



The Human Dimension of RBD

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*“In all of us, even in good men,
there is a lawless, wild-beast nature
which peers out in sleep.”*

(Plato, The Republic)

The human dimension of RBD encompasses the experience of RBD in the patient and in the spouse affected by the RBD, and the adverse physical, psychological, marital, and quality-of-life consequences from the RBD, including both idiopathic RBD (iRBD) and RBD associated with Parkinson’s disease (PD) and other neurological disorders.

2.1 The Experience of RBD in the Patient and Spouse

The typical clinical profile of chronic RBD consists of a middle-aged or older man with aggressive dream-enacting behaviors that cause repeated injury to himself and/or his wife. This profile was revealed in the first two large published series on RBD, involving 96 and 93 patients, respectively [1, 2]. In these two series, male predominance was 87.5 and 87%, mean age at RBD onset was 52 years and 61 years, dream-enacting behaviors were reported in 87 and 93% of patients, and sleep-related injury as the chief complaint was reported in 79 and 97% of patients. Injuries included ecchymoses, subdural hematomas, lacerations (arteries, nerves, tendons), fractures (including high cervical—C2), dislocations, abrasions/rug burns, tooth chipping,

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and hair pulling. RBD causing subdural hematomas has subsequently been reported in five additional cases [3–6]. A review of the published cases of RBD that were associated with potentially lethal behaviors identified choking/headlock in 22–24 patients, diving from bed in 10 patients, defenestration/near-defenestration in 7 patients, and punching a pregnant bed partner in 2 patients [7].

In the review just cited, the concept of “victim vulnerability factors” for increasing the risk of morbidity and mortality from vigorous RBD behaviors was discussed at length [7]. A “spectrum of vulnerability” can be formulated for RBD (and other parasomnias) whereby at one end of the spectrum is the degree of vigor and violence of the RBD behavior and at the other end of the spectrum is the degree of medical vulnerability of the victim (patient or spouse). Also, the fact that the patient or bed partner is asleep, and in which sleep stage (e.g., REM sleep with generalized muscle paralysis [REM atonia] in the bed partner or slow-wave NREM sleep in the bed partner predisposing to an agitated and violent confusional arousal induced by a RBD episode), or if the bed partner suffers from a sleep disorder predisposing to abnormal and potentially violent arousals (e.g., sleep apnea, sleep inertia, confusional arousals, sleep terrors, sleepwalking) would add an additional sleep-related vulnerability risk factor. The circumstances of the sleeping environment may also confer additional vulnerability. Some of the medical factors that can increase the morbidity and mortality risk from RBD behaviors include pregnancy, deafness, blindness, osteopenia, osteoporosis, bleeding disorder, anticoagulant therapy, status postsurgical procedure, spinal-vertebral disorder, and various advanced age-related vulnerabilities.

The experiences of the initial series of RBD patients and their spouses presenting to the Minnesota Regional Sleep Disorders Center beginning in 1982 were captured by audiotaped interviews (with signed permissions) that were transcribed and edited and then published in a book [8]. A powerful language was expressed when these patients and their spouses shared their amazing and harrowing “bedtime stories.” The strength and resilience of a successful, long-term marriage reveals how “true love can shine through the darkest of nights”. Usually patients with RBD have been married for decades before the onset of RBD, so the spouses know that the later-life onset of sleep violence is not reflective of the well-established waking personality. This is probably the main reason for having only two published cases of divorce and one case of marital discord related to RBD. Moreover, despite the risk of injury, the spouses (predominantly wives) often choose to sleep in the same bed, in order to protect the person (*viz.* husband) with RBD from becoming injured. On the other hand, RBD also carries a high risk for false accusations of spousal abuse, as described below.

A wide variety of self-protection measures have been used during sleep in RBD, including sleeping in a padded waterbed; putting the mattress on the floor; using pillow barricades; tethering oneself to the bed with dog leashes, belts, and ropes; etc. Also, misattributions about the cause of RBD are common among patients, family, friends, and physicians, including job-related stress in which the RBD would presumably resolve with retirement (not true, and often RBD progresses in severity after retirement), nocturnal psychosis, “familial alcoholic personality disorder”

coming out in sleep, dietary indiscretion, post-traumatic stress from combat exposure in World War II, or just “part of getting old, it’s one of those things that happens to older people.”

