Common language description of the term rheumatic and musculoskeletal diseases (RMDs) for use in communication with the lay public, healthcare providers and other stakeholders endorsed by the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR)

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Viewpoint/Special Article

A common language description of the term rheumatic and musculoskeletal diseases (RMDs) for use in communication with the lay public, healthcare providers and other stakeholders endorsed by European League Against Rheumatism (EULAR) and American College of Rheumatology (ACR)

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Abstract

A EULAR-ACR working group consisting of practicing and academic rheumatologists, a rheumatology researcher and a patient advocate created a succinct general statement describing rheumatic and musculoskeletal diseases (RMDs) in adults and children in language that can be used in conversations with the lay public, media, healthcare providers and other stakeholders. Based on the literature review, several elements were deemed important for inclusion in the description of RMDs. First, RMDs encompass many different diseases that can affect individuals at any age, including children. Second, there are various pathophysiological pathways underlying different RMDs. Third, the impact of RMDs on individuals and society should be emphasized. The working group agreed that the language should be comprehensible to the lay public. Thus, the following description of RMDs has been developed: "*Rheumatic and musculoskeletal diseases (RMDs) are a diverse group of diseases that commonly affect the joints, but can affect any organ of the body. There are more than 200 different RMDs, affecting both children and adults. They are usually caused by problems of the immune system, inflammation, infections or gradual deterioration of joints, muscles and bones. Many of these diseases are long term and worsen over time. They are typically painful and Iimit function. In severe cases, RMDs can result in significant disability, having a major impact on both quality of life and life expectancy*." This description can be used by rheumatology groups, researchers and those who work in advocacy and education related to RMDs.

The field of rheumatology encompasses a wide range of medical conditions that affect many organ systems. These conditions reflect diverse pathogenic mechanisms and result in functional limitations, diminished quality of life and increased patient mortality. In addition, although rheumatic conditions in total are among the most common of all medical problems, many of the individual diseases are uncommon or even rare. This situation results in an ever-present dilemma for the field. Most of the public and policy makers around the world do not know about many of the rheumatic and musculoskeletal diseases (RMDs) and even if they have heard of them, there is broad lack of awareness about the complexity and enormous importance of this area of medicine.

To further public awareness and support policies directed toward lessening the impact of these diseases on patients and society, a working group from the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR), consisting of practicing and academic rheumatologists, a patient representative and a rheumatology health professional, have developed a formal description of these conditions. The goal of this effort was to create a succinct general statement describing RMDs in adults and children in language that can be used in conversations with the general population with and without RMDs; media; healthcare providers; policy makers at local, national and international level; health insurance companies; charities; employers and other stakeholders.

Several elements were deemed important for inclusion in the description of RMDs by the group. First, it should be emphasised that RMDs encompass many different diseases that can affect persons at any age, including children. Second, it should be clear that there are various pathophysiological causes of RMDs. Third, the impact of RMDs on individuals and society should be emphasized. Finally, the language should be easily understood by the lay public.

Here we will discuss various aspects that provide relevant background information, which can be used during the discussion about the importance of RMDs with the relevant stakeholders.

Methodology

The participants of the working group were selected based on their position in the respective organisations. For EULAR this was the president, the chair of the EULAR standing committee of clinical affairs, the EULAR liaison to the ACR, and a patient representative. For the ACR, the president and president-elect of the ACR, the president of the ARHP, and the president of the Rheumatology Research Foundation were included. The group met once in person, had one TC and all other exchanges were conducted by email. There was a scoping review of the literature with emphasis on grey literature such as reports from the European Union.

