



The impact of REM-sleep behavior disorder on people with Parkinson's disease and their partners



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REM-sleep behavior disorder (RBD) may affect health-related quality of life (HRQoL) of people with Parkinson's disease (PwP) and partners. We aimed to determine how RBD affects HRQoL using a mixed-methods approach. Quantitatively, we analyzed data from the PRIME-NL Parkinson Evaluation study, including 829 PwP and 452 partners, using multivariable regression models to examine the association between screen-positive RBD and HRQoL. Qualitatively, we conducted interviews with 14 dyads of PwP with self-reported RBD and their partners. RBD was negatively associated with HRQoL in both groups, primarily due to short-term effects on daily life, co-existing symptoms like impaired cognition and autonomic issues, and sleep disturbances. Impact of RBD was already felt before or during the diagnostic process, with the main challenges being sleep-related complaints, anxiety and impact on relationships. PwP and partners employed both medical and non-medical coping strategies. These findings will help to optimize care for PwP with RBD and their partners.

REM sleep behavior disorder (RBD), affecting 30–50% of people with Parkinson's disease (PwP)¹, might impact health-related quality of life (HRQoL) of PwP and their partners in several ways. First, violent dreaming behavior might cause injuries to PwP and bedpartners². Second, RBD might lead to a poorer sleep quality and distress³. Third, the unpredictability and intimate nature of the symptoms, including potentially embarrassing behaviors, might make RBD a difficult topic to discuss⁴.

Previous studies indeed found a worse HRQoL in PwP with RBD^{1,5,6}. Parkinson's disease (PD) with RBD, however, has also been associated with more severe autonomic symptoms⁷, cognitive impairment, depression, and anxiety⁸. Consequently, these confounders could bias the association⁹. Moreover, the impact of non-motor symptoms on RBD severity has not yet been fully evaluated, and qualitative insights on how RBD might directly affect daily life are lacking. Finally, information on the impact of RBD on partners of PwP is limited. Understanding the direct and indirect impact of RBD on HRQoL of both PwP and their partners is pivotal for developing comprehensive care strategies, improving clinical outcomes, and enhancing the overall HRQoL for those affected.

The purpose of this mixed-methods study was: (1) to quantitatively investigate the association between RBD and HRQoL and (2) to qualitatively

identify in which ways RBD might influence HRQoL in PwP and their partners. By comparing and contrasting qualitative and quantitative data, the combined knowledge of this mixed-methods study helps to further explore the possible causality of the association between RBD and HRQoL and to tailor information on RBD to the needs of both PwP and their partners.

Results

Quantitative results

The study population consisted of 829 PwP and 452 partners. An overview of the population characteristics can be found in Table 1 for PwP and in Table 2 for partners. The mean (SD) age of PwP was 71 (7.9) years, and 40% were women. PD was diagnosed on average 7.6 (4.9) years prior to the study. The majority of partners were women (68%), and their mean age was 69 (9.3) years. Types of PD medication and comorbidities were recorded at baseline of the PRIME-NL study (two years prior) and can be found in Supplementary Table 1.

In total, 52 PwP (6%) had sRBD and 124 (15%) pRBD (Table 1). A total of 135 PwP (77%) with cRBD and 67 partners (82%) filled out the optional RBD questionnaire (Supplementary Table 3). Of these people, 14% of PwP used sleep medication and 8% used antidepressants. Sleep behaviors of PwP with cRBD during the night are visualized in Fig. 1. Dream enactment was

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Table 1 | Baseline characteristics of people with Parkinson's Disease (PwP) and their partners, and the subset of combined RBD (cRBD)

	PwP (N = 829)	PwP cRBD population (N = 176)
Gender (female)	330 (40%)	44 (25%)
Age (years)	71 (7.9)	70 (7.4)
Education level ^a		
Low	208 (25%)	35 (20%)
Medium	218 (26%)	46 (26%)
Higher	399 (49%)	95 (54%)
Work status (work)	121 (15%)	31 (18%)
Living situation		
Living alone	122 (15%)	21 (12%)
Living with partner or family	692 (83%)	152 (86%)
Facilitated care	15 (2%)	3 (2%)
Other	0 (0%)	0 (0%)
H&Y score ^b		
1	158 (19%)	22 (12%)
2	272 (33%)	73 (41%)
3	170 (21%)	37 (21%)
4	172 (21%)	36 (20%)
5	33 (4%)	5 (3%)
Time since PD diagnosis (years)	7.6 (4.9)	7.6 (4.6)
Age when diagnosed with PD (years)	63 (9.1)	63 (8.5)
PD treatment		
Oral medication	777 (94%)	168 (95%)
Duodopa pump	36 (4%)	5 (3%)
Deep Brain Stimulation (DBS)	49 (6%)	16 (9%)
None	22 (3%)	2 (1%)
Motor symptoms	14 (8.3)	15 (7.5)
Autonomic symptoms	17 (7.0)	18 (6.7)
Cognition	18 (3)	18 (3.1)
Hallucinations ^c	125 (15%)	39 (22%)
Anxiety	76 (19)	79 (20)
Depression	12 (7)	13 (7.2)
HRQoL	29 (13)	31 (13)
RBD		
Self-reported diagnosis	52 (6%)	52 (30%)
Screen-positive ^d	124 (15%)	124 (70%)

PD Parkinson's disease. H&Y Hoehn and Yahr. All values are given either in mean (SD) or n (%). Motor symptoms: UPDRS-II. Autonomic symptoms: SCOPA-AUT. Cognition: MoCA. Anxiety: STAI. Depression: BDI. HRQoL health-related quality of life, PDQ-39. Education level has 0.5% missing values and cognition has 1.1% missing values. H&Y score has 2.9% missing values for PwP and 1.7% for the cRBD subset.

^aLow: none, primary, lower secondary education; Medium: upper secondary education, post-secondary non-tertiary education; Higher: Short-cycle tertiary, Bachelor/Master/Doctoral or equivalent.

^bH&Y score: (1) Unilateral involvement only; (2) Bilateral involvement without impairment of balance; (3) Mild to moderate bilateral disease; some postural instability; physically independent; (4) Severe disability; still able to walk or stand unassisted; (5) Wheelchair bound or bedridden unless aided⁴⁰.

^cPresence of hallucinations in the past year yes/no.

^dBased on a score of 4 or higher¹¹.

often experienced by 50% of partners of PwP with cRBD. Most PwP and partners never experienced general anxiety or mood symptoms as a result of cRBD (64% of PwP, 70% of partners). However, 47% of PwP with cRBD and 34% of partners were afraid of injuries.

