

Conference “Early diagnosis / early referral: health, social and economic impacts of RMDs”

Date: 23rd February 2017, 09:30 - 12:30

Venue: Library Room, Assembly of the Republic (Palácio de S. Bento, 1249-068 Lisbon)

The importance of early diagnosis and referral of rheumatic diseases will be debated on 23rd February in a conference organized by the Portuguese League against Rheumatic Diseases, in partnership with the European League against Rheumatism (EULAR) and the Portuguese Society of Rheumatology. This forum aims to contribute to improve the care quality standards in Rheumatology in the Portuguese National Health Service.

Although in the last 15 years there has been a great evolution in the access to medical care provided by rheumatologists, several studies confirm that there are still areas in the country lacking adequate care of rheumatic diseases. There is evidence that adequate diagnosis and therapeutic intervention can reduce the impact of these diseases, on the quality of life of the affected people, as well as on society in general.

In Portugal, rheumatic diseases affect 56% of the population¹, they are the leading cause for medical consultations, for disability, for work absenteeism and the major cause of early retirement – representing of the main direct (consultations, medication, rehabilitation, etc.) and indirect (days of lack of work, lack of productivity) health expenditures.

Recent studies also demonstrate the existence of "window of opportunity", an optimal time interval for the establishment of effective therapy in order to significantly modify the evolution of the disease, preventing structural damage, functional disability, dependence on third parties and early mortality.

This event will promote the discussion of knowledge, with the presence of several entities (namely the Directorate-General for Health and the Parliamentary Health Commission) committed to help patients with Rheumatic diseases to be diagnosed as early as possible – and thus treated more adequately, with direct benefits for citizens and indirect gains for the Society.

Additional information:

In 2002, the Ministry of Health and the General Directorate for Health (DGS) approved the Referral Network Hospital of Rheumatology. Hospital Referral Networks have a central role as integrated, coordinated and hierarchical systems that promote the satisfaction of health needs at the most varied levels, namely: diagnosis and therapy; training; research and interdisciplinary collaboration, contributing to ensure the quality of care provided.

By that time (2002), only two to three dozens of rheumatologists² were working within the National Health Service and only six public hospitals had Rheumatology Units/Departments.

In 2014, the Ministry of Health acknowledged the need to revise the National Network of Hospital Specialties and Referencing, within the framework of the reorganization of hospital health institutions (regarding the availability and coordination of the service portfolio, organizational models and integration of care), and how they should be integrated into the National Health Service network, to reinforce the articulation and effective complementarity, with the different levels of care, in guaranteeing a better referral.

Therefore, in September 2015, a Working Group, coordinated by Prof. Jaime Branco, presented a proposal for the National Network of Hospital Specialties and Referencing in Rheumatology. According to this document, by 2015, in the mainland³, there existed 18 Public Hospitals had Rheumatology Units/Departments, with 83 rheumatologists and 53 Rheumatology Registrars. There were also two private non-for-profit institutions of social solidarity (IPSS): Instituto

Português de Reumatologia (IPR) with 23 rheumatologists in 2015, and Hospital Ortopédico de Sant'Ana, with one rheumatologist. The College of the Speciality of Rheumatology by the Order of Physicians has pointed out that 107 rheumatologists were working within the National Health Service. For a population of 10 million, there should be around 200-250 rheumatologists, and the ratio 1 rheumatologist : 50.000 inhabitants is considered for ensuring quality of care/services.

Although recognising the improvement made between 2002 and 2015, the document reports that most of the Hospitals that were expected to have Rheumatology Units/Departments, within the scope of Referral Network Hospital of Rheumatology in 2002, either did not have them, or do not have enough rheumatologists. It is the case of Centro Hospitalar (CH) do Alto Ave, CH do Porto, CH de Leiria, Hospital Distrital de Santarém, CH Lisboa Central, H. Cascais Dr. José Almeida, H. Prof. Dr. Fernando Fonseca, CH de Setúbal, H. Évora.

