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Editorial

Restless legs syndrome: the most common and least diagnosed sleep disorder

The paper by Dr van de Vijver and colleagues [1] reconfirms that most individuals with RLS symptoms are not diagnosed and treated. In this paper, the rate of RLS diagnosis was a quarter of one percent of all patients seen in a 5-year period. Previous studies on a variety of European and European-derived populations have consistently found that the prevalence of moderately frequent RLS symptoms is at least 5% [2–6]. Other studies, including a number of annual surveys by the National Sleep Foundation, have found that relatively few individuals with RLS symptoms have been diagnosed. In a recent study of five Western countries, it was found that the large majority of those with frequent (more than twice a week) and distressing symptoms who had also complained of these symptoms to their physicians still had not been given a diagnosis of RLS [6]. In an ongoing study at Johns Hopkins, we have been doing blind interviews of relatives of RLS patients. More than half of those with RLS report symptoms at least weekly [7]. Despite this fact, only one-tenth are receiving any form of appropriate treatment and many of those are only taking over-the-counter analgesics. This group, with treated RLS relatives, should be one that is exceptionally knowledgeable about the condition. As suggested by Dr van de Vijver's paper and other results, many RLS patients receive inappropriate diagnoses and treatments [1,6]. Since frequent RLS can have a quite significant impact on quality of life [5,8], this failure to diagnose and appropriately treat the condition is a major deficiency of current medical practice. Because RLS, like other common sleep complaints, usually presents first to the primary care practitioners, these generalists need to be familiar with the condition, even if they only refer patients for specialty management. It is clear that, as of today, many generalists, not to mention many specialists such as Neurologists or Pulmonologists, do not have sufficient ability to recognize RLS. They may not think of RLS when patients present with an insomnia complaint. Until awareness increases, RLS sufferers will continue to find that their symptoms are not being addressed.

However, there are some hopeful signs. Professional interest in RLS among specialists, and even some generalists, has increased logarithmically in the past decade.

Annual publications on RLS have increased from a handful to many dozens annually and the RLS foundation has increased awareness many-fold among the lay public. The development of approved medications for RLS-as has already happened in Central Europe [6]—is likely to facilitate recommended treatment [9–11]. Even in van de Vijver's paper, there are encouraging signs. While the group of physicians participating in the General Practice Research Database is likely to be an elite and knowledgeable group, even 5 years ago (when the paper's survey ended), almost all of the practices (94%) had made at least one diagnosis of RLS. This survey also does not cover the most recent period and it is likely that the frequency of RLS would have increased in the current period. It can be hoped that this degree of recognition will now extend to smaller or less elite practices. Since RLS presents so commonly to primary practices [12] and can be readily treated [9–11], it should be quite rewarding for generalists to include surveillance and management of RLS in their practices. To expedite this result, it will be important for those in the Sleep Medicine community to include RLS as a key element of their educational efforts for generalists and the lay public.

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