Information on RBD from the neurologist or PD nurse was received by 60% of PwP with sRBD and 38% of PwP with pRBD. Overall, sleep quality

Table 2 | Baseline characteristics of partners of people with Parkinson's disease (PwP) and partners of the subset of combined RBD (cRBD)

	Partners (N = 452)	Partners cRBD population (N = 82)
Gender (female)	308 (68%)	64 (78%)
Age (years)	69 (9.3)	69 (7.4)
Education level ^a		
Low	107 (24%)	13 (16%)
Medium	120 (27%)	24 (29%)
Higher	225 (50%)	45 (55%)
Work status (work)	106 (23%)	17 (21%)
Living situation		
Living alone	22 (5%)	1 (1%)
Living with partner or family	427 (94%)	80 (98%)
Facilitated care	3 (1%)	0 (0%)
Other	0 (0%)	1 (1%)
HRQoL	21 (17)	23 (16)
Caregiver burden	19 (13)	19 (12)

All values are given either in mean (SD) or n (%). HRQoL health-related quality of life, PDQ-39. Caregiver burden: Zarit burden interview.

^aLow: none, primary, lower secondary education; Medium: upper secondary education, post-secondary non-tertiary education; Higher: Short-cycle tertiary, Bachelor/Master/Doctoral or equivalent.

was rated negatively by 34% of PwP with cRBD and 22% of partners. An impact of cRBD on the relationship was experienced by 37% PwP with cRBD and 30% of partners. The overlap in answers between PwP and their partners is depicted in Supplementary Table 4. Disagreements were most prevalent in questions regarding dream enactment, where PwP frequently noticed specific dream behaviors that their partners did not observe.

The results of multiple linear regression analyses are shown in Fig. 2. Having cRBD was associated with worse autonomic symptoms (model 2: $\beta = 0.48$, 95% CI: 0.31 to 0.64), but not with motor symptoms ($\beta = 0.09$, 95% CI: -0.06 to 0.25). cRBD was also associated with worse depressive and anxiety symptoms (BDI: $\beta = 0.30$, 95% CI: 0.14 to 0.47; STAI: $\beta = 0.29$, 95% CI: 0.12 to 0.45) and with a lower HRQoL (PDQ-39: $\beta = -0.29$, 95% CI: -0.45 to -0.13). After adjusting for cognition and autonomic symptoms, the association largely disappeared (BDI: $\beta = 0.10$, 95% CI: -0.06 to 0.25; STAI: $\beta = 0.12$, 95% CI: -0.04 to 0.28; PDQ-39: $\beta = -0.07$, 95% CI: -0.21 to 0.06). In partners, cRBD was associated with an increased caregiver burden (Zarit burden interview: $\beta = 0.10$, 95% CI: -0.14 to 0.34) and a lower HRQoL (PDQ-Carer: $\beta = -0.26$, 95% CI: -0.49 to -0.02). Adjustment for cognition and autonomic symptoms diminished the effects (Zarit burden interview: $\beta = 0.01$, 95% CI: -0.23 to 0.25; PDQ-Carer: $\beta = -0.16$, 95% CI: -0.39 to 0.07).

In order to determine the effect of our broad definition of pRBD, we repeated the analyses with a more strict definition of RBD, which includes only participants with sRBD in the definition of RBD ($n = 52$). Having sRBD was not significantly associated with worse autonomic symptoms (model 2: $\beta = 0.47$, 95% CI = 0.19 to 0.74), or with motor symptoms (model 2: $\beta = 0.17$, 95% CI = -0.09 to 0.43), showing a larger coefficient and broader confidence intervals, most likely due to the much smaller sample size of PwP with RBD. The same was observed for the association between sRBD and depression (model 3: $\beta = 0.19$, 95% CI = -0.06 to 0.44), anxiety (model 3: $\beta = 0.26$, 95% CI 0.01 to 0.52), and HRQoL (model 3: $\beta = -0.12$, 95% CI: -0.34 to 0.10). The sample size of partners of PwP with sRBD ($n = 26$) was insufficient to demonstrate any significant effect.

Qualitative results

Sample characteristics of interviewees are shown in Fig. 3, and characteristics are summarized in Supplementary Table 5. RBD was confirmed by a polysomnography (PSG) in 4 of 14 PwP.

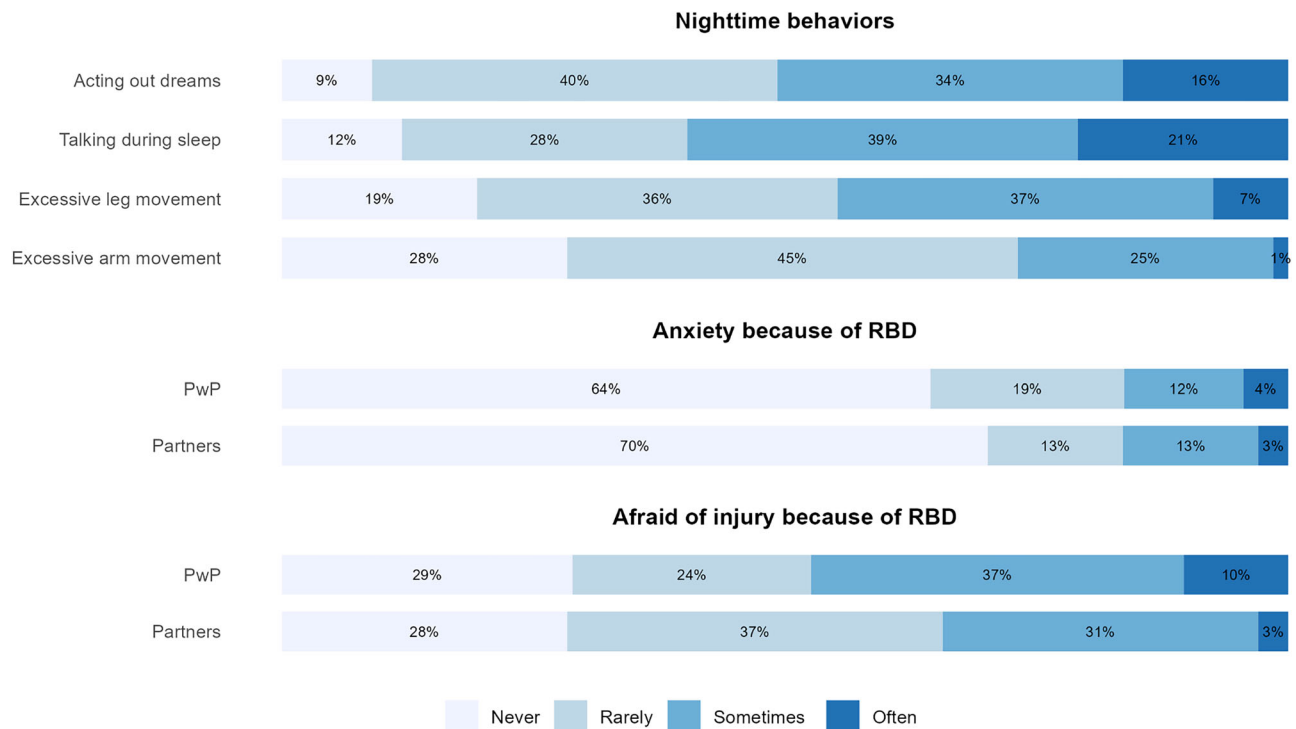


Fig. 1 | Manifestation of RBD. PwP people with Parkinson's disease. Total number of PwP ($n = 135$) is determined by the total number of PwP with cRBD ($n = 176$), excluding the 41 PwP that did not fill out the optional part of the questionnaire. Total

number of partners ($n = 73$) is determined by the number of partners of PwP who adhered to the general definition of cRBD ($n = 82$), excluding the 9 partners that did not fill out the optional part of the questionnaire.