Melvin Abel was the second RBD patient in our initial series, and he made frequent media appearances, because of his likeability (along with his wife Harriet)—and because of his striking deer dream that was reported in *Stern* magazine (Germany), “Medicine: Hunting Deer Under the Blanket” (translation), March 24, 1988, and in *The New York Times* Sunday magazine cover story, by Chip Brown: “The Man Who Mistook His Wife For a Deer (And Other Tales From the New Science of Extreme Sleep),” February 2, 2003. What follows is the interview I had with Mel and Harriet on page 68 of *Paradox Lost* [8]:

Harriet: “You know, we would be sitting and talking to friends, and we would tell them what he dreamed the night before, and they would sit and laugh about it. Nobody knew how serious it was.”

Mel: “My deer episode. When I was a little kid, I lived on a farm with my grandparents. My grandpa and me were in the haymound pitching hay around. This was my dream: I saw two deer go by the haymound and I told my grandpa, ‘Did you see those deer?’ He said, ‘No, where did they go?’ I said, ‘They must have gone to the other end of the barn.’ He says, ‘I’ll go down and roust them out,’ and I said, ‘I’ll wait here with the pitchfork and maybe I can get the doe.’ All of a sudden, here came that doe and I bashed her as hard as I could across the neck and down she went and laid there and blatted. ‘I know how to fix that up; just get you by the chin and head, and snap your neck.’ I reached over—and I got Harriet by the chin, and I just put my hand on top of her head, and she let out a holler, and jumped out of bed and said, ‘What in the world are you trying to do?’ I then came-to and I sat there for a while and then I started to cry.”

Harriet: “He was afraid of hurting me and what could have happened. He was upset.”

Mel: “I told her, ‘God, am I glad that you woke me up.’ She says, ‘what were you trying to do?’ I said, ‘I was going to break that deer’s neck. Just think what would have happened if you wouldn’t have hollered.’”

Harriet: “Many times he would swing his arm and I thought I may get a black eye or broken nose. How am I going to say, ‘Look what happened to me while my husband was sleeping.’ Nobody would believe me.”

Additional dialogues, and comments on the imminent dangers posed by RBD, are contained in Tables 2.1 and 2.2.

There have been two reported cases of divorce related to RBD [9, 10]. The first case involved a 28-year-old Italian man with narcolepsy type 1 for 8 years, and subsequent RBD, who 3 years earlier had married an 18-year-old female [9]. His young wife reported that from almost the start of their marriage, he screamed and episodically hurt her during sleep by kicking and slapping her. After 2 years of marriage, one night at 4 a.m. while she was asleep, he violently punched her, and then he lay down again and resumed sleep. She went to another room and locked the door. The next morning she went to the hospital because of intense breast pain, and an ultrasound revealed a 4 cm³ hematoma. The police were notified by the doctor, but she refused to press charges. The husband was “astonished and mortified” and reported that he only recalled that he “attempted to escape during a dream.” After he punched her again (in the face) while asleep, they agreed to sleep in separate rooms.