RMDs encompass many different diseases that can affect persons at any age, including children

Data suggest that there are over 200 RMDs; some conditions are very common, while others are rare. Lists of RMDs have been compiled in a number of publications and survey results. For example, the ACR website features a detailed list as does the EULAR website. [1,2] The latter is considered the official list as applied by the European Union (EU) of Medical Specialists (EUMS). [*see appendix*] In addition, the Arthritis Foundation, a patient organization in the USA as well as the ACR maintain patient-oriented lists of RMDs. [3,4]
Well-known and prevalent examples of RMDs are rheumatoid arthritis, osteoarthritis and gout. According to a conservative estimate of the United Nations, symptomatic osteoarthritis, or degenerative joint disease, affects 15% of people worldwide, and it is estimated that by 2050, over 130 million people will suffer from osteoarthritis worldwide and 40 million will be severely disabled. [5]
Rheumatoid arthritis is the most common autoimmune inflammatory form of arthritis and affects approximately 1 in 100 persons worldwide, with women affected twice as commonly as men. [6] Gout is the most common cause of inflammatory arthritis in men and has a prevalence in the US and Europe of about 4%. [7,8]
Many other RMDs are less common, but cause significant morbidity and mortality. For example, systemic lupus erythematosus (SLE), which affects women approximately 9 times more frequently than men, is a systemic autoimmune disease that frequently causes

arthritis and dysfunction of connective tissues among many other systemic manifestations. [9,10] The overall life-time risk for developing an inflammatory RMD including rheumatoid arthritis, gout, lupus and others for an adult in the US has been calculated as 1 in 12 for females, and 1 in 20 for males. [11] Many RMDs are uncommon or rare, which contributes to the lack of familiarity and/or experience with many RMDs on the part of general practitioners. RMDs frequently affect joints resulting in arthritis, but also frequently involve other internal organs and the skin. Although arthritis is commonly considered as a disease of aging, many RMDs – including many that cause disabling arthritis – occur in children. Lack of awareness of these conditions in both children and adults can lead to excessive and unnecessary damage and disability. [12-15]

There are various pathophysiological pathways of RMDs.

Review of these many diseases and conditions indicate that they develop through a diverse range of pathogenic pathways, most of which are not completely understood. Many result from dysregulation and activation of immune mechanisms that lead to inflammation and tissue damage. Some of these are classified as autoimmune diseases. Other RMDs result from acute or chronic damage to musculoskeletal structures including bone, cartilage, muscle, tendon, ligament and blood vessels. Other primary metabolic, endocrine, neurologic and infectious diseases can lead to secondary dysfunction and damage of musculoskeletal tissue. For example, prolonged hyperglycaemia in diabetes can result in changes in the structure of tendons and other soft tissues resulting in impaired mobility and joint function. The metabolic changes of the iron-storage disease hemochromatosis can result in degenerative arthritis in the hands. In addition, an increasing number of genetic variations and mutations are associated with the development of RMDs.

RMDs result in a major burden for both the individual and society.

Many of the diseases are chronic and as they can start as early as during childhood (e.g. juvenile idiopathic arthritis) or young adulthood (e.g. spondyloarthritis), patients suffer with

their disease for decades. Moreover, most RMDs worsen over time with increasing impact on both the physical and psychological condition of the patient. Some patients die prematurely as a result of the condition or co-morbidities, although if appropriately treated, mortality is relatively low in most of these conditions.

Large population studies emphasize that RMDs are highly prevalent worldwide. The eumusc.net project is a collaboration of 22 organizations in 17 member states of the EU investigating musculoskeletal health in Europe. [16] Their report summarizes the epidemiology of major RMDs, impact on the individual and society, and management and health services utilization. They concluded that musculoskeletal problems are the most common cause of severe long-term pain and disability in the EU and lead to significant healthcare and social support costs. Moreover, RMDs are a major cause of loss of work productivity resulting in significant economic costs and may have serious impact on quality of life, affecting those with the conditions and their relatives.

