

What patients do to counteract the symptoms of Willis-Ekbom disease (RLS/WED): Effect of gender and severity of illness

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Abstract

Objectives: This study was carried out to assess different counteracting strategies used by patients with idiopathic Willis-Ekbom disease (RLS/WED). Whether these strategies were influenced by gender or disease severity was also assessed. **Materials and Methods:** A total of 173 patients of idiopathic RLS/WED were included in this study. Their demographic data was recorded. Details regarding the RLS/WED and strategies that they used to counteract the symptoms were asked. The severity of RLS/WED was measured with the help of the Hindi version of international restless legs syndrome severity rating scale. They were asked to provide the details regarding the relief obtained from all the strategies they used on three-point scale: no relief, some relief, and complete relief. **Results:** Of the patients, 72% were females. Mean age of the subjects in this study was 39.6 ± 12.6 years, and male subjects were older than females. Four common strategies were reported by the patients to counter the sensations of RLS/WED: moving legs while in bed (85.5%), asking somebody to massage their legs or massaging legs themselves (76.9%), walking (53.2%), and tying a cloth/rope tightly on the legs (39.3%). Of all the patients who moved their legs, 6.7% did not experience any relief, 64.2% reported some relief, and 28.4% reported complete relief. Similarly, of all the patients who used "walking" to counteract symptoms, 50% reported complete relief, 44.5% reported some relief, and the rest did not experience any relief. Many of these patients reported that massage and tying a cloth/rope on legs brought greater relief than any of these strategies. Tying cloth on the leg was more common among females as compared to males (45.9% females vs. 23.5% males; $\chi^2 = 7.54$; $P = 0.006$), while patients with moderately severe to severe RLS/WED reported "moving legs in bed" (79.3% in mild to moderate RLS/WED; 91.8% in severe to very severe RLS; $\chi^2 = 5.36$; $P = 0.02$). **Conclusion:** Patients with RLS/WED use a variety of strategies to counteract symptoms. These strategies may be influenced by gender, disease severity, and cultural practices.

Key Words

Counter-acting strategies, gender, severity, Willis-Ekbom disease (RLS/WED)

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Introduction

Willis-Ekbom disease (RLS/WED) is characterized by an urge to move legs often accompanied by abnormal sensations in the legs, appearance of symptoms during periods of rest or inactivity, partial or complete improvement by walking or moving legs, and evening onset or worsening of symptoms.^[1,2]

People with RLS/WED have an irresistible urge to move their legs, and some of them start walking when the symptoms become intolerable.^[3]

Treatment strategies for the RLS/WED can be divided into pharmacotherapy and non-pharmacological methods of dealing with the RLS/WED. American Academy of Sleep Medicine had proposed the guidelines for the pharmacotherapy recently and recommended that dopaminergic drugs and gabapentin enacarbil can be used to improve the symptoms of RLS/WED.^[4] Apart from these, non-pharmacological management has also been reported to be effective and includes pneumatic compression and massage among other therapies.^[5,6] In addition, hot-bathing and applying ice and heat-pad have also been advised as treatment of RLS/WED.^[6]

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Patients with RLS/WED may themselves adopt non-pharmacological strategies to counteract their symptoms, e.g., moving legs, stretching, and walking. Among these, walking and stretching have been included in the revised diagnostic criteria of RLS/WED.^[7] There are fair chances that these measures may differ across genders as it is already known that gender may influence the presentation of RLS/WED.^[8] In addition, our clinical experience suggests that these strategies are affected by the severity of RLS/WED. However, we could not find any study that had systemically examined this issue. This information can help us in delineating the disorder with more clarity, understanding its pathophysiology, and developing non-pharmacological measures to counteract the symptoms, especially for patients with chronic intermittent RLS/WED. Hence, the present study was planned to specifically

1. Assess the strategies adopted by the patients to counteract the symptoms of RLS/WED;
2. To measure the improvement in RLS/WED from each of these measures;
3. And to compare the relief obtained by each of these strategies.

In addition, we also examined the influence of gender and severity of RLS/WED on these measures.

Materials and Methods

This study was conducted in the out-patient department of Sleep Clinic in a teaching hospital from June 2011 to December 2012 after obtaining permission from institutional ethics committee. All patients diagnosed with RLS/WED according to standard criteria were requested to participate in this study.^[1] The rationale of the study was explained to them and informed consent was obtained. Subjects having rheumatoid arthritis, edema in the limbs, peripheral neuropathy, chronic kidney disease, varicose veins, sciatica, and myalgia and those consuming opiates or opioids, dopaminergic drugs, antidepressants, and neuroleptic medications were excluded based on history, general physical, and neurological examinations. Subjects below 18 years of age and pregnant females were not included. Subjects with epilepsy, stroke, Parkinson's disease, and dementia were also excluded. Care was also taken to exclude subjects having nocturnal leg cramps, habitual leg movement, burning feet syndrome, and positional discomfort. None of the patients was earlier diagnosed with RLS/WED.

