

Hindi translation and validation of Cambridge-Hopkins Diagnostic Questionnaire for RLS (CHRLSq)

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Abstract

Background: Restless legs syndrome also known as Willis-Ekbom's Disease (RLS/WED) is a common illness. Cambridge-Hopkins diagnostic questionnaire for RLS (CHRLSq) is a good diagnostic tool and can be used in the epidemiological studies. However, its Hindi version is not available. Thus, this study was conducted to translate and validate it in the Hindi speaking population. **Materials and Methods:** After obtaining the permission from the author of the CHRLSq, it was translated into Hindi language by two independent translators. After a series of forward and back translations, the finalized Hindi version was administered to two groups by one of the authors, who were blinded to the clinical diagnosis. First group consisted of RLS/WED patients, where diagnosis was made upon face to face interview and the other group — the control group included subjects with somatic symptoms disorders or exertional myalgia or chronic insomnia. Each group had 30 subjects. Diagnosis made on CHRLSq was compared with the clinical diagnosis. **Statistical Analysis:** Analysis was done using Statistical Package for Social Sciences (SPSS) v 21.0. Descriptive statistics was calculated. Proportions were compared using chi-square test; whereas, categorical variables were compared using independent sample *t*-test. Sensitivity, specificity, and positive predictive value of the translated version of questionnaire were calculated. **Results:** Average age was comparable between the cases and control group (RLS/WED = 39.1 ± 10.1 years vs 36.2 ± 11.4 years in controls; *P* = 0.29). Women outnumbered men in the RLS/WED group (87% in RLS/WED group vs 57% among controls; $\chi^2 = 6.64$; *P* = 0.01). Both the sensitivity and specificity of the translated version was 83.3%. It had the positive predictive value of 86.6%. **Conclusion:** Hindi version of CHRLSq has positive predictive value of 87% and it can be used to diagnose RLS in Hindi speaking population.

Key Words

CHRLSq, restless legs syndrome, translation, validation, Willis-Ekbom's disease

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Introduction

Restless legs syndrome, recently named as Willis-Ekbom's Disease (RLS/WED) is a common illness with the reported prevalence of 2-11% across different studies.^[1-6] This variation in the prevalence could be ascribed to the difference in methodologies adopted for the diagnosis of RLS/WED. Despite it being a common problem, it still remains an under diagnosed entity.^[7,8] However, over diagnosis is also not uncommon and this can be related to the misidentification of conditions that mimic RLS/WED.^[9]

The Cambridge-Hopkins RLS diagnostic questionnaire (CHRLSq) was developed to make a reliable diagnosis of RLS/WED during surveys and epidemiological studies. It contains 22 items that are completed by patient himself. It has been found to have 87% sensitivity and 94% specificity along with positive predictive value of 86% in a study done in Cambridge, England.^[10] This questionnaire seeks to exclude some conditions that mimic RLS/WED to improve the identification of 'true RLS/WED'.^[10]

CHRLSq was originally developed in English language. However, many Indians do not have adequate knowledge of English language. This is a major issue when we try to assess the prevalence of RLS/WED in Hindi speaking region of India. Thus, we planned the present study to translate and validate the CHRLSq in Hindi. We have followed the same methodology during the process of translation and validation of this instrument, which was adopted during translation and validation of International RLS Severity Rating Scale (IRLS) and RLS related Quality of life questionnaire (RLSQoL) in Hindi.^[11-14]

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Materials and Methods

This study was conducted in the Sleep Clinic of a tertiary care teaching hospital after obtaining permission from the principal authors of CHRLSq between April 2014 and June 2014.^[10] All the subjects included in this study were explained the rationale of this study and were requested to participate. An informed consent was obtained from all the subjects.

Study population

All adult patients attending sleep clinic were screened for the presence of RLS/WED according to the criteria proposed by International RLS Study group by an expert.^[15] Patients having conditions that mimicked RLS/WED were excluded; so were the patients on psychotropic medications. Patients with chronic medical illness, substance abuse, and neurological disorders were also excluded. The control group consisted of subjects with medically unexplained somatic symptoms or presenting with exertional myalgia in legs or those suffering from insomnia, but not meeting the criteria for RLS/WED on clinical evaluation.^[15-17]

Their demographic data was recorded. It included age, gender, and years of education. Based upon the literacy status, subjects were divided into four groups: Those who had never attended the school-illiterate; those who had 1-5 years of education-primary; those with 6-12 years of education- secondary; and lastly, who completed 13 or more years of education- graduate.