In these hospitals, RMDs patients don't have access to the appropriate care, and are assessed by doctors without specific training in Rheumatology. Once these misleading Rheumatology units offer consultations to RMD patients by non-Rheumatologists doctors, the unmet need is considered to be resolved, and therefore, there is no opening of vacancies for Rheumatologists for those hospitals.

Since patients are referred for the assessment by Rheumatology units, mostly in Public Hospitals, in the above-mentioned situations, patients are frequently prevented from accessing to the most adequate and updated health care for RMDs. This creates significant territorial asymmetries, denying many citizens the constitutional rights of equality and equity in access to differentiated health care.

Besides, half of the 18 Rheumatology Units had less than three Rheumatologists, in 2015, and five of them had only one Rheumatologist. Currently, there is a bigger ratio rheumatologist/inhabitants in the metropolitan and littoral areas, while other areas have few or none rheumatologists within the National Health Service, which is the case of Alentejo.

Therefore, the proposal for the National Network of Hospital Specialities and Referencing in Rheumatology, approved by order of the Minister of Health in 23rd of November 2015, suggests that until 2019 new Rheumatology Units/Departments should be created in 20 Hospitals⁴ that are not providing these services.

The high prevalence of DRM, its potential impact on patient's mobility, and the frequent need for periodic assessment, justifies an appropriate territorial dispersion of Hospital Rheumatology services to ensure the proximity of specialized healthcare to patients, avoiding unnecessary travel, unnecessary costs and associated risks.

The services must be located in a way to ensure that all the population served have access to the specialty within a maximum radius of 100 km. Considering the need for a critical mass and the guarantee of care in case of absences, each service/unit must have a minimum of three rheumatologists. It is also suggested to reinforce human resources in Rheumatology Units/Departments of 11 Hospitals⁵.

The approved National Network of Hospital Specialities and Referencing in Rheumatology should be implemented until 2019, providing 38 Rheumatology Units/Departments. Hence, in two years' time, the 20 new Rheumatology Units should be properly created, namely in **Hospital Prof. Doutor Fernando da Fonseca, Centro Hospitalar de Lisboa Oriental, Hospital de Cascais – Dr. José de Almeida, Centro Hospitalar do Porto, Hospital da Senhora da Oliveira – Guimarães.**

Recent data from Epireuma.pt shows that 37.2% of the population aged between 50 and 64 years have at least one rheumatic disease with a clear impact on their work capacity. In this

national epidemiological study, 22.7% of the respondents with rheumatic diseases were retired – what corresponds to one-third of all retirees due to illness (30.4%). The annual cost of premature exit from the labor market of rheumatic patients is 910 million euros per year in Portugal, which represents almost 10% of the health budget – considering that the overall budget of the Ministry of Health equals 9.5 thousand millions. In addition, to these costs we will have to add costs with the use of resources (consultations, medicines, etc.) to get an overview of the case.

Difficulties in being referred from the Primary Care doctors to Rheumatology Units in SNS is one of the most frequent complains that lead patients to the contact with the Portuguese League Against Rheumatic Diseases. In these situations, if patients have enough economic resources, they decide to arrange for a consultation with a Rheumatologist, in private practice. If not, they may remain without proper treatment or intervention, which may aggravate their health conditions.

The document suggests that informal pathways of contact between Primary Health Units and Rheumatology services should be created and maintained to accelerate the referral of urgent cases. The articulation between the Family Doctor and the Rheumatologist should allow the patient to have access to quality health care, with the least possible number of trips to hospitals, and an appropriate consideration of costs and benefits. Patients referred to the rheumatology consultation should be observed accordingly to the established priority, which should reflect the potential or verified severity of their clinical condition, and, thus, benefit from a specialized intervention in order to improve the patient's prognosis and quality of life, in the short and long term. After consulting Rheumatology, the patient should be accompanied by information written by the rheumatologist to the Family Doctor. The need for regular assessment of RMDs patients by a Rheumatologist it is also recognised.

