

Diagnostic Delay in REM Sleep Behavior Disorder (RBD)

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Study Objectives: REM sleep behavior disorder (RBD) is a parasomnia in which normal muscle atonia of REM sleep is lost. The aim of this study was to confirm if diagnostic delay exists in RBD and identify any contributing factors.

Methods: A database was compiled of 49 patients with RBD seen at a tertiary referral center from 2005 to 2011 by retrospective review of referral letters and polysomnographic (PSG) reports. Patients with comorbid narcolepsy were excluded. A questionnaire was sent to investigate diagnostic delay, management, and comorbidities.

Results: Mean diagnostic delay was 8.7 ± 11 (median 4.5, IQR 1.75-11.75) years in 30 questionnaire responders. Common reasons for diagnostic delay included belief that symptoms were not serious enough to consult a doctor (59%), mild or infrequent occur-

rence of sleep behavior (56%), belief that symptoms may resolve (47%), and lack of knowledge of treatment options (47%). The bed partner was an important influence, with the decision to seek medical attention being made jointly by the patient and partner in 47%.

Conclusions: This study has demonstrated the existence of significant diagnostic delay in RBD, mainly due to lack of understanding of the disorder and its treatment by patients and members of the medical profession.

Keywords: REM sleep behavior disorder, parasomnias, sleep-related violence, delayed diagnosis, polysomnography, parkinsonian disorders, clonazepam, melatonin

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REM sleep behavior disorder (RBD) is a parasomnia characterized by loss of normal muscle atonia in REM sleep.¹ Patients may act out dreams, causing injury to themselves or their bed partner, resulting in relationship problems and decreased quality of life. Dream enactment in RBD occasionally has lethal results.²

There are two main diagnostic categories of RBD. Secondary or symptomatic RBD occurs in association with comorbid neurological disease such as narcolepsy or neurodegenerative disease, most commonly Parkinson disease (PD), Lewy body dementia, and multiple system atrophy^{3,4}; or medication, including β -blockers and antidepressants.⁵⁻⁷ Idiopathic RBD occurs in the absence of any associated neurological condition or medication.

RBD appears to be underdiagnosed,^{3,8,9} with prevalence estimated at 0.5% of the UK population.^{9,10} RBD occurs predominantly in men, the majority of patients presenting between 52 and 61 years of age.⁵

RBD was first described in humans in 1986,¹¹ and research in the area has accelerated in recent years, with advances in neuroimaging, and better recognition and understanding of the condition.^{3,4} However, an important clinical aspect of this disorder which has been neglected is diagnostic delay—a problem encountered in other sleep disorders, especially narcolepsy.^{12,13}

This study aimed to document the degree of diagnostic delay in RBD patients presenting to a tertiary referral center in the UK. The presence of comorbid sleep disorders and presence of a bed partner were hypothesized to reduce diagnostic delay.

BRIEF SUMMARY

Current Knowledge/Study Rationale: REM sleep behavior disorder (RBD) is a potentially lethal parasomnia in which normal muscle atonia during rapid eye movement (REM) sleep is lost. Although diagnostic delay is documented in other sleep disorders, such as narcolepsy, diagnostic delay in RBD has not, thus far, been investigated.

Study Impact: This is the first study to focus specifically on diagnostic delay in RBD. The study demonstrates the existence of significant diagnostic delay, highlighting the need for greater awareness of the disorder and its treatment options amongst patients and medical professionals.

METHODS

A questionnaire (**Appendix 1**) was developed to explore aspects of diagnosis and management of RBD: symptom duration before diagnosis; factors delaying diagnosis; features of RBD contributing to seeking medical help; identification of potential triggers (stress, menstruation, medication); management of RBD—pharmacological and behavioral; medication adherence and side effects; control of RBD; and comorbidities including other sleep disorders. All questionnaires were anonymized and mailed to patients with a covering letter. Ethical approval is not required by NHS Lothian for case series or audit.