Thereafter, subjects were interviewed using the Hindi version of CHRLSq by other authors who were blinded to the clinical diagnosis. Responses were noted for of the each items and diagnosis of RLS/WED was made according to the responses provided on this questionnaire.

Translation of the instrument

We have followed the guidelines for the cross-cultural translation and validation as suggested by Sousa and Rojjanasrirat.^[16]

Firstly, CHRLSq was translated by two bilingual persons into Hindi language (version 1 and 2). Thereafter, these versions were compared for the translational inconsistencies, they were discussed among both the translators and finally a third Hindi version was obtained. This version was back translated in English by two bilingual translators independently (4th and 5th versions). These versions were again compared for the translational inconsistencies and after discussing the issues, 6th common version of the CHRLSq was obtained. The 6th version was compared with the original instrument and inconsistencies were sorted. All the four translators now worked together, discussed the inconsistencies, and thus appropriate changes were made in the 3rd version so as to bring it closest to the original instrument. This provided us the finalized 7th version in Hindi which was used for the validation in clinical population.

Statistical analysis

Statistical analysis was done using Statistical Package for Social Sciences (SPSS) v 21.0. Descriptive statistics was analyzed. Independent sample *t*-test was used to compare categorical variables between two groups and chi-square was used for the comparison of proportions. Sensitivity and specificity of the diagnosis by the questionnaire were calculated against the clinical interview. Positive predictive value was also calculated.

Results

Thirty patients of RLS/WED and 30 controls were included in this study. Average age was comparable between the cases and control group (RLS = 39.1 ± 10.1 years vs 36.2 ± 11.4 years in controls; *P* = 0.29). As expected, women outnumbered men in the RLS/WED group (87 vs 57% among controls; $\chi^2 = 6.64$; *P* = 0.01). Twenty-seven percent of RLS/WED patients and 17% of controls were illiterate; however, the level of education (primary, secondary, or graduate) was comparable between both the groups. In the control group, 23% had major depressive disorder with somatic symptoms, 30% had chronic insomnia, and 47% were suffering from somatic symptoms disorder.

Forty percent of the controls and 100% of the RLS patients replied 'yes' to the item number 1; 40% of the controls and 97% of the RLS patients replied 'yes' to item number 2. Interestingly, 37% of the controls marked 'yes' to both the items, that is, items 1 and 2; on the contrary, among RLS group, all except one subject responded 'yes' to both of these items. Gender, education level, and the diagnosis did not appear to have any effect on the responses to either of these items in the control group.

Sensitivity and specificity

The clinical diagnosis of RLS/WED is considered to be the gold standard and hence, the diagnosis made by the questionnaire was checked against it. We had four diagnostic categories from the questionnaire — definite RLS/WED, definitely not RLS/WED, probable RLS/WED, and uncertain diagnosis. In the control group, distribution of subjects was as follows: 'Definitely not RLS/WED' -17 subjects; 'definite RLS/WED' — four subjects; 'probable RLS/WED' — one subject; and 'uncertain diagnosis' — eight subjects. In the RLS/WED group, 20 subjects received the diagnosis of 'definite RLS/WED'; five subjects fell into the rubric of 'probable RLS/WED'; while five subjects were categorized as 'uncertain diagnosis'. None of the subjects in this category was diagnosed as "definitely no RLS/WED". From the clinical point of view, 'definite RLS/WED' and 'probable RLS/WED' were considered as RLS/WED while the remaining two categories as not RLS/WED [Table 1]. These results were obtained when item 6 of the questionnaire on relief with movement was controlled as in the cases of severe RLS, even the movement may not bring the complete relief. Thus, the sensitivity and specificity of the translated version, both were 83.3%. With this method, positive predictive value was 86.6%.

However, without controlling the responses on item 6, that is, when the relief obtained with the movement was not controlled for the severity of RLS, the sensitivity dropped to 72.2%, but specificity increased to 86.7%, respectively. With this method, positive predictive value of the translated questionnaire was 83.3%.

Linguistic translation

Some problems were observed during linguistic translation as colloquial use of word differs from the literal translation. We chose to make it more user friendly as literal translation may limit the use of questionnaire in the clinical practice owing to the use of uncommon words and phrases [Table 2].