Table 2.1 Sample dialogues of men with RBD and their wives^a

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|-------------------------------------|---|
| A 57-year-old man with RBD and wife | |
| • | “It seems like I am extra strong when I sleep”—man |
| • | “It almost seems like a force picks him up”—wife |
| • | “He is sleeping and his body is in motion”—wife |
| • | “I don’t think he ever could hit as hard while awake as he hits during sleep. A year ago he punched right through a wall board in our bedroom at our lake cabin”—wife |
| • | “Oh yes, there were always bloody sheets” wife |
| A 67-year-old man with RBD and wife | |
| • | “It’s amazing. You should see the energy behind that activity. Oh, it’s so unreal.”—wife |
| • | “He pounded my head one night and my head still hurt for another 2 weeks.”—wife |
| • | “His legs go fast, just like he’s running.”—wife |
| • | “We’ve put as much distance between us in bed as we can.”—wife |
| • | “I didn’t really sleep soundly until he got up in the morning.”—wife |
| A 65-year-old man with RBD and wife | |
| • | “I was wrestling someone and I had her by the head. What scares me is what a catastrophe that would be to wake up and find that I had broken her by the neck.”—man |
| • | “This went on for 3 years, and then I retired—but nothing changed afterwards whatsoever.”—man |
| • | “What happens to people like my husband who don’t get diagnosed? Do they kill their wives in these experiences? Do we know?”—wife |
| A 70-year-old man with RBD and wife | |
| • | “I didn’t remember the dream because I knocked myself out”—man |
| • | “The next morning I asked her what I had done, and she told me I had beat her”—man |
| • | “It was hard for me to sleep, because I never knew when I was going to get hit”—wife |
| • | “When all this started, I figured it was part of getting old, part of being normal, I guess”—wife |
| A 75-year-old man with RBD and wife | |
| • | “I just started kicking—the big, faceless, shapeless figures were still there. And my wife was afraid for herself, the dog, and for me”—man |
| • | “I told him I’d have a Devil of a time explaining how I got a broken arm in bed with both of us asleep”—wife |
| • | “When a man his size comes down on that floor, honestly, it’s a miracle he has not broken a hip or a shoulder”—wife |

^aFrom reference [8]

Table 2.2 Comments by patients and spouses on RBD behaviors causing imminent danger^a

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|------------------------------------|--|
| <i>1. Comments by RBD patients</i> | |
| | “I ran right smack into the wall, an animal was chasing me. I think it was a big black dog” (p. 157) |
| | “I thought I was wrestling someone and I had her by the head” (p. 136) |
| | “Pounding through the curlers into her head” (p. 157) |
| | “What scares me is what a catastrophe that would be to wake up and find that I had broken her neck” (p. 137) |
| | “I have hit her in the back too, and she has had a couple of (vertebral) disc operations.” (p. 143) |

(continued)

Table 2.2 (continued)

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| “One night I woke up as I was beating the hell out of her pillow...that’s when I realized that I had a problem” (p. 106) |
| “Just recently, I rammed into her pelvis with my head...during a dream.” (p. 93) |
| 2. <i>Comments by the wives</i> |
| “It’s amazing. You should see the energy behind that activity, oh, it’s unreal.”(p. 107) |
| “He literally just kind of flew out of bed and landed on the floor with tremendous strength” (p. 53) |
| “It almost seems like a force picks him up.” (p. 130) |
| “His legs go so fast, just like he’s running” (p. 155) |
| “It is his kicking, violent kicking, his feet are just like giant hammers when they hit you over and over again” (p. 73) |
| “I felt that kick on the ankle for two months afterwards” (p. 82) |
| “That’s the reason we got the waterbed—because he was wrecking his hands on the wooden bed” (p. 111) |
| “Oh, yes, there were always bloody sheets” (p. 105) |
| “Roaring like a wounded wild animal: he roared, he crouched, he punched” (p. 75) |

^aFrom reference [8]

Seven months later he underwent a full sleep evaluation that confirmed the diagnoses of narcolepsy type 1 and RBD. However, the wife was not fully convinced of the husband’s unintentional nocturnal violence, and 6 months later she left him and reported the nocturnal beatings. At trial, he was fully acquitted because the violence toward the wife was determined to have originated from sleep (i.e., RBD).

The second case of RBD causing divorce involved a 63-year-old Chinese man whose four consecutive wives had divorced him because of his aggressive and violent dream-enacting behaviors, including repeated biting [10]. For example, with his first wife, one night he dreamed that he was eating an apple, but instead he was biting her ear. On subsequent nights, during similar dreams he would bite her ears, nose, and face, which culminated with his wife divorcing him after 4 years of marriage. His three next marriages were also terminated by the wives on account of his repeated RBD-related sleep violence, including aggressive biting during dreams. These marriages had lasted 2.5 years, 10 years, and 1.5 years, respectively. In addition, three brief relationships with girlfriends were also terminated for the same RBD-related reasons. After the eventual diagnosis of RBD by clinical sleep evaluation and vPSG, therapy with clonazepam, 0.5 mg at bedtime, was successful in substantially controlling the RBD.