All patients with suspected RBD at a tertiary referral sleep center from 2005 to March 2011 were reviewed ($n = 66$). Patients were excluded if they had a diagnosis of RBD with narcolepsy (the etiology of RBD in this group may be multifactorial and differ from RBD without narcolepsy^{14,15}) or if they did not fulfil ICSD-2 criteria for diagnosis of RBD.¹⁶ The medical case

Table 1—Factors influencing patients' decision to consult a doctor regarding abnormal sleep behavior

	Males (n = 29)			Females (n = 3)			p
	No or small impact	Moderate impact	Strong or very strong impact	No or small impact	Moderate impact	Strong or very strong impact	
Injury to self	13	6	1	2	0	0	0.60
Injury to partner	2	7	11	1	0	1	0.24
Increased frequency of behavior	0	5	18	1	0	1	0.002
Increasing injury/violence	5	4	11	1	0	1	0.66
Partner noticed more regular behavior	0	2	22	1	0	1	0.002
Partner noticed increase in force or violence of behavior	2	2	18	1	0	1	0.24
Partner moved into separate bed	9	2	6	1	0	0	0.66
Impact on job	11	0	5	0	0	1	0.35
Impact on relationship	8	6	7	0	0	2	0.18

notes and polysomnographic sleep study (PSG) data of the remaining 49 patients were reviewed. Diagnosis was based on history (from both patient and partner where possible) and standard video PSG, in accordance with ICSD-2 criteria.

Statistical analysis was undertaken using SPSS17 (Chicago, Illinois). Student's t-test, χ^2 test, and Fisher exact test were used to assess parametric data, and Mann Whitney U test for non-normally distributed variables. All tests were 2-sided. Statistical significance was taken at $p < 0.05$. Results were reported as mean \pm standard deviation (SD) or as a median with interquartile range (IQR 25-75). As not all patients answered every question, n is reported as the number of patients responding to each particular question.

RESULTS

Of 49 RBD patients included in the study, 44 (90%) were male and 5 (10%) female. The mean age at first referral was 55 ± 14 years for males and 36 ± 10 females ($p = 0.006$). Forty-one patients (36 male: 5 female) were diagnosed with idiopathic RBD, 6 (all male) with RBD secondary to neurological disease, and 2 (both male) secondary to medication (citalopram and bupropion); $p = 0.6$.

The response rate to the questionnaire was 65% ($n = 32$). Non-responders were significantly younger than responders (responders male 61 ± 9 , female 38 ± 11 v. non-responders (male 44 ± 16 , female 34 ± 13 , $p < 0.0001$), but did not differ significantly in terms of sex distribution or RBD type (data not shown).

Polysomnographic Data

PSG data were available for all 49 patients. Twenty-seven patients (55%) had evidence of dream enactment on video, with no significant sex ($p = 0.16$) or age ($p = 0.41$) differences. All patients were positive for REM sleep without atonia (RSWA).

Fifty-three percent of patients had an apnea-hypopnea index (AHI) > 15 per hour, indicative of moderate-to-severe sleep disordered breathing. This differed significantly by age ($p = 0.005$); those with AHI < 15 were younger than those with a higher AHI (47 ± 15 years v. 59 ± 13 years). There was no significant difference by sex ($p = 0.17$) or RBD type ($p = 0.6$).

Diagnostic Delay

Overall, the mean delay in diagnosing RBD was 8.7 ± 11 years (median 4.5, IQR 1.75-11.75; $n = 30$). There was a significant gender difference with women having a longer diagnostic delay than men (22 ± 11 years v. 7 ± 10 years, respectively; $p = 0.03$). There was no significant difference in diagnostic delay between the different types of RBD ($p = 0.56$): idiopathic RBD 9.4 ± 11.4 years, neurological RBD 8.7 ± 9.9 years, RBD secondary to medication 0.5 ± 0.7 years. Of the 32 people who responded, the most common reason for not seeking medical help was a belief that the symptoms were not serious enough to consult a doctor (59%; $n = 19$). Other common reasons were mild or infrequent occurrence of the sleep behavior (56%; $n = 18$), belief that the symptoms would eventually settle (47%; $n = 15$) and failure to realize that there might be treatment options for the condition (47%; $n = 15$). Thirty-one percent of patients ($n = 10$) were never asked about sleep by their doctor. There were no significant gender differences. There was no significant difference in reasons for diagnostic delay with RBD type or age, although those older than 50 years were more likely to experience delay due to their doctor not recognizing RBD, with a trend towards significance ($p = 0.07$). AHI and symptoms of possible obstructive sleep apnea did not play a role in bringing attention to RBD ($p = 0.72$): AHI < 15 8 ± 10 years ($n = 12$), AHI > 15 9 ± 12 years ($n = 18$).

