

Restless Leg Syndrome Across the Globe

Epidemiology of the Restless Legs Syndrome/Willis-Ekbom Disease



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KEYWORDS

• Restless legs syndrome • RLS • Epidemiology • World • Willis-Ekbom disease

KEY POINTS

- There are more than 50 epidemiologic studies measuring restless legs syndrome (RLS)/Willis-Ekbom disease (WED) prevalence across 5 of the 6 inhabited continents (not Australia), most conducted in North America and Europe.
- There is historical precedent for the large number of studies that have been conducted in Europe, especially in Scandinavia.
- Limitations when comparing prevalence across these studies are related to use of various ascertainment methods and differing RLS/WED criteria.
- Sufficient studies have been conducted in Asia, North America, and Europe to make inferences on RLS/WED prevalence by region.
- RLS/WED prevalence is thought to be highest in North America and Europe with most estimates ranging from 5.5% to 11.6% and lower in Asia with most estimates ranging from 1.0% to 7.5%.
- These differences across regions may be explained by cultural, environmental, and genetic factors.
- Future investigation is needed to determine to what extent each of these different factors affects expression of RLS/WED according to world region.

BACKGROUND

The restless legs syndrome, recently renamed Willis-Ekbom Disease (RLS/WED), is a neurologic condition that consists of an inexorable urge to move the legs in the evening and nighttime, when rest is most desired. The first widely accepted historical account of RLS/WED originated from London, England, in 1685 and was described by Sir Thomas Willis, after whom the first half of the disorder is named.¹ The first truly convincing published account of RLS may have

actually come before these writings in the ancient Chinese book of *Neike Zhajiyao* (Internal summary), written by Xue Ji in 1529.² It was not until several centuries later in the 1940s that RLS/WED was described and studied in detail in Upsala, Sweden, by Karl Ekbom, after whom the latter half of the disorder is named.³ In modern times, investigation of RLS/WED has primarily been conducted in North America and Europe. It is clear from this history of description and research that RLS/WED is a condition that affects persons around the world

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with diverse ethnic, cultural, and genetic backgrounds.

RLS/WED is common, and the epidemiology, namely, prevalence, of this disorder has been studied in persons living on 5 of the 6 inhabited continents (not Australia).^{4–8} This article outlines the world epidemiology of RLS/WED. To do this, different epidemiologic studies of RLS/WED carried out in community populations are reviewed by continent. Following this epidemiologic summary, genetic variation in RLS and how this may affect global RLS expression are discussed. Studies that have specifically focused on the question of ethnic variability in RLS are reviewed. Finally, the many factors other than genetic, ethnic, and geographic that could affect RLS prevalence are discussed. Briefly, these factors include differing RLS/WED definitions used over the years, varying methodology used to diagnose RLS/WED, and cultural aspects of disease perception.

RESTLESS LEGS SYNDROME/WILLIS-EKBOM DISEASE CRITERIA

Properly designed epidemiologic studies that aimed to determine the prevalence of RLS/WED used the accepted diagnostic criteria at the time of the study. RLS/WED diagnostic criteria have undergone different revisions over the years, and thus, before moving on to describe different epidemiologic studies of RLS/WED, it is important to provide an overview of some of these changes. RLS/WED was first officially defined by the International RLS Study Group in 1995, including 4 minimal criteria for diagnosis: (1) a desire to move the extremities, often associated with paresthesias/dysesthesias; (2) motor restlessness; (3) worsening of symptoms at rest with at least temporary relief by activity; and (4) worsening of symptoms in the evening or night.⁹ In 2003, these criteria were revised with some changes in wording; the criterion of motor restlessness was removed, and the previous criterion (3) was separated into 2 criteria so that the final criteria included (1) an urge to move the legs, usually accompanied by uncomfortable sensations in the legs, (2) the urge to move or unpleasant sensations begin or worsen during periods of rest or inactivity, (3) the urge to move or unpleasant sensations are partially or completely relieved by movement, and (4) worsening of symptoms in the evening or night.¹⁰

Again in 2014, RLS/WED criteria were amended. The 4 criteria outlined in 2003 were kept, but a fifth criterion of differential diagnosis was added. In addition, specifiers were added to delineate clinically significant RLS/WED and to classify RLS/WED as chronic-persistent or intermittent.¹¹

It should also be noted that RLS/WED diagnostic criteria were published by 3 different organizations: the American Academy of Sleep Medicine, the American Psychiatric Association, and the International Restless Legs Syndrome Study Group (IRLSSG); luckily the criteria were similar for all groups.^{11–13}

All of these studies, discussed in this monograph, were conducted before the release of the various 2014 criteria and used criteria that were current at the time each study was conducted. Each of the studies is described in **Table 1**, including location, year of publication, ages included, numbers, criteria used, number of questions used, prevalence, and important notes.

AFRICA

There have been only 2 studies that have examined the prevalence of RLS/WED in regions of Africa. These studies were conducted in Tanzania, a 2010 study in a rural area and a 2014 study in an urban area.^{5,14} Both studies modeled questions based on the four 2007 IRLSSG criteria and translated these questions into Kiswahili and then back to English to ensure accuracy. Prevalence estimates were low, partly because of the 2-phase screening approach: first questionnaire screening and, if positive, then an interview and examination by a neurologist. In the 2010 study, only 10 of 7654 persons screened positive and only 1 person was thought to have RLS by physician interview, yielding a screening RLS/WED prevalence of 0.11% and actual prevalence of 0.013%. In the 2014 study, only 156 of 28,606 persons screened positive for RLS/WED and there were only 10 confirmed cases of RLS/WED, which yielded a screening prevalence of 0.55% and an actual RLS/WED prevalence of 0.037%.

ASIA

Studies to determine RLS prevalence in Asia have been conducted in South Korea, Taiwan, Japan, Singapore, China, Saudi Arabia, and India. Most studies to measure RLS prevalence were carried out in South Korea. There was a wide range of RLS prevalence in different South Korean studies, varying from 0.9% to 12.1%.^{6,15–18} This wide prevalence variation likely is attributable to the ranging stringency in criteria used to define RLS/WED. For example, in the study finding 12.1% prevalence, RLS/WED was considered if there was an affirmative answer to only 1 question: “Have you ever experienced an urge to move your legs or unpleasant sensations like creepy-crawling feelings in your legs before sleep?”,¹⁷ whereas studies that

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