Another case of RBD with biting involved duloxetine-induced RBD in a 62-year-old woman who one night dreamed of biting something, but she was actually biting the hand of her grandson [11]. Also, in a series of 203 consecutive idiopathic RBD patients, the prevalence of biting in RBD was 8.4%, which usually involved bed partners [12]. The full range of personal consequences from the RBD in these 203 patients and their spouses is described in detail in Chap. 4 by Alex Iranzo, one of the authors of that study.

There was an additional published case of marital discord, without divorce, caused by RBD [13]. A recently married, young adult Taiwanese woman with RBD attempted suicide because her husband would not sleep with her at night after complaining that her RBD disrupted his sleep excessively and compromised his work productivity. Fortunately, once her RBD was diagnosed and effectively treated with clonazepam, the husband resumed sleeping with her (albeit in a larger bed), and their marriage was preserved.

Violent RBD carries an increased forensic risk, including both inadvertent death (“parasomnia pseudo-suicide” [14]) and inadvertent homicide [15]. The manifestations and associated issues related to milder forms of RBD are discussed in Chaps. 11, 15, and 16.

2.2 Other Issues Related to the Personal Experience of RBD

Although RBD usually features dream enactment of fighting with unfamiliar people or animals, a series of five patients with atypical dream-enacting behaviors in RBD has been reported, involving abuse/retaliation dreams, a culture-specific dream, and a religion-specific dream [16]. A 43-year-old female had repeated dream enactment observed by her husband in which there were defensive posturing, arm flailing, and punching that corresponded to dreams of her mother and sister who often berated her and beat her during childhood. She never retaliated in childhood, but only later during dream enactment with RBD. Clonazepam controlled RBD dream-enacting behaviors and the associated retaliation dreams. A 43-year-old man developed RBD with “fighting dreams” observed by his wife that involved hitting back at his previously verbally and physically abusive alcoholic father. A 58-year-old married man developed RBD with some of his recurrent dream enactments involving “punching out” a hypercritical father during his childhood, while he was actually hitting his wife in bed. In the mornings upon awakening, he never felt remorse about his retaliation dreams against his father, but felt remorse over hitting his wife while asleep. Prior to developing RBD, he did not have retaliation dreams, but did have dreams about his hypercritical father. Clonazepam therapy at bedtime controlled both the dream-enacting behaviors and the retaliation dreams. An example of culture-specific dream enactment involved a 51-year-old Japanese man who enacted a classic Samurai warrior film sequence during a presumed RBD episode captured by a home sleep video recording (prior to vPSG confirmation of his RBD). The episode lasted from 2:43:58 a.m. to 2:45:59 a.m. and culminated with his grabbing an imaginary sword with both hands and stabbing vigorously up and down 12 times in rapid succession. A religion-specific dream enactment involved a 26-year-old Taiwanese man with narcolepsy type 1 and RBD. He was a devotee Taoist, and three times daily at home he enacted a Taoist temple worship ceremony with prayer that lasted almost 5 min. During a vPSG study, in REM sleep he faithfully enacted this temple worship ceremony in the sleep lab bed, with sitting up, kneeling and fully bowing down, immobile, but with full muscle tone, while softly chanting his prayer.

Knowledge about the range of behaviors and associated clinical features in RBD continues to expand. For example, one study searched for laughing during RBD

episodes [17]. Records of 67 consecutive vPSG recordings of RBD patients at a neurological sleep center were reviewed and found that 21% (14/67) had repeatedly laughed during REM sleep, with 71% (10/14) being males and with a mean age of 63 ± 11 years. Ten of these 14 patients had idiopathic PD, 3 had multiple system atrophy, and 1 patient had dementia with Lewy bodies. Other RBD-associated behaviors included smiling, crying, aggression, screaming, and somnolency. Therefore, laughing was documented to belong to the spectrum of behavioral manifestations of RBD. A notable finding was that 9/14 patients (64%) with laughing during RBD episodes were clinically depressed during daytime, thus indicating a state-dependent dissociation between waking vs. REM sleep emotional expression in RBD, at least in the context of an alpha-synuclein neurodegenerative disorder.