The National Network of Hospital Specialties and Referencing in Rheumatology aims for earlier diagnosis and intervention with effective treatments to prevent disabilities more efficiently. To ensure the implementation of the approved National Network of Hospital Specialties and Referencing in Rheumatology by 2019, is to ensure better quality of life for people affected by RMDs and a step forward in reducing the global burden (direct and indirect costs, DALYs) of RMDs.

About Portuguese League Against Rheumatic Diseases

The Portuguese League Against Rheumatic Diseases was created in 1982 with the aim of promoting the social education of the rheumatic patient and the population in general, disseminating information about the nature, treatment, prevention and social repercussions of rheumatic diseases.

For more information, visit: www.lpcdr.org.pt.

About EULAR

The European League Against Rheumatism (EULAR) is an umbrella organisation which represents scientific societies, health professional associations and organisations for people with Rheumatic Musculoskeletal Diseases (RMD) throughout Europe.

EULAR aims to promote, stimulate and support the research, prevention, and treatment of RMD and the rehabilitation of those it affects.

EULAR underlines the importance of combating rheumatic diseases not only by medical means, but also through a wider context of care for rheumatic patients and a thorough understanding of their social and other needs. EULAR is supported in this mission by its 45 scientific member societies, 36 PARE (People with Arthritis/Rheumatism in Europe) organisations, 22 HPR (Health Professionals in Rheumatology) associations and 23 corporate members.

The EULAR Annual European Congress of Rheumatology is the foremost international medical meeting announcing the latest research on rheumatic and musculoskeletal diseases. EULAR

2016 is expected to attract over 14'000 delegates from around 120 countries. Most if not all professions working in the vast field of RMD will be represented.

To find out more about the activities of EULAR, visit: www.eular.org

About Portuguese Society of Rheumatology

Founded in 1972, the Portuguese Society of Rheumatology is a scientific organization whose objective is to promote the development of rheumatology at the service of health of the Portuguese population. Its purpose is to promote knowledge of rheumatic diseases, favoring medical training, as well as the development of studies and research projects in Rheumatology. The Portuguese Society of Rheumatology also assumes itself as a documentation center intended for professionals, through the publication of specialized medical scientific information, and for the general public, through its website. In addition, it cooperates with patient associations and plans education for the general population. Currently, it represents 200 professionals, with which it collaborates in the defense of the title of Rheumatologist and the good name of the specialty. For more information, please visit: www.spreumatologia.pt.

Notes

¹ EpiReuma.pt 2014.

² According to the Referral Network Hospital of Rheumatology 2002 and the National Network of Hospital Specialties and Referencing in Rheumatology 2015.

³ The Portuguese Islands have their own Regional Health Services that are out of the scope of the Network. However, in 2015, the main Hospital in Madeira had four rheumatologists, there were three rheumatologists in the main Hospital of S. Miguel and one in Terceira Island.

⁴ CH do Alto Ave (Guimarães, Fafe), CH do Médio Ave (Famalicão, Santo Tirso), H. de Santa Maria Maior (Barcelos), CH Tâmega e Sousa (Vale do Sousa and Amarante), Unidade Local de Saúde (ULS) do Nordeste (Bragança), ULS Matosinhos, CH Póvoa de Varzim – Vila do Conde, CH Porto, CH Leiria, HD de Santarém, CH Caldas da Rainha, H. de Vila Franca de Xira, CH de Lisboa Central, H. Prof. Dr. Fernando Fonseca, Hospital Cascais Dr. José Almeida, CH Barreiro e Montijo, CH Setúbal, ULS Norte Alentejano (Portalegre), ULS Baixo Alentejo (Beja), Hospital Espírito Santo (Évora).

⁵¹ H. de Braga, CH Trás-os-Montes e Alto Douro (Vila Real, Chaves and Lamego), CH Gaia Espinho, CH Entre Douro e Vouga (Santa Maria da Feira, São João da Madeira and Oliveira de Azeméis), CH Cova da Beira (Covilhã), CH Baixo Vouga (Aveiro and Águeda), CH Tondela Viseu, ULS Guarda, ULS Castelo Branco, CH Médio Tejo (Torres Novas, Tomar) e CH Algarve (Faro and Portimão).