Their demographic data was recorded. Diagnosis of RLS/WED was made upon the history following standard RLS/WED criteria.^[1] During the course of interview, subjects were specifically asked what they usually did to counteract the urge to move legs or when they had abnormal sensations in the legs. This was an open-ended question, and all responses provided by the patients were recorded. Once they finished, we asked them, "Did you ever do anything else too, that brought the slightest relief in your symptoms?"

Since "moving legs" and "walking" have been described in standard criteria as common response to RLS/WED symptoms, they were encouraged to assess the amount of relief that they had obtained with each of these strategies on a three points scale — "no relief", "some relief" and "complete relief". Then

they were asked to compare the relief in the symptoms of RLS/WED with each of the strategies that they had adopted.

Severity of RLS/WED was measured with the help of the Hindi version of International Restless Legs Syndrome Severity Rating Scale.^[9,10] Based on the IRLSSG score, the whole sample was categorized in two groups: those with mild to moderate RLS/WED (Group A) and subjects with severe to very severe RLS/WED (Group B). Family history of RLS/WED was also noted.

Statistical Analysis

Statistical analysis was performed using the SPSS software 17.0 (Chicago, IL, USA). Descriptive statistics was calculated. To compare proportions, Chi-square test was used.

Results

A total of 191 patients with idiopathic RLS/WED were requested to participate in this study. Of these, 18 patients did not want to enroll in this study. Hence, the data of 173 patients of RLS/WED was analyzed. Of these, 122 (70.5%) were females. Average age of the subjects in this study was 39.6 ± 12.6 years and male subjects were older than females (Male: mean 42.6 years (range: 19-67 years); Female: 38.4 years (range: 19-65 years)). Of 173 patients, 125 (72.3%) patients reported RLS/WED symptoms during the day in addition to nighttime symptoms, and 76 (43.9%) subjects mentioned that their symptoms used to aggravate with more than usual physical activity during the evening.

Four common strategies were reported by the patients to counter the sensations of RLS/WED: moving legs while in bed (148; 85.5%), asking somebody to massage their legs or massaging legs themselves (133; 76.9%), walking (92; 53.2%), and tying a cloth/rope tightly on the legs (68; 39.3%). In addition, three subjects reported that dipping feet in cold water or applying ice over calves brought some relief. All subjects were using more than one strategy [Figure 1].

When we asked for the extent of relief with these strategies, patients gave varied responses. Of all the patients who moved

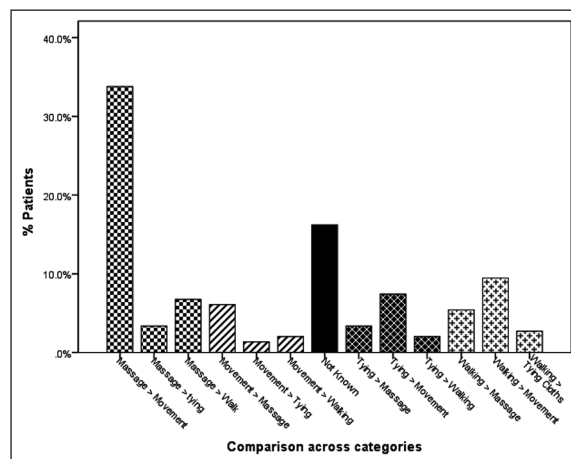


Figure 1: Comparison of relief obtained across different strategies in the study sample

legs, 11 (6.7%) did not experience any relief, 103 (64.2%) reported some relief, and 46 (28.4%) reported complete relief. Similarly, of all the patients who used “walking” to counteract symptoms, 58 (50%) reported complete relief, 52 (44.5%) reported some relief, and the rest did not experience any relief. Figure 1 depicts the comparison of relief obtained by these strategies. Many of the patients reported that massage and tying a cloth/rope on legs brought greater relief than walking or moving legs. The subjects could not provide a reliable response whether these strategies brought more relief in the sensory or motor part of WED/RLS instead they reported “simply relief in symptoms”.

When we examined the difference in these strategies between genders, we found that tying cloth on the leg was more common among females as compared to males; 56 females (45.9%) vs. 12 males (23.5%); $\chi^2 = 7.54$; $P = 0.006$. However, we did not find any difference with regards to other strategies between genders. Walking was reported by 26 males (51%) and 66 females (54.1%); moving legs in bed by 42 males (82.4%) and 106 females (86.9%); massaging legs by 39 males (76.5%) and 94 females (77%).

We further examined whether the strategies differ between two groups based on the severity of RLS/WED. Frequency of “walking” (Group A: 41 (47.1%); Group B: 50 (58.8%); $\chi^2 = 2.36$; $P = 0.12$), “massaging the limbs” (Group A: 68 (78.2%); Group B: 64 (75.3%); $\chi^2 = 0.19$; $P = 0.65$), and “tying cloths on the legs” (Group A: 38 (43.7%); Group B: 30 (35.3%); $\chi^2 = 1.26$; $P = 0.26$) was comparable across groups. However, a higher proportion in Group B reported moving legs in bed (Group A: 69 (79.3%); Group B: 78 (91.8%); $\chi^2 = 5.36$; $P = 0.02$).