Autonomic symptoms and motor symptoms in PwP

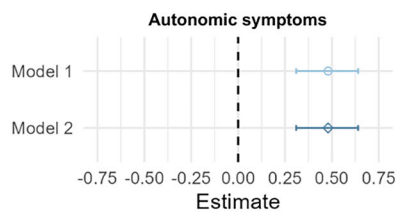


Fig. 2 | Association of RBD with outcomes in PwP and in partners. PwP people with Parkinson's disease. Points represent the regression coefficients of the linear models, and bars the 95% confidence intervals. Model 1: corrected for age and gender; Model 2: additionally corrected for education level, living situation, work status, and disease duration; Model 3: additionally corrected for autonomic symptoms and cognition.

Semi-structured interviews revealed five main themes (Fig. 4): (1) First symptoms and diagnosis of RBD; (2) Sleep-related complaints; (3) Impact of RBD on anxiety and depression; (4) Impact of RBD on relationships; and (5) Reducing the impact of RBD. Accompanying quotes can be found in Table

3. The most illustrative quotes were also added to the theme descriptions below. Two subthemes were identified for the theme Sleep-related complaints: (1) Manifestation of RBD and (2) Impact of sleep quality; and for Coping: (1) Information and support and (2) Measures.

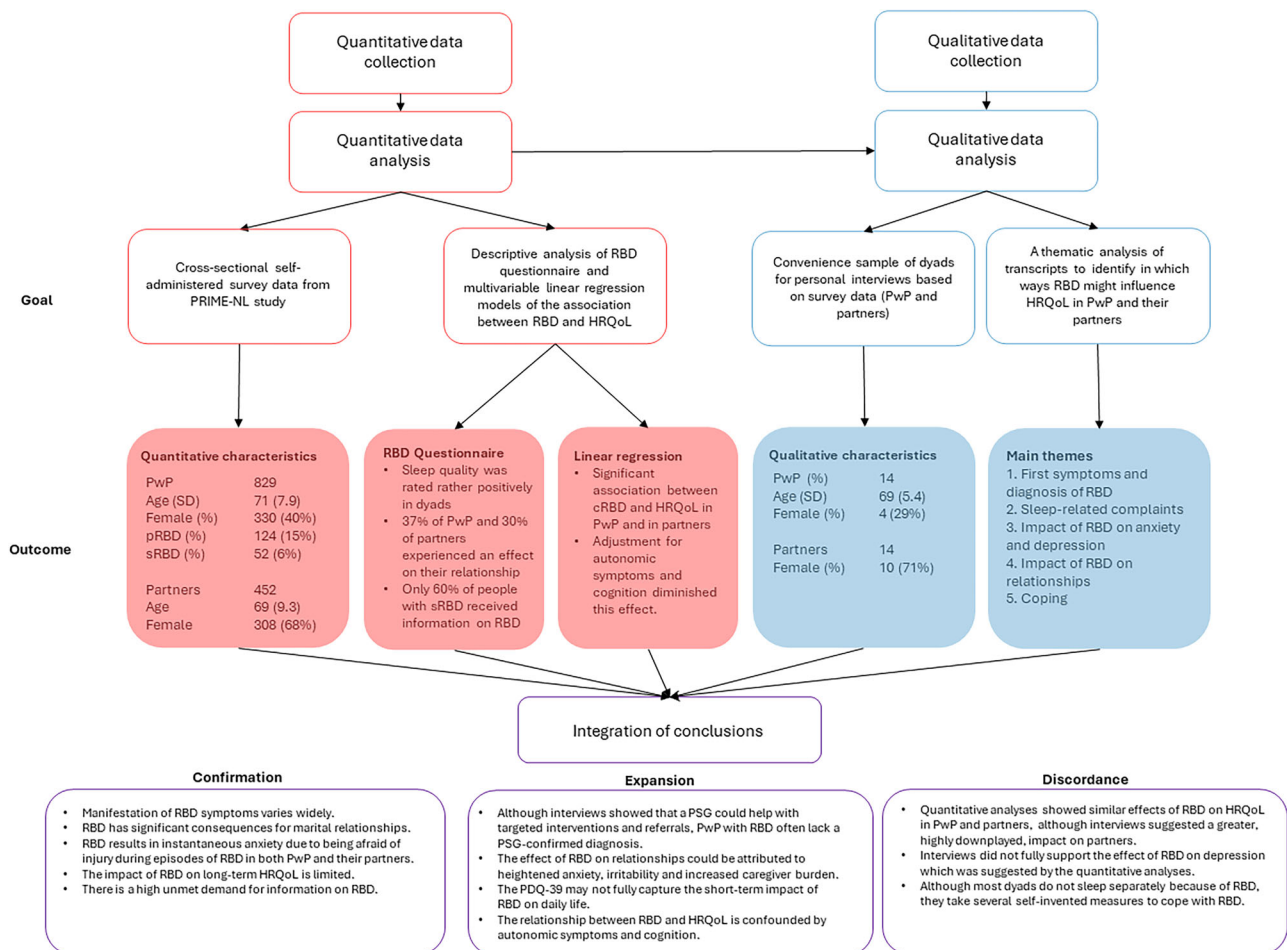


Fig. 3 | Mixed-methods study design. PwP people with Parkinson's disease, HRQoL health-related quality of life, pRBD probable RBD, sRBD self-reported RBD, cRBD combined RBD.

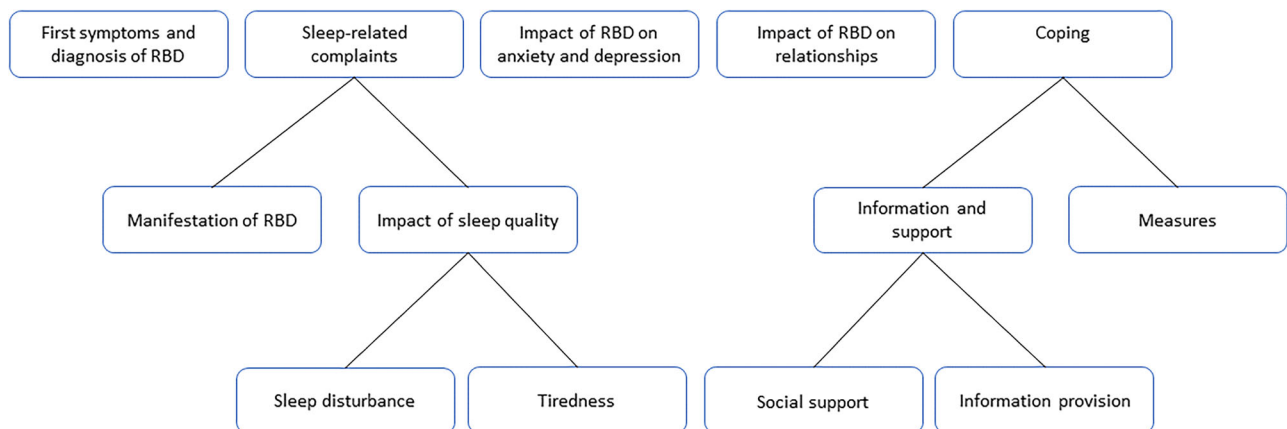


Fig. 4 | Themes defined by the qualitative analysis.

