Restless Legs Syndrome: Increase disease awareness to reduce patient suffering and reduce societal cost

Jaarsma J1, Dauvilliers Y2, Ferri R3, Rijsman R4, Sakkas GK5, Guldemond N6, Trenkwalder C7 and Oertel W8

1European Alliance for Restless Legs Syndrome (EARLS); 2Gui-de-Chauliac Hospital; 3Oasi Research Institute (IRCCS); 4Center for Sleep and Wake disorders, Haaglanden MC; 5Plymouth Marjon University; 6The Institute of Health Policy & Management (iBMG), Erasmus University; 7Paracelsus Elena Klinik and Goettingen University; 8European Academy of Neurology (EAN)

Background

Restless Legs Syndrome (RLS) (or Willis/Bibbon Disease – WBD) is a common neurological disease which is often unrecognized or misdiagnosed. 2.7% of the European population suffer from moderate to severe RLS: an uncontrollable urge to move the legs due to highly unpleasant pain-like sensations, leading to chronic sleep deprivation [1]. Wrong diagnoses and wrong treatments occur due to lack of knowledge and expertise at both the primary and secondary care levels, and as a consequence wrong routing of the patient. As a result RLS patients often have to wait many years before getting a correct diagnosis. Access to appropriate RLS care is not generally available across Europe. RLS cannot be cured, medicines are available and provide symptom suppression only. Side effects of the medicines of first choice have created new and serious problems. In this study the authors describe the patient’s journey through the healthcare systems in three countries (DE, FR, IT) and describe the barriers to optimal treatment and the unmet needs of patients.

Methods

The RLS care pathway was mapped in order to identify the unmet needs of patients as well as the underlying causal factors. Which are the barriers to optimal treatment? A case study including all possible aspects of the typical RLS patient was written, an extensive literature search on RLS and its treatment was done, a working group was formed. The group set out to identify the typical stages in the patient journey. Diagnostic delay, access to good care, the cost of non-treatment, sick leave, loss of income/job, proportion of drug resistant patients, awareness of RLS among medical professionals, (lack of) available medicines and – importantly – incorrect application and dosages, that cause adverse reactions thereof, possible prevention, screening/prodroma, early intervention, and overall disease management were all mapped. Based on the data thus gathered and the stories of three hypothetical patients, each in the three countries studied (DE, FR, IT), the cost differences between adequate and inadequate treatment could be calculated, and the burden of the lack of awareness and the resulting societal cost unveiled.

Treatment Gaps & Unmet Needs

- There is a huge lack of awareness and knowledge of Restless Legs Syndrome. As a result patients are not taken seriously, wrong diagnoses are made and false treatments are given
- The knowledge among in particular primary care physicians leaves much to be desired, referrals to specialists are often not done, resulting in delayed or false diagnoses and either no or wrong treatment
- Medicines for RLS do exist: treatment of first choice to date are the dopamine agonists. Adverse reactions if applied incorrectly to these drugs in RLS patients are frequent, the most severe adverse reaction being the paradoxical phenomenon called augmentation
- Augmentation is a severe adverse reaction of the dopamine agonists in RLS. With high doses RLS symptoms become much worse and spread over the entire body during many hours per day.
- A significant aspect of augmentation is often a misinterpretation of this phenomenon: when symptoms get worse, the doctor will assume loss of efficacy and increase the dosage. This results in even more severe augmentation. More is not better in RLS treatment!
- Due to this a drug holiday is often advised, an almost impossible journey for the patient due to extreme withdrawal symptoms and no sleep for many days.
- The number of truly knowledgeable RLS specialists in Europe is very limited to non-existing in some countries
- Due to lack of awareness medicines are not reimbursed for RLS in many countries
- All available medicines were registered for other diseases in the first place, there is no systematic pharmacological research for RLS per se.

Recommendations

Policies aiming to increase disease awareness and recognition among primary care physicians and specialists would allow patients to receive adequate treatment and alleviate their suffering. Thus:

- Include RLS disease in general medical education across all of Europe
- Improve access to information
- Increase research budgets
- Support patient organisations

Conclusions

Restless Legs Syndrome (RLS) is a chronic progressive sleep-motor pain disorder of still unknown cause. Despite its high prevalence, awareness for RLS in the population is low. Patients often wait for years before a correct diagnosis is made and thus receive inadequate therapy. Effective symptomatic therapy for RLS is available, but its long term use carries the risk to even augment the symptoms. Thus education about RLS is urgently needed to increase expertise of healthcare professionals on how to diagnose and manage RLS. Equally important the search into the cause(s) of RLS and for new treatment strategies have to be intensified in order to reduce the suffering of people with RLS and to reduce the substantial societal costs.

References:


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Acknowledgements:

Restless legs syndrome (RLS) is one of the most common neurological disorders. Adult prevalence of RLS in European population is about 2.7%, with women affected twice as often as men [1]. The key characteristics of RLS, including severe sleep disorders, restlessness in the evening and discomfort while at rest, have substantial impact on normal daily activities and lives of sufferers and their families. Given its high prevalence in the general population and how it affects their lives, it is necessary to evaluate the socio-economic impact of RLS and the inadequate RLS treatment across different EU healthcare systems.

Methods

Socio economic impact of RLS

The economic burden of RLS was estimated for the first time across EU settings using the framework adopted by the EBC in “The economic impact of non-communicable diseases in Europe, 2010” [2] in three separate healthcare systems: France, Germany and Italy as examples of EU nations with different healthcare systems with regard to delivery of services, financing and coverage. Epidemiological and cost data were derived from the literature [1-4]. The estimates included health care costs as well as indirect costs to society, such as lost productivity due to reduced ability to work or to work of full capacity.

Socio economic impact of inadequate RLS treatment

RLS patients often receive no or a delayed diagnosis and this prevents them from timely and adequate access to treatment, resulting in poor clinical outcome and increased healthcare and societal costs. In this economic analysis, we calculated the cost difference between adequate and inadequate treatment in three typical RLS cases, depicting the story of three hypothetical patients (see box below). A panel of experts from the three countries was consulted and asked to create the three case studies, gather their personal data on the use of resources in the different scenarios as well as provide source of unit cost from their local country public tariff (when available) and their personal data. For each of the three scenarios two alternative were compared, including baseline scenario (i.e. delayed diagnosis, insufficient response and augmentation) vs. their respective target adequate RLS treatment. Timeframe varied according to the personal life story described in the three case studies. Cost included those for the one person described in the case study and covered those incurred by the health care provider or society pending on the individual cases. Discount rate of 3.5% was applied as appropriate.

References:


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