Seventy-two percent ($n = 23$) of patients consulted a doctor specifically regarding their sleep behavior, with no significant age or gender differences observed. The decision to consult a doctor was most commonly a joint decision by both partners (47%, $n = 15$). All females making the decision to consult a doctor did so themselves ($p = 0.023$, $n = 3$); however, the low number of responders in this group should be noted.

Factors influencing the decision by patients to seek medical assessment of their nocturnal behavior are shown in **Table 1**. The most important factors cited by patients as having a strong or very strong impact on their decision to seek medical review were: (i) the partner noticing more regular abnormal sleep behaviors (88%, $n = 23$); (ii) the partner noticing an increase in the violence or force of the behavior (79%, $n = 19$); (iii) increased frequency of behavior (76%, $n = 19$); (iv) injury to the partner (55%, $n = 12$); and (v) increasing injury/violence (54%; $n = 12$). No significant age differences were evident (data not shown).

However, men were significantly more likely to consult on the basis of factors i and iii above (both $p = 0.002$).

The impact of RBD on the individual's career was important in 53% of patients, with 9 of 17 patients rating this as having at least a small impact on their decision to seek treatment.

Comorbidities

Twenty-five of 31 responders (81%) reported that they had one or more comorbid sleep disorders. Thirteen patients (41%) had comorbid sleep apnea (defined as an AHI > 15), 8 of whom (62%) were using continuous positive airway pressure (CPAP) treatment. Six users (75%) found CPAP improved their RBD symptoms. No significant differences in mean diagnostic delay were found between those with or without comorbid sleep disorders (data not shown).

Treatment

Current treatment information was provided by 28 responders. Thirty-six percent were not on medication; 50% were taking clonazepam only, at doses in the range 0.5-2 mg per night; 4% were taking melatonin only, 2-6 mg per night; 7% were on combined clonazepam and melatonin therapy. One patient stated he was taking mirtazapine as his only treatment for RBD. In terms of medication use, there were no significant differences with age, gender or RBD type (data not shown).

Lifestyle

Thirty-eight percent of responders stated that lifestyle changes had been recommended to them ($n = 12$). Changes to sleeping arrangements were recommended to 14 of the 31 patients: sleeping in separate beds (19%), sleeping in a separate room (19%) and putting a guard around the bed (6%). Along with sleeping in separate beds or rooms, caffeine reduction (19%) was the most common lifestyle change. Other recommended changes included alcohol reduction and increased exercise (both 16%). Of the 12 patients who made lifestyle changes, 5 (42%) stated that lifestyle changes made a difference to their symptoms, and 6 (50%) stated they made no difference (1 patient did not answer). Lifestyle changes showed no significant association with sex, age, or RBD type (data not shown).

DISCUSSION

This is the first study to specifically focus on diagnostic delay of an under-diagnosed and potentially lethal parasomnia. Our patient group is comparable to previously published series,^{4,17} with male predominance (90%) and mean age at first referral of 55 ± 14 years.

Although 72% of patients consulted specifically about their sleep behavior, the mean delay of 8.7 ± 11 years (median 4.5, IQR 1.75-11.75) shows that patients tolerated symptoms for some time before diagnosis. Additionally, 56% of patients classified their sleep behavior as initially mild/infrequent. The course of RBD often fluctuates,¹⁸ and these patients may delay seeking medical attention due to these periods of normal or only mildly disrupted sleep.