Theme 1: first symptoms and diagnosis of RBD

Interviewees mentioned that RBD symptoms gradually progressed from increased dreaming to talking or shouting, and eventually kicking or hitting. RBD diagnosis often occurred years after the first symptoms, commonly coinciding with a PD diagnosis. Neurologist intervention for RBD was often only sought subsequent to the PD diagnosis. Many interviewees initially thought a PSG was unhelpful, doubting its reliability and consequences. Nevertheless, when performed, this

diagnostic led to targeted treatments or referrals and increased satisfaction.

"At one point we did such a sleep study. [...] We went to a specialist through the neurologist himself and he indeed prescribed some kind of drug, clonazepam. And from that moment on it became quieter, while now it is becoming more and more again. So in the beginning [after the sleep study], which was a few years ago, it was really a relief." [partner 3]

Table 3 | Illustrative quotes

Key theme	Subtheme	Illustrative quote ^a
First symptoms and diagnosis of RBD		<p>"I doubt its effectiveness and value. I think even if you were in a [sleep] center where you lived for a week with a reasonable daily rhythm and observation at night, with such a helmet on or whatever, you could achieve a result within 7 days. But I do not think just once makes any sense." [partner 5]^b</p> <p>"At one point, we did such a sleep study. [...] We went to a specialist through the neurologist himself, and he indeed prescribed some kind of drug, clonazepam. And from that moment on it became quieter, while now it is becoming more and more again. So in the beginning [after the sleep study], which was a few years ago, it was really a relief." [partner 3]</p> <p>"I have always been a bad sleeper, anyway. Even before I knew I had Parkinson's, I also had dreams, but not to the extent of after being diagnosed, and after I started taking medication. I do not know whether the medication has an influence on this, but it actually started quite quickly afterwards." [PwP 6]</p>
Sleep-related complaints	Manifestation of RBD	<p>"It was a really loud scream, [...] I sat upright in my bed, with my heart pounding. I thought, 'what is happening here?'" Not once, but it was really often that she did that." [partner 3]</p> <p>"Those are often not the pleasantest dreams, often involving violence. I do not have the feeling that I am experiencing or processing trauma, it is quite bizarre sometimes. [Interviewer: so quite random?] Quite random indeed, what the subject is and whether I [for example] hit children. That is a little bit traumatic because you should not do that of course. Or I grab my wife, I have also dreamt of that sometimes, and then it actually happened, once. But yes, that is part of it of course." [PwP 1]</p>
	Impact of sleep quality—Sleep disturbance	<p>"Those wild nights, it often starts to simmer before it gets really intense, and then I often wake up already. Then I am half asleep, but I am already on my guard. Sometimes I see her moving in her sleep, then she turns over, and then she wants to kick me out of bed too. Then I lie on the edge of the bed, as far away as possible, so that nothing happens." [partner 6]</p> <p>"As a partner, I would find it quite annoying if you had to get up early the next day, because I really have sometimes almost punched him and kicked him out of bed. That seems very frustrating to me." [PwP 6]</p>
	Impact of sleep quality—Tiredness	<p>"Then he is so terribly tired in the morning that I just let him sit on his bed for half an hour until he recovers." [partner 12]</p> <p>"You cannot just blame everything on the complaints of [name partner] because it is just a part of myself." [partner 13]</p>
Impact of anxiety and depression		<p>"During the time that he was sleeping so poorly, I also noticed that he became a bit more sad. Not super depressed, but despondent, heavy. [name of partner] is in any case someone who sees obstacles in the way rather than solutions and during the time when he slept poorly, this was very noticeable. [...] Mentally speaking, I think that since he sleeps better, he can also handle more things." [partner 8]</p> <p>"I was just awake for three nights because I did not dare to sleep anymore. Then I thought, something has to change, because this does not work like this." [partner 10]</p>
Impact of RBD on relationships		<p>"My wife has been suggesting more and more lately that we should sleep separately, but then you start living completely like brother and sister and I do not want that. Bad things are also part of it, it is what it is. [partner 6]"</p> <p>"I find it soothing, and of course we are used to it now. The first time I slept through the night, I did not hear him. I felt completely guilty. But I do not have that anymore. I mean he likes sleeping there [...] Yes, and we are actually used to it. And you can also cuddle during the day." [partner 12]</p> <p>"Well, the relationship will come under quite a bit of pressure, because I want him to understand how I feel, but of course I also have to be clear about what I want him to show compassion for. I just assume he knows it all, but of course it doesn't work that way. That is difficult. But I also hear that more often from other PwP." [PwP 3]</p>
Coping	Information and support—Social support	<p>"I think about what they think, that it must be very bad, that it greatly irritates me because I talk about it. But that is thinking what others think. But it is fine when I talk to my sisters, they also know [partner's name] well and they know what is going on." [partner 4]</p> <p>"For example, I believe I sleep relatively short, and other people are sometimes laconic about it because according to them, everyone suffers from that sometimes. That is not very encouraging to talk about it with others, no." [PwP 5]</p> <p>"That was discussed a while ago. There was a lecture, and then the speaker said, I do not know how he said it, he was talking about kicking and punching during REM-sleep. And the whole room was buzzing [because of the feeling of recognition]. [partner 7]</p>
	Information and support—Information provision	<p>"The thing that is very important for the partner of a person with Parkinson's disease is to pay attention [to RBD] because they do that for a reason. Not sleeping well, there are hundreds of people who sleep poorly, but for this, there was a reason. And I think that as soon as the neurologist of a Parkinson's patient hears that, a bell should ring." [partner 10]</p> <p>"I often left the neurologist within five minutes, and I was often frustrated about that. Now more attention is paid to non-physical symptoms, but that has not been the case for a long time. Those answers from which you think they are simply of no use to me. And now you are stuck with those lists that mean you do not actually see the neurologist very often, if you do, it must be really urgent." [PwP 5]</p>
	Measures	<p>"And what I really felt good about was adjusting sleep hygiene. A very clear, fixed rhythm: at 10 o'clock I take a shower, after I shower I go downstairs to read a book. No television, no telephone [...] no blue light, no more coffee after 6 PM. I am very strict about that and that has actually been a very good step." [PwP 8]</p> <p>"And yes, the neurologist then says, you can get medication for it, but I think I already have enough. So as long as [name of partner] does not threaten to leave me, I will not take medication for it." [PwP 2]</p> <p>"The doctor got me to sleep again with sleeping pills, because I did not dare to sleep anymore. And I personally think that it is somewhat unrecognized in Parkinson's. Then they say 'yes, yes, sleep, just go and lie a little more separately', but it does not work that way." [partner 10]</p>

^aAll quotes have been translated from Dutch to English.^bThese numbers correspond to the patient numbers in Supplementary Table 5.**Theme 2: sleep related complaints**

Nighttime behaviors in people with RBD varied widely, both among and within individuals. Manifestations included talking, counting, singing, screaming, cursing, sitting up, scratching, petting, grabbing, hitting,

kicking, squeezing, and rarely walking or falling out of bed. Partners often noticed powerful movements, possibly overlooking subtler movements when sleeping. If injuries occurred, partners were most often affected. Many couples experienced periods with worsening of RBD symptoms,

some related this to stress, and expressed their concerns about symptom progression.

