Care in Italian Multiple Sclerosis Centres." *Eur J Neurol* 24 (2017): 631-637.
14. Soelberg, SP, Giovannoni G, Montalban X, and Thalheim C, et al. "The Multiple Sclerosis Care Unit." *Mult Scler* 25 (2018): 627-636.

How to cite this article: Monica Di Luca, Claudio Bassetti, Joke Jaarsma, and Per Soelberg Sorensen, Maura Pugliatti, Mario Alberto Battaglia, Cristina Tiu, Ludwig Kappos, Massimo Filippi, Hans-Peter Hartung, Giancarlo Comi, Jenny Freeman, Kerstin Hellwig, Elisabeth Kasilingam, Pedro Carrascal and Vinciane Quoidbach*. "Rethinking MS in Europe: Prioritising Timely, Integrated Care for People with Multiple Sclerosis." *J Clin Neurol Neurosurg* 3 (2020): 119
doi: 10.37421/jcnn.2020.3.119