In this study, many patients initially dismissed their behavior as neither serious nor medically important. However, a large proportion consulted specifically about their sleep (72%, $n =$

23), showing the cumulative effect of chronic sleep disorders causing major disruption to patients' lives. Common factors for delaying diagnosis included the belief that the symptoms were not serious enough to consult a doctor (59%) and failure to realize that treatment options were available (47%). Heightening public awareness of sleep disorders could reduce diagnostic delay and improve quality of life with many RBD, patients, but this is a challenging agenda.¹⁹

The impact of RBD on the bed partner appeared to be the major driver for patients to seek medical advice. Four patients (13%) were unaware of their sleep behavior, thus delaying diagnosis. If the impact of RBD on the bed partner is more significant than the impact on the patient independently, under-diagnosis of patients who are single or have mild sleep behaviors may occur.

The absence of daytime symptoms may also delay presentation. In narcolepsy, patients with cataplexy have a shorter diagnostic delay than those without.¹³ If RBD patients do not have dramatic nocturnal symptoms such as violent dream enactment or injurious behavior, the condition may be tolerable. Dream enactment behavior is found in the normal, healthy population but is usually less violent and frequent than RBD.²⁰ If this behavior is considered "subclinical RBD,"²¹ this may explain why increased frequency and severity of RBD symptoms were a strong or very strong prompt for presentation to a doctor in the majority of patients.

Diagnostic delay can be attributed to obstacles in health service provision.²² Lack of access to PSG can hinder diagnosis. In this study, failure to recognize the presence of RBD in primary care contributed to diagnostic delay in 31% of patients ($n = 10$). Thorough history-taking with direct questioning about RBD symptoms is required.^{9,23} To this end, an RBD screening questionnaire has been developed, and its routine use in clinical practice (particularly in at-risk populations such as PD) could aid prompt diagnosis.²⁴ This may have particular bearing upon delayed recognition of neurodegenerative disease. Postuma et al.²⁵ found a mean RBD diagnostic delay of 7.2 years, with 26 of 93 patients developing either PD or dementia at 11.5 ± 6.6 years from onset of symptoms.

No significant difference was found in mean diagnostic delay between those with or without comorbid sleep disorders, which suggests that the impact of RBD on the individual and their partner may be an independent factor in a patient's diagnostic delay, not influenced by the presence of comorbidities.

Clonazepam, a sedating benzodiazepine which reduces phasic EMG activity,²⁶ is considered first-line therapy in RBD, although the evidence for its use is not strong and it should only be used in selected groups.^{27,28} Clonazepam contributed to improvement in 77% ($n = 10$) of patients. This is lower than the quoted figure from some studies, but supports others.^{4,14,17} Only one responder was taking melatonin, the other major treatment option, and he reported that it improved his symptoms. Melatonin can be used either alone or in conjunction with clonazepam, but again there have been few studies examining its use in detail.^{27,29,30} Two of our patients were taking a combination of melatonin and clonazepam, and both stated this had improved their symptoms.

A number of limitations should be considered when interpreting the results of this study, namely small sample size, the

use of an unvalidated, self-administered questionnaire, and possible responder bias. In future studies, we would consider the use of a partner questionnaire in tandem with the patient questionnaire to further explore partner aspects of diagnostic delay.

This study has demonstrated the existence of significant diagnostic delay in RBD, mainly due to lack of knowledge of the disorder and its treatment options among both patients and medical professionals. We suggest that increasing knowledge of sleep disorders by targeting medical education and public awareness, particularly with RBD, would improve patients' quality of life and limit potential harm to the patient and their bed partner. Additionally, it has been suggested that RBD is an early marker of neurodegenerative disease, and identifying these patients may allow for improved treatment with neuroprotective agents in the future.^{1,28,31}

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Appendix 1—Questionnaire

Your current age: Male / Female

Marital Status: Occupation:

1. Which year was your REM behavior disorder diagnosed?
2. Which year, approximately, did your symptoms begin?
3. Had you heard of REM behavior disorder prior to your diagnosis? YES / NO
4. Does anyone in your family have REM behavior disorder? YES / NO
5. Do you feel you have a good understanding of REM behavior disorder? YES / NO

Have the following been useful in helping your understanding? (please circle)

Information from doctor TV Internet Other _____

Is there any resource you think would improve your understanding?