Discussion

The translated version of the CHRLSq, after controlling the response for item number 6, showed (Appendix 1) 86.7%

Appendix 1

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Cambridge-Hopkins Restless Legs Syndrome
Diagnostic Questionnaire- Hindi Translation (Snippet only)

जहाँ तक सम्भव हो सके कृपया सभी प्रश्नों के उत्तर दें। हर प्रश्न के सबसे सही उत्तर पर गोला लगायें।

1	क्या इन दिनों या पहले कभी, बैठने या लेटने पर आपने कभी अपने पाँव में बार-बार बैचेनीया हडकल का अनुभव किया है?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं
2	क्या इन दिनों या पहले कभी बैठनेया लेटने पर बार-बार पाँव हिलाने की तीव्र इच्छा अनुभव होती है या जरूरत लगती है?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं
<p>प्रत्येक व्यक्ति खण्ड ब का के सभी प्रश्नों का उत्तर दें। अगर अपने पहले या दूसरे सवाल का जवाब "हाँ" दिया है तो खण्ड अ के सवालों का जवाब दें (प्रश्न 3) अगर आपने दोनों सवालों का जवाब "नहीं" दिया है तो खण्ड ब अन्तिम पृष्ठ पर जायें। खण्ड आपके इन अनुभवों से सम्बंधित है।</p>		
[खण्ड अ]		
3	आप इन अनुभवों एवं पाँव हिलाने की इच्छा को कैसे बता सकते हैं? ये अधिकतर	<input type="checkbox"/> बैचेनी से ज्यादा दर्द है <input type="checkbox"/> बैचेनी है पर दर्द नहीं <input type="checkbox"/> दर्द और बैचेनी दोनों है
4	आपको यह अनुभव होने की ज्यादा सम्भावना आराम करते हुए; बैठे या लेटे हुये हैं या जब आप कोई शारीरिक काम कर रहे होते हैं?	<input type="checkbox"/> आराम करते हुए <input type="checkbox"/> काम करते हुए
5	क्या यह अनुभव आराम के समय; बैठे या लेटने पर शुरू होते हैं? 	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं
6	जब आप को यह अनुभव होते हैं उस वक्त आप खड़े हो जायें या घूमने लगे तो क्या घूमते समय इन अनुभवों में कमी आती है?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं <input type="checkbox"/> पता नहीं
7	क्या कभी आप बिना किसी वजहके इसलिये भी घूमते या खड़े हो जाते हैं क्योंकि आपके पाँव में यह अनुभव हो रहे होतें हैं?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं <input type="checkbox"/> यकीन से नहीं कह सकता
8	क्या यह अनुभव कभी इस हद तक भी बढ़ जाते हैं कि क्या आप घूमना बन्द नहीं कर सकते?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं <input type="checkbox"/> पता नहीं
9	जब आप जगे होते हैं और यह अनुभव करते हैं, कितनी बार ऐसा हुआ कि आपने पाँव नहीं हिलाया, फिर भी आपने पाँव को अपने आप हिलते या उंचलते हुये पाया?	<input type="checkbox"/> कभी नहीं <input type="checkbox"/> कभी कभी <input type="checkbox"/> अक्सर <input type="checkbox"/> करीब करीबहमेशा <input type="checkbox"/> हमेशा
10अ	आपके पाँव में यह अनुभव होने की सबसे ज्यादा सम्भावना दिन के किस समय होती है? एक या एक से अधिक उत्तर पर गोला लगायें।	<input type="checkbox"/> सुबह मध्याह्न में <input type="checkbox"/> दोपहर बाद रात को <input type="checkbox"/> हर समय एक सा ही रहता है
10ब	आपके पाँव में यह अनुभव होने की सबसे कम सम्भावना दिन के किस समय होती है? एक या एक से अधिक उत्तर पर गोला लगायें।	<input type="checkbox"/> सुबह मध्याह्न में <input type="checkbox"/> दोपहर बाद रात को <input type="checkbox"/> हर समय एक सा ही रहता है
11	क्या सिर्फ पाँव की स्थिति एक बार बदल लेने से, बिना पाँव को बार – बार हिलाये, इन अनुभवों में अधिकतर आराम आ जाता है?	<input type="checkbox"/> अधिकतर आराम आ जाता है, <input type="checkbox"/> अधिकतर आराम नहीं आता है, <input type="checkbox"/> पता नहीं
12अ	क्या यह अनुभव कभी नस पर नस चढ़ जाने या बाँयटे आने की वजह से होते हैं?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं <input type="checkbox"/> पता नहीं
12ब	यदि हाँ, तो क्या यह अनुभव हमेशा नस पर नस चढ़ जाने या बाँयटे आने की वजह से होते हैं?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं <input type="checkbox"/> पता नहीं
13	क्या यह अनुभव केवल बैठने या लेटने पर होते हैं?	<input type="checkbox"/> दोनों में से कोई नहीं <input type="checkbox"/> केवल बैठने पर <input type="checkbox"/> केवल लेटने पर <input type="checkbox"/> बैठने और लेटने दोनों समय
14	जब आप वास्तव में या आपके पाँव में ये अनुभव महसूस करतें हैं वो कितना परेशान करने वाले होतें हैं?	<input type="checkbox"/> बिल्कुल नहीं <input type="checkbox"/> कुछ हद तक <input type="checkbox"/> मध्यम <input type="checkbox"/> बहुत ज्यादा परेशान करने वाली
15	क्या यह अनुभव रात में या शाम को, दिन के बाकी समय ये ज्यादा होते हैं?	<input type="checkbox"/> शाम या रात को ज्यादा <input type="checkbox"/> बाकी समय ज्यादा <input type="checkbox"/> कोई अन्तर नहीं