Dreams with RBD behaviors ranged from everyday scenarios to improbable situations. Although themes were often random, some repetitive patterns emerged, with dreams sometimes reflecting recent experiences. Dreams were vivid, realistic, and emotionally charged, with fear, anger, and frustration playing prominent roles. Partners occasionally doubted whether to wake PwP from these dreams, and many couples made agreements on this based on what worked best.

“Those are often not the pleasantest dreams, often involving violence. I do not have the feeling that I am experiencing or processing trauma; it is quite bizarre sometimes. [Interviewer: so quite random?] Quite random indeed, what the subject is and whether I [for example] hit children. That is a little bit traumatic because you should not do that, of course. Or I grab my wife, I have also dreamt of that sometimes, and then it actually happened, once. But yes, that is part of it, of course.” [PwP 1]

Most PwP did not consider RBD highly disabling as it did not significantly affect their sleep quality. Nonetheless, many struggled with the idea of keeping their partner awake. Partners experienced RBD symptoms of PwP more intensely, leading them to stay awake, sometimes anxiously, and needing time to recover after severe episodes. They were vigilant about RBD behaviors, which disrupted their sleep or caused trouble falling asleep, though they became well-equipped to predict quiet or active nights. Over time, partners often grew accustomed to RBD, reducing their concerns and allowing them to fall asleep more quickly.

“As a partner, I would find it quite annoying if you had to get up early the next day, because I really have sometimes almost punched him and kicked him out of bed. That seems very frustrating to me.” [PwP 6]

Some PwP recognized increased tiredness after severe RBD symptoms or after having been woken up by their partner. Partners also noticed reduced clarity and concentration in PwP after nights with intense RBD behaviors. Partners usually downplayed their own tiredness, although they expressed the need to take it easy, take naps, and, in one instance, even take off mornings from work after restless nights. In general, partners appeared hesitant to blame the PwP for their tiredness.

“Then he is so terribly tired in the morning that I just let him sit on his bed for half an hour until he recovers.” [partner 12]

Theme 3: impact of RBD on anxiety and depression

RBD often disrupts nights and decreases energy, thereby leading to increased irritability and stress, exacerbating PD challenges and reducing mental resilience in couples. Many interviewees also experienced that heavy emotions during the day or an excess of stimuli led to more RBD behaviors.

Some PwP mentioned fear of intense nightmares, although fear was mainly related to possibly injuring their partners. Many PwP demonstrated compassion towards their partners, were shocked by their own RBD symptoms, and felt guilty if their behavior affected their partners or caused fear. Partners, in turn, commonly feared injury both to themselves and the PwP.

No interviewee reported feeling ashamed of RBD symptoms. However, various interviewees mentioned concerns with neighbors or children noticing RBD behaviors. In unknown environments, some partners were also more alert to RBD behaviors, for example, to make sure other guests were not awakened, when staying in a hotel.

“During the time that he was sleeping so poorly, I also noticed that he became a bit more sad. Not super depressed, but despondent, heavy. [name of partner] is, in any case, someone who sees obstacles in the way

rather than solutions and during the time when he slept poorly, this was very noticeable. [...] Mentally speaking, I think that since he sleeps better, he can also handle more things.” [partner 8]

“I was awake for three nights because I did not dare to sleep anymore. Then I thought, something has to change, because this does not work like this.” [partner 10]

Theme 4: impact of RBD on relationships

Measures to address RBD, including separate duvets or beds, or sleeping in different rooms, were sometimes seen as possible relationship obstacles. Sleeping in different rooms was often proposed by PwP when RBD symptoms might worsen, but most partners did not seriously consider this measure in order to prevent potential strain on the relationship. Those who did sleep separately felt initial guilt, but grew accustomed to the situation and noted that intimacy was still possible during the day.

“I find it soothing, and of course, we are used to it now. The first time I slept through the night, I did not hear him. I felt completely guilty. But I do not have that anymore. I mean, he likes sleeping there [...] Yes, and we are actually used to it. And you can also cuddle during the day.” [partner 12]

Partners commonly experienced initial frustration, anger, and anxiety, especially during aggressive episodes and periods with frequent nighttime falls or injuries. However, they often downplayed their struggles with RBD, seeking help from professionals only when truly exhausted.

The impact of RBD on children was generally limited because most children of our interviewees had already moved out. In some cases, however, participants thought daytime irritability from RBD-related tiredness affected interactions with children.

Theme 5: coping

Many couples stressed the importance of open discussions about RBD symptoms. Partners often briefly and lightheartedly recounted nighttime events, considering the PwP's limited awareness of RBD symptoms. PwP hoped that their partners would inform upon troublesome symptoms, but many sensed that their partners withheld information to protect them. The impact of RBD was not discussed in depth, although a few mentioned that a neurologist visit might prompt discussions.

Couples often hesitated to share nighttime experiences with others, considering sleep a personal matter. RBD symptoms were discussed in general terms only with close friends or family. Explaining RBD to those unfamiliar with the context was challenging, often met with a lack of understanding or dismissive responses. Some partners preferred discussing sensitive topics with friends, who handled them better than their partner.

“I think about what they think, that it must be very bad, that it greatly irritates me because I talk about it. But that is thinking what others think. But it is fine when I talk to my sisters, they also know [partner's name] well, and they know what is going on.” [partner 4]

Recognition of RBD symptoms during lectures or informal settings with peers was appreciated, allowing exchange of coping strategies and medication experiences. However, many were aware that RBD manifests differently in each person and not all solutions work universally.

“That was discussed a while ago. There was a lecture, and then the speaker said, I do not know how he said it, he was talking about kicking and punching during REM-sleep. And the whole room was buzzing [because of the feeling of recognition].” [partner 7]

Couples considered RBD one of many PD symptoms that they must learn to cope with. Once familiar with the nighttime behaviors and measures

were taken to prevent injury, the impact of RBD decreased, and couples often forgot its previous impact. Some approached RBD with humor, making jokes about bedtime behaviors, together or with close friends and family. Partners often showed selfless behaviors and chose to deal with RBD themselves without blaming the PwP. However, many mentioned that open communication about nighttime behavior helps to prevent feelings from being bottled up.

"For example, I believe I sleep relatively short, and other people are sometimes laconic about it because, according to them, everyone suffers from that sometimes. That is not very encouraging to talk about it with others, no." [PwP 5] Information and support—information provision

The need for information about RBD varied, with a greater need in the initial phase of RBD. Interviewees gathered information from various sources, including fellow PwP, Parkinson café meetings, ParkinsonTV, the Parkinson association website and newsletters, scientific articles, and healthcare providers. Some were familiar with RBD symptoms before experiencing them, although others never received proper information about RBD from their neurologist.