6. If there is a delay between 1 and 2, (see above), is there a reason for this delay? (tick as appropriate)

Sleep behavior initially mild/infrequent	
Felt too busy to consult a doctor	
Felt too healthy to consult a doctor	
Did not think it was serious enough to see doctor	
Thought this was "normal" sleep behavior	
Thought the sleep behavior would eventually settle	
Did not realize there were treatment options	
Was unaware of behavior (no bed partner/work abroad)	
Embarrassed to discuss behavior	
Doctor did not recognize RBD	
Was never asked about sleep by doctor	
RBD was initially diagnosed as another condition	
Other – please state	

7. Did you go to the doctor specifically about your sleep behavior? YES / NO

8. Who made the decision to consult a doctor? (circle as appropriate):

You Your partner Both you & your partner Other (please state) _____

Appendix 1 continues on the following page

Appendix 1 (continued)—Questionnaire

9. How did these factors contribute to your decision to consult a doctor?

	No impact	Small impact	Moderate impact	Strong impact	Very strong
Injury to self					
Injury to partner					
Increased frequency of behavior					
Increasing injury/violence					
Partner noticed more regular behavior					
Partner noticed increase in force or violence of behavior					
Partner moved into separate bed					
Impact on job					
Impact on relationship					
Other (please state)					

10. Did the symptoms start at the same time as taking medication? YES / NO

If YES please state medication:

11. Did your REM behavior disorder start at the same time as a stressful life event (for example, new job, new home, bereavement)? YES / NO

If YES, please state the event:

12. Does anything trigger your REM behavior disorder, makes it occur more regularly or with increased force/violence? YES / NO

If YES please describe:

13. If you are FEMALE:

Does your RBD change throughout your menstrual cycle? YES / NO

If YES, please describe:

Do you have any children? YES / NO

If YES, how many?

How was your REM behavior disorder during pregnancy? (please circle)

Better Worse No change

14. What medication are you taking for RBD **at present**?

	Tick	Dose	Date started
No treatment			
Clonazepam			
Melatonin			
Other(state)			

15. Do you think this treatment has improved your REM behavior disorder? YES / NO

16. On average, how many days per week do you take your medication? (please circle)

0 1 2 3 4 5 6 7 *varies*

17. If you do not take your medication every day, please state why:

18. Do you experience any side effects from the above treatment(s)? YES / NO

If YES, please state:

Appendix 1 continues on the following page

Appendix 1 (continued)—Questionnaire

19. Have you taken any of these medications **in the past** for your RBD?

Treatment	Tick	Reason for stopping
Clonazepam		
Melatonin		
Other (please state)		

20. Were you advised to make lifestyle changes? YES / NO

If **YES**, tick all that apply:

Stress control		Increased exercise	
Alcohol reduction		Caffeine reduction	
Sleeping in separate room to partner		Sleeping in separate bed to partner	
Putting a "guard" around bed		Other (please state)	

21. Do you feel these lifestyle changes made a difference? YES / NO

22. Do you have any of the following sleep problems? (please circle)

Sleep apnea *Sleep walking* *Sleep talking* *Insomnia*
Narcolepsy *Restless Leg Syndrome* *Other (please state)*

23. If **YES** to any of the above, are you receiving treatment? YES / NO

24. If **YES** please state what treatment you are receiving:

25. Has this improved your REM behavior disorder? YES / NO

26. Do you use a CPAP machine at night? YES / NO

27. If you use a CPAP machine at night, has this improved your REM behavior disorder? YES / NO

28. Have you ever had any of the following conditions? (tick any that apply)

Asthma		Emphysema		High blood pressure		Angina	
Stroke		Kidney/liver problems		Thyroid problems		Heart attack	
Depression/Anxiety		Epilepsy		Parkinson's Disease		Diabetes	

29. Finally, has your sense of smell (tick one that applies best to you):

Stayed the same over time		Improved over time	
Diminished over time		Never had a sense of smell	

Many thanks for completing this questionnaire.