Musculoskeletal pain is prevalent in the EU with just over one-fifth (22%) of the population reporting current or long-term muscle, bone and joint problems in a survey performed by the European Union in 2007. [17] Exactly a quarter of all EU respondents say that at some point in their life they have experienced chronic (lasting for at least 3 months) restrictive pain affecting muscles, joints, neck or back which affected their ability to carry out activities of daily living. Such pain is reported more by women than by men (28% vs. 22%). Musculoskeletal pain is the second most common complaint underlying long-term treatment attributing to major health care costs. [17]. Twenty four percent of the respondents to the survey received long-term treatment for RMDs (second after hypertension with 36% of respondents). It is likely that the overall burden of arthritis is underestimated in virtually every population. A recent study from the US. using national data from a health interview survey and doctor-diagnosed arthritis and symptoms revealed that arthritis affected 91.2 million (36.8%) of the adult population, including about 29% of men and 55% of women between the ages of 18 and 65. [18]

RMDs are the most frequent reason among non-infectious diseases to consult the primary care physician in the UK in 2003, and this is increasing with age and higher in female patients in all age categories. [16] In Germany 11.2% of the total cost of illness in 2008 were spent on musculoskeletal and connective tissue diseases. [16]. These numbers appear to be rapidly increasing. For example, a recent report provides data on doctor-diagnosed osteoarthritis in

the US between 2013 and 2015. [19] A total of 54.4 million Americans (22.7%) had doctor-diagnosed osteoarthritis and this percentage was even higher among adults with heart disease (49.3%), diabetes (47.1%) and obesity (30.6%). In 2012, 54% of people in the U.S over age 18 reported suffering a musculoskeletal problem and the prevalence approached 75% for those aged 65 and older (BMUSUS)[20]. Several factors have an impact on the prevalence of RMDs, including gender, age, BMI and physical activity. As the population is aging this has a major impact on the prevalence of RMDs. For example, the EU will have 58 million more people aged 65 and over in 2050 in comparison to 2004. [16]. Similarly, obesity is increasing, which again will lead to a higher prevalence of RMDs. [16]

RMDs have led to significant reduction in function and quality of life as well as increased disability. Among those with osteoarthritis, 43.5% of the adults experienced limitations in activity attributable to osteoarthritis, and there was a significant increase of 20% in the proportion of adults reporting these limitations since 2002. The Disability Adjusted Life Year (DALY) is a measure to compare impact of various diseases on disability and can be interpreted as the loss of 1 year of healthy life. The World Health Organization (WHO listed osteoarthritis as the 8th leading cause of impact measured by DALYs in their report on global burden of disease. [21] Another way of assessing the impact on disability is the Years Lived with Disability (YLD). The WHO listed Musculoskeletal diseases as the third cause for disability among non-communicable diseases assessed by YLDs. And among musculoskeletal diseases, osteoarthritis was the most common disease followed by RA, 'other musculoskeletal diseases' and gout. [22]. As common and impactful as musculoskeletal diseases are, such surveys do not always include the entire range of RMDs. This further underscores the high prevalence and cost of these conditions and emphasizes the need for a unifying definition of RMD. An example of defining the global burden of 'other musculoskeletal disorders' was presented in a large study in 2010. [23,24]

The International Quality of Life Assessment project examined the effect of multiple chronic conditions on populations in Denmark, France, Germany, Italy, Japan, the Netherlands, Norway and the US using the SF-36. This showed that arthritis, chronic lung disease and congestive heart failure were the conditions with the highest impact on SF-36 physical summary score. RA had a significant negative effect on the SF36 mental summary score. Arthritis had the highest impact on health-related quality of life in the general population [25]. A large survey study in the Netherlands which compared health related quality of life

(using SF-36 or SF-24) across a wide range of long term conditions found that people with musculoskeletal conditions (included are back impairments, RA, osteoarthritis/other joint complaints) reported the lowest levels of physical functioning, role functioning and pain. [26]

A Spanish study found that rheumatic diseases are among the diseases that produce the largest impairment in Health-Related Quality of Life (HRQoL) and daily functioning. [27]

When the definition of the burden of disease includes a measure of function and of HRQoL that is weighted by the prevalence of disease, RMDs, as a group, may be considered on a par with other major diseases such as neurological, cardiac, or pulmonary diseases. [16]