Continued

Appendix 1

16	पिछले 12 महीनों में आपने यह अनुभव अपने पाँव में कितनी बार महसूस किये? कृपया एक ही उत्तर पर गोला लगायें।	<input type="checkbox"/> हर रोज <input type="checkbox"/> सप्ताह में 4-5 दिन <input type="checkbox"/> सप्ताह में 2-3 दिन <input type="checkbox"/> सप्ताह में 1 दिन <input type="checkbox"/> महीने में 2 दिन <input type="checkbox"/> महीने में 1 दिन या कम <input type="checkbox"/> कभी भी नहीं
17	और एक साल पहले आम तौर पर, यह अनुभव आपने कितनी बार महसूस किये? कृपया एक ही उत्तर पर गोला लगायें।	<input type="checkbox"/> हर रोज <input type="checkbox"/> सप्ताह में 4-5 दिन <input type="checkbox"/> सप्ताह में 2-3 दिन <input type="checkbox"/> सप्ताह में 1 दिन <input type="checkbox"/> महीने में 2 दिन <input type="checkbox"/> महीने में 1 दिन या कम <input type="checkbox"/> कभी भी नहीं
18	और 5 साल पहले, आम तौर पर यह अनुभव आपने कितनी बार महसूस किये? कृपया एक ही उत्तर पर गोला लगायें।	<input type="checkbox"/> हर रोज <input type="checkbox"/> सप्ताह में 4-5 दिन <input type="checkbox"/> सप्ताह में 2-3 दिन <input type="checkbox"/> सप्ताह में 1 दिन <input type="checkbox"/> महीने में 2 दिन <input type="checkbox"/> महीने में 1 दिन या कम <input type="checkbox"/> कभी भी नहीं
19	जब आपने पहली बार आपके पाँव में यह अनुभव महसूस किये, उस समय अन्दाज़न आपकी उम्र कितनी थी? कृपया उम्र लिखें।	<input type="checkbox"/>
19अ	जब आपने अपने पाँव में पहली बार यह अनुभव महसूस किये, तब क्या आप गर्भवती थीं?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं
	अगर हाँ, तो गर्भावस्था के खत्म होने के बाद जब यह अनुभव आपके पाँव में होने शुरू हुये तब आपकी उम्र कितनी थी।	<input type="checkbox"/>
अब हम आपके रक्त सम्बन्धियों के बारे में जानना चाहेंगे कि क्या उनको भी पाँव में इस तरह के अनुभव होते हैं? कृपया उनकी संख्या लिखें जिनको यह अनुभव होते हैं या नहीं होते हैं और उनकी संख्या भी लिखें जिनके बारे में आपको पता नहीं कि क्या उनको यह अनुभव होते हैं। अगर आपके बच्चे या सगे भाई बहन नहीं हैं तो निशान लगायें।		
20	अपने बच्चों के बारे में सोच कर बतायें, आपके विचार से उन बच्चों में कितनों को पाँव में इस तरह के अनुभव होते हैं? अगर बच्चे नहीं हैं तो यहाँ निशान लगायें।को यह अनुभव होते हैंको यह अनुभव नहीं होते हैंपता नहीं कि उनको यह अनुभव होते हैं या नहीं
21	अपने सगे भाई बहनों के बारे में सोच कर बतायें, आपके सगे भाई बहनों में कितनों को पाँव में इस तरह के अनुभव होते हैं? अगर भाई बहन नहीं हैं तो यहाँ निशान लगायें।को यह अनुभव होते हैंको यह अनुभव नहीं होते हैंपता नहीं कि उनको यह अनुभव होते हैं या नहीं
22अ	क्या आपकी माताजी पाँव में इस तरह के अनुभव महसूस करती हैं या करती थीं?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं <input type="checkbox"/> पता नहीं
22ब	क्या आपके पिताजी पाँव में इस तरह के अनुभव महसूस करते हैं या करते थे?	<input type="checkbox"/> हाँ <input type="checkbox"/> नहीं <input type="checkbox"/> पता नहीं

