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Multiple Sclerosis on behalf SFSEP

Organization of healthcare in multiple sclerosis

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ABSTRACT

The organization of healthcare for patients with multiple sclerosis (MS) has changed considerably over the past 15 years, with the creation of health networks providing a new impetus towards better coordination of healthcare through a multidisciplinary approach, and improvement of educational training for both patients and healthcare professionals. In this context, therapeutic educational programs (TEPs) for patients have placed patients at the center of their own care pathway, thereby changing the doctor-patient relationship. Today, TEPs cover the various needs of patients in their everyday lives, whether they are medical, social or psychological. However, the arrival of a wide range of new medications, the complexity of therapeutic decisions and management of risk increase the need for organized expertise via centers of resources and competencies (CRCs) for MS, approved since 2016 as part of the French National Neurodegenerative Diseases Plan (NDDP). This NDDP 2014–2019 provides an incentive to change the organization of healthcare for MS patients by adapting it according to regional specificities and resources. Whatever the chosen system of organization, it should allow for a good well-coordinated multidisciplinary care pathway that is easily accessed by patients.

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1. Introduction

The organization of healthcare for patients with multiple sclerosis (MS) has changed considerably over the past 15 years first because of the creation of healthcare networks, which have improved access to care and care pathways by patients and, second, because of the development of patients' therapeutic education programs (TEPs). More recently, the introduction of different measures as part of the French National Neurodegenerative Diseases Plan (NDDP), including

the creation of centers of resources and competencies (CRCs), has led to a move towards a new system of organization for patient care.

2. Benefits of MS health networks

Healthcare provision based on neurologists (whether private or hospital-based) working in collaboration with general practitioners (GPs) has been strengthened by the creation of networks following Alain Juppé's reforms of 1996 [1]. Since

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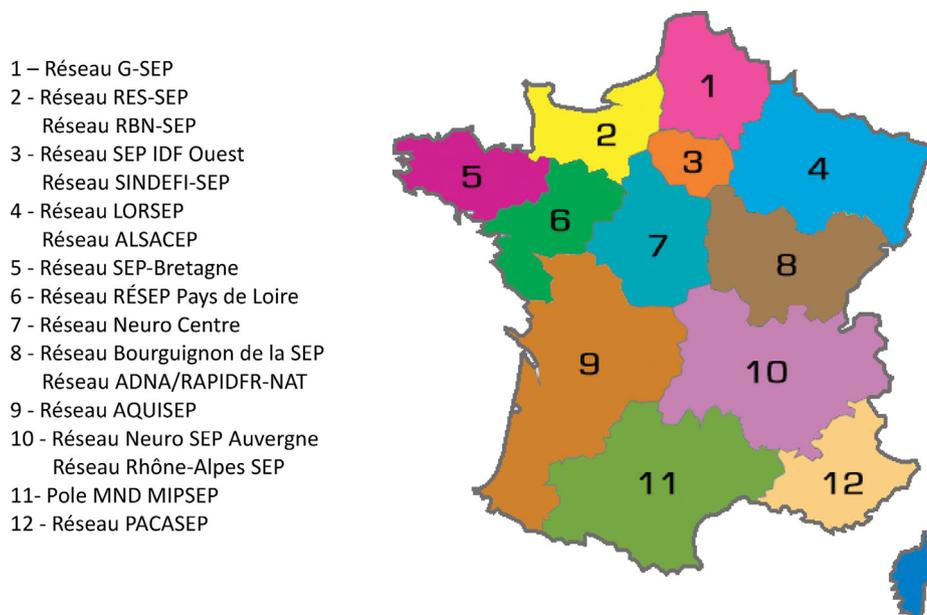


Fig. 1 – French healthcare networks (*réseaux*) for multiple sclerosis by region.

then, these MS networks have gradually developed and spread to different regions of France, each with their own specificities (Fig. 1). Today, there are 16 MS networks in France and one neurodegenerative diseases center [Midi-Pyrénées Multiple Sclerosis (MIPSEP)]. These networks are financed by regional endowment funds (FIR) managed by regional health agencies (ARS), and annual assessment of each network's activity is carried out by the ARS before financing is renewed: active files are especially considered, and patients' quality-of-life scales and feedback forms are also evaluated.

2.1. Objectives

The main network objectives are to improve both access to healthcare and the assessment practices of health professionals when dealing with MS patients. The creation of these networks has strengthened collaborations between community medicine and hospitals, and also encouraged multidisciplinary healthcare. In addition, their activities have led to better treatment coordination for patients in terms of both social and sociomedical aspects. Moreover, the networks link the relevant people at different healthcare facilities, hospital centers [university hospitals, regional hospitals (...)], and rehabilitation and recuperative care facilities (SSR). Patient associations are also involved in the work to inform and communicate with patients as well as the general public.

2.2. Actions

By joining networks free of charge in their different regions, patients can benefit from personalized services, and access information from centers closest to where they live. Patients' care pathways are established by these networks in consultation with neurologists, GPs and local neighbourhood health professionals, all of whom are trained by the network and, thus, have a better understanding of the disease. The network

healthcare team is multidisciplinary and may include nurses, social workers, psychologists, neuropsychologists, ergotherapists and doctors of different specialities, such as neurologists, rehabilitation physicians, psychiatrists, occupational physicians and urologists. The network nurse could then coordinate the administration of corticosteroids at home, inform the patient of new treatments and follow-up the doctor's announcement of the diagnosis, a key stage in the care pathway for patients with chronic illnesses. This could also instead involve a psychologist within the MS network, as per the 2014 recommendations of the French National Health Authority (HAS) [2]. The implementation of networks has been adapted to regional specificities; for example, some networks have mobile teams that can visit patients at home.

Network teams also regularly organize training courses for different health professionals and create common references shared by the network during information-exchange meetings and through websites, including, for example, information from various ongoing MS therapeutic trials.

2.3. Multidisciplinary

The creation of networks has reduced inequalities of access to care and developed more global multidisciplinary patient care. The activities of the different professionals dealing with each patient is coordinated and sometimes even initiated by the network, and communicated to different participants, notably the GPs. This multidisciplinary is vital for supporting patients, especially those who have complex situations either psychosocially [isolation, dependence, family situations (...)] or medically [disability, polyopathy, treatment side effects (...)]. Indeed, such complex patients can benefit from personalized healthcare plans that include overall assessment, care coordination, and medical and sociomedical support with the help of their doctors. A multidisciplinary summary report is then produced and sent to the various

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