"The doctor got me to sleep again with sleeping pills, because I did not dare to sleep anymore. And I personally think that it is somewhat unrecognized in Parkinson's. Then they say "yes, yes, sleep, just go and lie a little more separately", but it does not work that way." [partner 10]

Couples felt that general neurologists might not have prioritized sleep symptoms enough, and felt reluctance to initiate discussions about RBD. Some were content with alternative sources of information, referring to the neurologists' demanding schedule. Others felt their concerns were not addressed, and even changed neurologists because sleep problems were not taken seriously. Partners emphasized the importance of recognizing and listening to them and providing a supportive presence during neurologist consultations. They often felt neglected while they experienced most consequences of RBD. Building a good connection with the neurologist and the PD nurse, who often has more time and provides more practical tips, was found crucial. Many interviewees also expressed a need for specialized RBD care that reaches beyond medical advice. They highlighted the importance of a holistic approach that includes psychological support, education about the disorder, and strategies for managing daily life challenges. Interviewees who had a specialized PD neurologist tended to be more satisfied because the health professional paid more attention to sleep issues.

"The thing that is very important for the partner of a person with Parkinson's disease is to pay attention [to RBD] because they do that for a reason. Not sleeping well, there are hundreds of people who sleep poorly, but for this, there was a reason. And I think that as soon as the neurologist of a Parkinson's patient hears that, a bell should ring." [partner 10]

"I often left the neurologist within five minutes, and I was often frustrated about that. Now, more attention is paid to non-physical symptoms, but that has not been the case for a long time. Those answers from that you think they are simply of no use to me. And now you are stuck with those lists that mean you do not actually see the neurologist very often, if you do, it must be really urgent." [PwP 5]

Interviewees often experimented with different measures and adhered to those that proved most effective. Partners often lied as far away as possible from the PwP with their backs turned against them, placed a pillow in between, or used separate mattresses and duvets to prevent injuries. Many also had an extra bedroom as a precaution, to which partners resorted during severely disruptive nights. Some interviewees slept in separate rooms, but usually kept the door open to feel connected or keep an eye out. Mats or gates were employed if the PwP fell out of bed.

Many interviewees noticed that stress during the day impacted nighttime RBD symptoms, which prompted some to practice relaxation exercises or to establish a strict bedtime routine, avoiding intense TV, caffeine, screens, or alcohol hours before bedtime. Some PwP found significant benefits from visiting sleep psychologists who proposed sleep hygiene solutions.

"And what I really felt good about was adjusting sleep hygiene. A very clear, fixed rhythm: at 10 o'clock I take a shower, after I shower I go downstairs to read a book. No television, no telephone [...] no blue light, no more coffee after 6 PM. I am very strict about that, and that has actually been a very good step." [PwP 8]

Most PwP were initially hesitant to take sleep medication for RBD symptoms, preferring alternative measures. Some also mentioned not wanting to initiate sleep medication because their own sleep quality was not impaired by RBD. Melatonin and clonazepam were, however, sometimes used and led to a significant decrease in severity of RBD symptoms. These medicines also reduced the impact of RBD and alleviated uncertainty for partners. In exceptional cases, partners of PwP took sleep medication to suffer less from the RBD behaviors of their partner.

"And yes, the neurologist then says, you can get medication for it, but I think I already have enough. So as long as [name of partner] does not threaten to leave me, I will not take medication for it." [PwP 2]

Many couples emphasized the importance of open discussions about RBD to prevent bottled-up feelings, often sharing nighttime events lightly or with humor. Nevertheless, partners often showed selfless behaviors and sometimes withheld information to protect PwP. Couples were hesitant to share experiences outside their close circle due to the personal nature of sleep problems and fear of dismissive responses. Recognition of RBD in peer settings was valued for exchanging coping strategies.

Qualitative analysis of sleep clinic participants

We interviewed two additional participants with polysomnography-confirmed RBD who were recruited from sleep centers (Kempenhaghe and SEIN) and their partners. Several differences were noted between the interviews within PRIME study participants and the two additional interviews. Firstly, in contrast to the regular interviews, these two patients did not have PD at the time of the RBD diagnosis and were informed about the risk of developing PD by their somnologist. This led to a highly uncertain period with the looming risk of developing PD. Value was found in consulting a somnologist for in-depth expertise, regular contacts, and occasional sleep studies to provide ongoing monitoring.

Secondly, the two interviewed patients showed more serious RBD symptoms than the other interviewees, including throwing objects, jumping out of bed, and causing regular or serious injuries. These RBD behaviors improved importantly with medication. While the idea of lifelong dependence on RBD medication was unpleasant, maintaining a normal life took precedence.

In addition, more elaborate measures were taken by the interviewees, including removing all potential risks from the bedroom, installation of safety features, and meticulously checking holiday accommodations for safety. Also, partners occasionally used sleep medication, although they tried to avoid complete dependence on sleeping pills.

Thirdly, interviewees with RBD experienced a lack of energy during the day, especially disturbing when still working, which they attributed at least partly to RBD. Disturbed nights, moreover, frequently depleted mental energy and increased stress. Mental effort of the day was also processed in the sleep, which made RBD complaints worse.

Finally, because RBD was going on for a longer period of time in these patients, the partners were more accustomed to the consequences. Despite these challenges that RBD posed, partners remained selfless and, for

instance, dismissed a bruise as merely a temporary issue. RBD certainly affected the partners' sleep, but couples adjusted their rhythms or took measures in order to live with it. It was, however, hard for interviewees to explain to others what RBD is. Many people did not seem to understand the nature of the sleep disorder or were even afraid that the affected person was going to hurt them.

"You sleep as if you have small kids, listening to see if anything is happening, and you do the same with someone like that. You always sleep with your ears open." [partner sleep clinic]

Integration of qualitative and quantitative results

An overview of the integration of results can be found in Fig. 3. Both quantitative and qualitative analyses revealed a wide variety of RBD manifestations and an impact of RBD on marital relationships. Additionally, both analyses revealed short-term fear for injuries, but supported that the long-term impact of RBD on HRQoL is limited. The interviews expanded the quantitative results by explaining that although in clinical practice PSGs are often not performed, this diagnostic would help to introduce targeted interventions. Furthermore, qualitative analyses showed that the PDQ-39 may not fully capture the short-term impact of RBD on daily life and provided understanding of how marital relationships could be influenced by RBD. Quantitative analyses supported that autonomic symptoms and cognition are important confounders in the association between RBD and HRQoL. Discordance in the quantitative and qualitative results was found in the association of RBD with depression, which was only captured by quantitative analyses. Additionally, although interviews revealed that partners experienced a greater impact on RBD, this difference was not as clear in quantitative results. Finally, quantitative results showed that drastic measures, such as separate beds, were often not taken by PwP and partners, but interviews revealed many other ways of dealing with the impact of RBD.