खण्ड ब

यह खण्ड आपके बारे में है एवं सभी को पूरा करना है।

आप का पूरा नाम	
आपकी जन्म तिथि; दिन / माह/...../.....
आपका कदफीट इंच
आपका वजनkg
लिंग	<input type="checkbox"/> पुरुष <input type="checkbox"/> महिला
आज की तारीख; दिन / माह	

अगर आप इस प्रश्नावली के बारे में कुछ बताना चाहते हैं या किसी प्रश्नको समझने में आपको कोई दिक्कत हुई तो नीचे दिए स्थान में अपने विचार लिखें।

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Table 1: Results on the diagnosis via CHRLSq vs clinical diagnosis (N = 30 in each group)

Diagnosis on CHRLSq	RLS on clinical interview	Not RLS on clinical interview
After ignoring item 6 for the RLS severity		
RLS on questionnaire	26	4
Not RLS on questionnaire	10	20
After controlling item 6 for the RLS severity		
RLS on questionnaire	25	5
Not RLS on questionnaire	5	25

CHRLSq = Cambridge-Hopkins diagnostic questionnaire for restless legs syndrome

Table 2: Translation process of CHRLSq

Original	Version 3	Version 6	Version 7
Uncomfortable Feelings or sensations	Baichaini ya hadkal Mahsoos kiye hain	Uneasiness or restlessness	Baichaini ya hadkal Anubhav
Urge	Ichchha	Intense feelings	Teevra ichchha
Uncomfortable Active	Baichaini Kaam karte huye	Restlessness Working	Baichaini Kaam karte huye
Any better	Kuchh aaraam	Some decrement	Kuchh aaraam
Most Simply	Adhiktar Kewal	Usually Only	Sabse zyada Kewal
Cramps	Nas par nas chadh jaane ya baanyte aane	Nerves getting on each other	Nas par nas chadh jaane ya baanyte aane
Distressing	Pareshaankarne waale	Disturbance	Pareshan karne wale
How often	Kitni baar	How many times	Kitni baar
Biological mother	Mataji	Mother	Mataji
Biological father	Pitaji	Father	Pitaji

specificity and 72.2% sensitivity. Moreover, we have included population from different categories of occupations having varied level of education. Despite the fact that population belonged to such diverse background, none of them found any difficulty in understanding any of the items of the translated version.

Original instrument has also been designed to be more specific than the sensitive, similar to the results of this study.^[10] However, the present translated version was found to be less specific and sensitive than the original questionnaire because of the difference in the populations in which the questionnaire was applied. The original questionnaire was applied to the population of blood donors not necessarily having RLS/WED, while in our study 20 out of 30 subjects in the RLS group were suffering from chronic persistent RLS and rest from chronic intermittent RLS.^[15] In the original study, controls were not suffering from any of the conditions that mitigated RLS/WED; however, in this study, a sizable number of subjects (70%) in the control group were suffering from somatic symptoms disorder, which present with pains and aches involving various areas of the body. In such a context it is more important that the questionnaire picks up true cases, that is, need to be more specific. However, when we controlled the results for the item no 6 as discussed above, which asks for the relief obtained by the movement, the sensitivity decreased with a slight

improvement in specificity. However, it must be remembered that this questionnaire was designed for the increased specificity; hence, it may miss some cases of the 'definite RLS/WED' when not accompanied by clinical examination which may be a limiting factor for its use in some of the studies.^[8]

Original version had the positive predictive value of 85.5% and we found similar values (86.6 and 83.3%, respectively) by either of the methods suggesting that this instrument can be used in clinical settings. In conclusion, Hindi translation of the CHRLSq showed good specificity and positive predictive value. We did not find any problem during administration of this questionnaire in the population belonging to a diverse background, and thus it appears to be a useful tool for screening RLS/WED among the Indian Hindi speaking population.

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