Table 1 compares the relief obtained by “walking” and “moving legs” with respects to gender and severity of RLS/WED.

Discussion

This study suggests that patients with RLS/WED adopt a variety of measures to counteract the symptoms. There was a difference in the counteractive strategies based on gender and severity of illness, where women tied cloth on their legs more commonly than men, and those with severe disease used

to “move legs” in bed. These strategies could be the natural responses of the patients or could be an acquired behavior with physiological underpinnings.

All of our patients reported relief with deep massage and none with light or superficial massage. It was done in one of the two ways: (i) to and fro between ankle and knee placing the palm over skin and giving a deep rub or (ii) pressing the muscles with hand between knee and ankle that lead to sequential compression of the calf muscles. A number of non-pharmacological measures have been proposed earlier and were found effective in a both idiopathic and secondary RLS/WED. Massage has been reported to be effective in management of RLS/WED.^[5] Massage can help in amelioration of RLS/WED through a number of different ways — by increasing vascular or lymphatic flow, gating the sensations at the spinal level, or by increasing the opioids in the brain.^[5] Similarly, sequential pneumatic compression devices have been found effective for the treatment of RLS/WED, which worked on the principles of the massage therapy, as mentioned above.^[11,12] We would like to mention here that most of the patients asked their family members to massage the legs, particularly the younger ones. It is still a practice in many of the Indian families that younger members of the family give a deep massage to the legs of the elders at bedtime. This could be one reason why RLS/WED remains underreported in Indian culture.^[13]

Most of the women tied a cloth/rope on their legs and it provided a deep continuous compression. Female preponderance in this group could be related to social structure as India follows a patriarchal social culture. Tying the rope/cloth on the legs was tight enough to prevent the blood flow in the veins and could lead to venous stasis. Relief in RLS/WED symptoms with this measure suggests that lymphatic or venous stasis may not cause RLS/WED as suggested by some of the earlier papers.^[5] However, this measure will exert a continuous pressure and can help in gating of the sensations at spinal level. A number of studies have shown that RLS/WED patients have increased excitability of spinal neurons and/or diminished supraspinal inhibition, although data is inconclusive.^[14-16] Pressure has been found to reduce the excitability of spinal neurons in a dose-dependent manner, and this could be one reason why a number of subjects found “tying a cloth” provided more relief as compared to the other strategies like massage.^[17]

Walking and moving legs in bed were the other common strategies seen in this group of patients. Walking and moving legs activate the muscle which can increase the blood flow and reduce the stasis of blood and lymph in calf muscles, thus they were expected to improve the symptoms of RLS/WED.^[5] Moreover, walking has been found to modulate the H reflex, which is a measure of spinal neuronal excitability.^[18] Spinal neuronal excitability has been found to be modulated by dopaminergic neurons of the hypothalamus in RLS/WED patients.^[19] This could be one reason why moving legs, walking, and dopaminergic drugs all relieve the symptoms of RLS/WED. We found that patients with severe to very severe illness reported moving legs in bed more frequently as compared to other group. Is it just the manifestation of illness or a response to relieve the symptoms is not known? It is also not known whether RLS/WED in different severities is pathophysiologically different. Further research is required in this area.

Table 1: Relief obtained by different strategies to counteract Willis-Ekbom disease (RLS/WED)

Strategy	No relief (%)	Some relief (%)	Complete relief (%)	P
Walking (N = 92)				
Male	2 (7.7)	11 (42.3)	13 (50)	0.82
Female	3 (4.5)	30 (45.5)	33 (50)	
Group A	1 (2.4)	10 (24.4)	30 (73.2)	<0.001
Group B	4 (8)	30 (60)	16 (32)	
Moving legs in bed (N = 148)				
Male	5 (11.9)	23 (54.8)	14 (33.3)	0.26
Female	5 (4.7)	72 (67.9)	28 (26.4)	
Group A	7 (10.1)	39 (56.5)	23 (33.3)	0.16
Group B	3 (3.8)	55 (70.5)	19 (24.4)	

Group A = Mild to moderately severe RLS, Group B = Severe to Very severe RLS

Utilization of these strategies had shown that perhaps RLS/WED is a neuronal problem and counter-strategies provide the sensory gating to reduce the sensations as one of the strategies, “tying cloths”, does not favor the vascular hypothesis. However, these strategies do not indicate whether this disorder primarily reflects problem in central nervous system or peripheral nervous system.

However, this study had some methodological limitations. First, all the data was gathered on the retrospective information; hence, the possibility of recall bias could not be excluded. Second, we asked to quantify the improvement regarding only two strategies. These issues should be addressed in future studies. However, this was the first systematic examination of counter strategies among RLS/WED patients and had shown that cultural practices, severity of illness, and gender modulate them. Such type of data can be important in understanding the presentation of illness across different cultures and while developing the rating scales for RLS/WED.

In conclusion, this study suggests that RLS/WED patients use a variety of strategies to counter the symptoms of RLS/WED. These strategies may be influenced by cultural practices, disease severity and gender as well.

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