Discussion

In this mixed-methods study, we aimed to identify whether and in which ways RBD influences HRQoL in PwP and their partners. Our quantitative results showed that RBD is associated with worse HRQoL in both PwP and their partners, but this association is largely confounded by other non-motor symptoms co-existing in PwP with RBD. Our qualitative findings revealed that RBD can affect the daily lives of PwP and partners on several themes related to the diagnostic process, sleep-related complaints, anxiety, and marital relationships. Finally, this study identified manners in which the impact of RBD could potentially be reduced.

Our observation that CRBD was strongly associated with autonomic symptoms and cognition, but not with motor symptoms^{9,10}, corroborates previous observations that RBD might highlight a body-first subtype of PD¹¹. This subtype is linked to poorer cognitive, functional, and emotional outcomes and can, to a certain extent, also explain the association with HRQoL, anxiety, and depression^{3,5,12–16}. Although studies previously reported an association between RBD and HRQoL^{1,3,17}, only one study so far included autonomic symptoms as a measure of interest and showed a profound association with RBD³. These important confounders should be considered in future research.

Qualitative analysis offered a more detailed insight into the influence of RBD on daily life. Interviews revealed a direct link between RBD and short-term anxiety of injury, but did not support a link with depression, although less mental resilience after severe RBD episodes was mentioned and an influence of daytime stress on symptoms, as suggested by previous literature⁶, was also found. RBD had only limited impact on sleep of PwP, but significantly affected sleep of their partners. Surprisingly, in quantitative analyses, partners rated their overall sleep quality relatively positively, possibly suggesting that this effect is only temporary or may be greater than partners acknowledge.

Both our quantitative and qualitative analyses showed the impact of RBD on interpersonal relationships. This aligns with previous research

linking RBD to decreased QoL in marital relationships¹⁸. Our integrative results revealed that this link could be attributed to heightened anxiety, irritability, and sometimes guilt. The impact of RBD on children and work was more limited than we expected, which might be explained by our sample, with an average age of 71 years. Such negative effects will likely be more pronounced in younger PwP¹⁹.

A large information gap was found in this study, with 40% of PwP with diagnosed RBD not receiving information on RBD and 62% of PwP with several RBD symptoms but without a formal diagnosis. Also, partners are often not prioritized enough in consultations. These results serve as a reminder for healthcare providers to actively ask PwP about sleep problems, individualize information provision, and involve partners in these consultations. Furthermore, a referral to a specialized sleep clinic should be considered, because our study showed that referred patients and partners found comfort in the support of a somnologist and valued the specific information and strategies that they offered.

There are various ways in which the impact of RBD could be reduced. While our study showed that separate bedrooms are beneficial for some couples, many found it, similarly to previous findings¹⁸, to be a bridge too far. Nevertheless, with help of healthcare providers, peer groups, or creative thinking, PwP and partners came up with many solutions to challenges caused by RBD. Healthcare providers are to be reminded to encourage couples to collaboratively explore the advantages of self-management, coping strategies, and safety measures. This includes considering alternative approaches such as stress management and maintaining a healthy bedtime routine. If these methods prove insufficient, the possibility of medication can be discussed as part of a shared decision-making process.

A strength of our study includes the large and representative sample of PwP in the general population²⁰. Additionally, we have provided a unique insight into the often left-out perspective of partners, although different effects may be seen in PwP without a partner or living alone, which is of interest to future studies. Moreover, we actively involved patient researchers in co-creating the study design, which prevented us from leaving out unforeseen relevant questions in interviews and in our RBD questionnaire. Finally, using both quantitative and qualitative methods, we were able to triangulate our findings and understand the association between RBD and HRQoL more in-depth. We would invite future studies to not only explore how qualitative data influences quantitative analyses, but also to examine the reverse relationship.

Several limitations of this study should be considered. First, most participants with RBD were not diagnosed using PSG, which is the gold standard³. In clinical practice, however, PSGs are often not performed, and our study thus resembles the real-world situation. Clinical judgment and validated questionnaires often lead to higher prevalences of RBD^{1,3,5,21}, but in our study, this prevalence was 21%, which is even lower than the often described 30–50% prevalence of RBD in PwP^{22,23}. Second, although a significant improvement of the topic guide and interviewing enhanced the quality of the interviews iteratively, first performing a couple pilot interviews could have led to more detailed questioning from the start. Third, the low UPDRS-II mean score, H&Y scores, and relatively short disease duration suggest that our study population primarily consisted of individuals with mild to moderate PD, which may slightly limit the generalizability of our findings to the broader PD population²⁴. Future research should include individuals with more advanced PD to improve the accuracy and applicability of the results. It is also important to note that information on levodopa and dopaminergic agonist dosages—medications known to cause autonomic disturbances and affect sleep architecture^{25,26}—was unavailable, which may influence severity of sleep-related symptoms, including RBD symptoms. A final limitation of this study includes the cross-sectional design, which prevents us from drawing causal relationships. However, with our qualitative data, we were able to shed light on possible pathways of the association between RBD and HRQoL.

In summary, our mixed-methods study contributes valuable insights into the effects of RBD on HRQoL in PwP and their partners. With only a small portion of PwP receiving an RBD diagnosis using PSG in clinical

practice, clinicians should consider that PwP are often unaware of RBD symptoms and lack sufficient information about their condition. Future qualitative research should focus on the impact of an RBD diagnosis in individuals without PD. For quantitative research, the primary challenge lies in conducting longitudinal analyses of the effect of RBD on HRQoL. In this way, we can further explore effective strategies for managing RBD and improving quality of life in PwP and their partners.

Methods

Quantitative data collection and measures

This cross-sectional study was embedded within the third year of the PRIME-NL Parkinson Evaluation study, a prospective observational study among people with parkinsonism, informal caregivers, and healthcare professionals in the Netherlands²⁰. Eligible for the quantitative part of this study were PwP who (i) were clinically diagnosed with PD by a neurologist and/or GP (Supplementary Table 1); (ii) visited the neurology outpatient clinic of a community hospital at least once during the past year; and (iii) filled out an RBD questionnaire as part of the study questionnaires. Partners of eligible patients were included if they filled out the RBD questionnaire. Data were gathered through self-administered online questionnaires and telephone interviews conducted between January 2022 and February 2023. The PRIME-NL study was reviewed and approved by the Ethical Board of the Radboud University Medical Center (file number: 2019-5618). All participants provided written informed consent.

In the RBD questionnaire, participants indicated whether they were diagnosed with RBD (self-reported RBD (sRBD)). If not, participants completed an additional question (RBD1Q)²⁷, a validated “yes-no” question with a sensitivity of 93.8% and a specificity of 87.2% in the general population. If the single-question was screen-positive, participants completed five subsequent screening questions based on the Innsbruck RBD Inventory to further increase the positive predictive value^{28,29}. A score of four or higher on the five-question screening was considered as probable RBD (pRBD); “I do not know” was assigned half a point²⁸.

Both individuals with sRBD and pRBD were included in the analyses (combined RBD (cRBD)), and the answers of PwP, not of partners, determined the cRBD status. The RBD questionnaire additionally included questions on the manifestation and impact of RBD.