For many of the RMDs, it is important to recognize the disease early to have the best option to start treatment early and prevent or limit long-term consequences. To achieve this, EULAR has started the awareness campaign 'Don't delay, connect today'. The best example is rheumatoid arthritis. Early diagnosis, improved treatment options and applying treat to target principles has not only improved the percentage of patients in (sustained) remission, but also improved quality of life and work productivity. [28,29] Even overall excess mortality in patients with rheumatoid arthritis in comparison to the general population, which was apparent in previous decades, is lower and even no longer present when diagnosed and treated early and intensively. [30,31]

Cause specific morbidities, such as cardiovascular disease, are greater in many of the RMDs, and may also be declining with improved disease management. [32]

Workforce taking care of patients with RMDs

A range of practitioners manage musculoskeletal problems. These include medical specialists, general practitioners, community pharmacists, physical therapists (physiotherapists, chiropractors), occupational therapists, and behavioural therapists (counsellors, psychologists and social workers). Rheumatologists, including pediatric rheumatologists, are the specialists with the most broad and specific training for diagnosing and treating RMDs. Rheumatology specialty training standardized by EUMS across the EU and the Accreditation Council for Graduate Medical Education (ACGME) in the U.S. requires proficiency in general internal medicine followed by detailed training in the pathogenesis, diagnosis and management of the entire range of RMDs. [1,2]

The number of practicing rheumatologists varies widely. The average number of rheumatologists in EU is 1.7 per 100.000 inhabitants, ranging from 0.5 in Ireland to 4.2 in France. [16]. Similarly, in the U.S. the number of rheumatologists ranges from greater than 2 per 100,000 in heavily populated regions to less than 1.5 per 1000,000 in more rural regions. [30] However, due to a variety of factors affecting physician workforce, including the increasing prevalence of RMDs, these numbers are changing rapidly. For example, recent workforce projections in the U.S. estimate that by 2025 the average number of rheumatologists in the large majority of the country will be 0.5 - 1.0 per 100, 000 inhabitants. [33] There is also a severe shortage of pediatric rheumatologists as substantiated by a survey in the US. [34] Other specialists caring for patients with RMDs are orthopedic surgeons, internists and rehabilitation specialists. There is also a wide variation in the workforce of allied health professionals. The number of physiotherapists varies enormously across EU countries from 34 in Ireland to 234 per 100.000 inhabitants in Finland. [16] Similarly, the variation in occupational therapists ranges from 2 in Italy to 100 per 100.000 inhabitants in Sweden and Denmark. [16] In contrast, in the US there were about 114,600 occupational therapy jobs listed in 2014 for a population of close to 318,500,000 (360 per 100.000). [35]

Based on the above data and considerations, the following common language description of RMDs was endorsed by both EULAR and ACR.

Rheumatic and musculoskeletal diseases (RMDs) are a diverse group of diseases that commonly affect the joints, but can affect any organ of the body. There are more than 200 different RMDs, affecting both children and adults. They are usually caused by problems of the immune system, inflammation, infections or gradual deterioration of joints, muscles and bones. Many of these diseases are long term and worsen over time. They are typically painful and limit function. In severe cases, RMDs can result in significant disability, having a major impact on both quality of life and life expectancy.

Summary

The description of RMDs is a succinct statement in common language detailing many of the important aspects of these conditions. Given the prevalence and impact of RMDs as well as the availability of effective management options, it is important to be able to communicate clearly what RMDs are with the public and stakeholders. It is especially imperative to communicate the impact and importance of RMDs to healthcare policy makers.
The many unanswered questions about the causes of RMDs, the importance of improved diagnosis for RMDs and clear need for effective and safe treatments that are unavailable for many of these diseases emphasize the importance of increased research on RMDs. At the same time, the fact that many recent advances have been made in developing new therapies for RMDs so that many people are now treated very effectively – with prevention of disability and comorbidity – emphasizes how critical it is that patients have ready access to diagnosis and care for these conditions. We hope that the description of RMDs provided in this manuscript will enable improved communication about and advocacy for these conditions and the patients who suffer from them.

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