HRQoL in PwP was measured using the Dutch version of the PDQ-39³⁰ for PwP and the PDQ-Carer³¹ in partners. Items were scored on a five-point scale, ranging from 0 (“never”) to 4 (“always”), and a total score from 0 to 100 was calculated, with higher scores indicating worse HRQoL.

The following socio-demographic variables were included: gender, age, education level, disease duration, work status, and living situation. We solely included covariates that were potential confounders, including autonomic symptoms and cognition, for which the directed acyclic graph (DAG)³² is shown in Supplementary Fig. 1. Work status was recoded to two categories, including having a paid job or either an unpaid or no job. Living situation consisted of living alone, living with a partner or family, and living in facilitated care. Education level was subdivided into three levels: primary education, secondary education, and higher education.

Motor symptoms were assessed with part II of the MDS-Unified Parkinson's Disease Rating Scale (MDS-UDPRS). This is a 13-item questionnaire on which participants can score symptoms on a 5-point Likert scale ranging from 0 (“normal”) to 4 (“severe”). The total score results from the sum of the items, with a maximum of 52³³. Autonomic symptoms were measured using the SCOPA-AUT. This questionnaire consists of 25 items assessing the following regions: gastrointestinal (7), urinary (6), cardiovascular (3), thermoregulatory (4), pupillomotor (1), and sexual (2 items for men and 2 for women) dysfunction. Scores ranged from 0 (“never”) to 3 (“often”) and were summed, excluding the sexual dysfunction questions, with a maximum score of 63³⁴. The State-Trait Anxiety Inventory for adults (STAI) was used to evaluate the level of anxiety³⁵. The STAI measures two dimensions: (1) state anxiety, which assesses the current emotional state of anxiety, and (2) trait anxiety, which refers to the type of anxiety characteristics for the individual's personality. The STAI composes of 40 items

and is based on a 4-point Likert scale ranging from 0 (“almost never”) to 3 (“almost always”). The total score of each dimension ranges from 20 to 80. We only used the state anxiety. The Beck Depressive Inventory (BDI) is a 21-item questionnaire, which was used to measure the severity of depressive symptoms³⁶. Each item is composed of four statements, each depicting a particular symptom. Participants can score each item on a 4-point Likert scale ranging from 0 (“no symptoms”) to 3 (“very intense symptoms”). Total BDI scores range from 0 to 63. Cognition was measured using the MoCA administered by telephone (T-MoCA). The T-MoCA generates a total score with a maximum of 22 points, eliminating the items from the MoCA that require visual stimuli or the use of paper and pencil³⁷. MoCA scores were additionally corrected for missing place and city (+2), as these could not be verified remotely, and for day of the week (+1, if missing). Caregiver burden was measured using the Zarit Burden Interview, consisting of 22 items³⁸. Questions were scored on a Likert scale from 0 (“Never”) to 4 (“Nearly Always”), with a total sum score ranging from 0 to 88.

Qualitative data collection

PwP eligible for the qualitative part of this study had to (i) be included in the quantitative analysis; (ii) have sRBD; (iii) have a partner participating in the study, and (iv) be willing to be interviewed. Partners of eligible PwP willing to be interviewed were also eligible. Only PwP with sRBD were included, as this group was most relevant for questions about the diagnostic process and evaluation of care, and it ensured a higher certainty of RBD diagnosis. Of all eligible participants, a convenience sample of dyads was selected for the interviews.

An interview guide, created together with co-authored neurologists, somnologists, and patient researchers, was used for the semi-structured interviews (Supplementary Table 2). This guide covered broad topics such as RBD diagnosis, symptoms, and treatment, and questions on quality of life, cognition, anxiety, and depression. Interviews were conducted either at the participants' home or at the Radboud University Medical Center. No relationship was established between the researchers and interviewees prior to the study. Interviews were held with PwP and partners separately, for the participants to be able to speak freely. Interviewees gave written informed consent on (i) audio recording, and (ii) information retrieval about their RBD diagnosis from their GP or neurologist.

Data analysis

R Studio (version 4.1.3) was used for all analyses. The RBD questionnaire was descriptively analyzed. Multivariable linear regression analyses were built to assess the association of cRBD with autonomic symptoms and cognition, motor symptoms, anxiety, depression, and HRQoL in PwP, and with HRQoL and caregiver burden in partners. Model 1 was adjusted for age and gender, model 2 additionally for education level, living situation, work status, and disease duration and, model 3 additionally for autonomic symptoms and cognition. HRQoL was inverted prior to analysis (higher scores representing better HRQoL), and all outcomes were standardized.

Interviews were transcribed and analyzed with Atlas TI (version 5.20). Data analyses were conducted concurrently with the interviews, and preliminary results were used to adjust the interview guide. Initial codes were created based on the interview guide, which were extended and adapted iteratively. All transcripts were coded and analyzed back-to-back by two authors [EMP, NV]; disagreements were resolved by discussion. Themes were formulated by three authors [EMP, NV, LJD] and adapted with input of all co-authors. Data saturation was reached after 20 interviews, 10 with PwP and 10 with their partners. Four more interviews with PwP and four partners were then conducted to validate that additional information did not lead to new insights.

We used a convergent parallel design³⁹ to identify areas of convergence or divergence between qualitative and quantitative results. Qualitative and quantitative data were collected simultaneously, analyzed separately, and compared in a final analysis. The quantitative approach provided insight into the relationship between RBD and HRQoL in a large sample of PwP and partners, but was not expected to help disentangle underlying

mechanisms. The qualitative analysis, although less generalizable to the broader population of PwP, did provide insight into these mechanisms by creating a nuanced view on personal experiences and contextualizing the impact of RBD on daily lives. The qualitative and quantitative findings thus complemented each other. A visual representation of the study design can be found in Fig. 3.

We performed two sensitivity analyses. First, we repeated the analyses with a more strict definition of RBD, including only participants with sRBD ($n = 52$). Second, we interviewed two additional participants with RBD and their partners recruited at a sleep center in order to determine the impact of RBD in participants with presumably more severe symptoms.

Data availability

The data generated during the present study are available from the corresponding author for researchers who have a specific question that can be answered with this data.

Code availability

The code generated for the analysis will be available upon request.

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Author contributions

1. Research project: A. Conception, B. Organization, C. Execution; 2. Statistical Analysis: A. Design, B. Execution, C. Review and Critique; 3. Manuscript Preparation: A. Writing of the first draft, B. Review and Critique. E.M.P.: 1A, 1B, 1C, 2A, 2B, 3A. AP: 1A, 1B, 2C, 3B. N.V.: 2A, 2B, 3A. S.K.L.D.: 1A, 1B, 2A, 2C, 3B. A.D.G.: 1A, 2C. M.J.M.: 1A, 2C, 3B. B.R.B.: 2C, 3B. K.D.D.: 1A, 1B, 2C, 3B. L.D.: 1A, 1B, 2A, 2B, 2C, 3B.

Competing interests

The authors declare no competing interests.

Additional information

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