A surprising feature of RBD dream enactment is how sexual dream content and sexual acting-out behavior are virtually never reported. Freud would have been surprised, as the loss of REM atonia and the emergence of RBD would appear to be an ideal context for sexual acting-out. However, there is a shift in the bias of dream content with RBD, away from sex and toward confrontation and fighting [18]. On the other hand, “sexsomnia” (i.e., sexual behaviors during sleep) is a well-documented parasomnia that typically emerges from deep NREM sleep and that involves the release of a full spectrum of sexual behaviors without associated dreaming [19]. So “sexual acting-out” in sleep is not linked with dreaming, a distinctly non-Freudian phenomenon.

2.3 Adverse Consequences from RBD and Quality-of-Life Issues

RBD is associated with major quality-of-life (QOL) burdens. Repeated injuries to self and spouse are common, including potentially lethal behaviors [1, 2, 7, 12]. There are also marital burdens [9, 10, 12, 13, 20, 21] and worse motor and non-motor symptoms and QOL in RBD-PD compared to PD-without RBD [22–24].

A cross-sectional study in idiopathic RBD (iRBD) was recently reported on the impact of “noxious” RBD symptoms (most notably recurrent sleep-related injuries) on the spouses affecting the quality of their sleep and their physical, mental, and marital well-being [20]. Results were compared to those from spouses of age- and sex-matched obstructive sleep apnea (OSA) patients. Forty iRBD patients (90% male) and their spouses and 35 OSA patients (80% male) and their spouses were studied. Almost all iRBD spouses (90%) reported disturbances from the nocturnal RBD behaviors of their bed partners; 62.5% of the iRBD spouses reported a history of being injured during sleep. Spouses of both iRBD and OSA patients reported a comparably high prevalence of insomnia, anxiety, and depressive symptoms. Spouses of iRBD patients, however, reported more impaired quality of life and adverse effects on the marital relationship from the RBD behaviors. However, nearly two-thirds of RBD couples continued co-sleeping, despite the ongoing risk of sleep-related injuries and secondary nocturnal sleep disturbances affecting the spouse (as described in the previous section of this chapter). The authors concluded that both iRBD and OSA spouses exhibited a high prevalence of insomnia and mood problems. In particular,

iRBD significantly and negatively affect the spouses' quality of life and the marital relationship.

In another study, QOL was negatively impacted in patients with probable RBD (pRBD) (questionnaire based) and early PD, compared to early PD patients without pRBD in a study of 475 PD patients evaluated within 3.5 years of PD diagnosis [22]. There was a 47% frequency of pRBD (without any prior recognition). The two groups did not differ on motor phenotype, and they scored comparably on objective motor scales. However, the pRBD group more frequently reported problems with the motor aspects of daily living, and also the pRBD group had significantly greater cognitive impairment, sleepiness, and depression. This study calls attention to how pRBD (and presumably vPSG-confirmed RBD) is both common and under-recognized in patients with early PD. Furthermore, pRBD is associated with both increased severity and frequency of non-motor features of PD, with diminished motor performance, and a greater negative impact on health-related quality of life.

A case-control study from Japan evaluated the characteristics of nocturnal disturbances and other motor and non-motor features related to RBD in patients with PD and the impact of RBD on their quality of life [23]. A consecutive series of 93 PD patients was gathered, with mean age of 70 years, involving 50 men and 43 women, along with 93 age- and gender-matched control subjects. The mean disease duration in the PD patients was 6.8 ± 6.1 years. pRBD was evaluated using the Japanese version of the RBD screening questionnaire (RBDSQ-J). When comparing PD patients with pRBD ($n = 18$) and those without pRBD ($n = 59$), after the exclusion of RLS and snorers, the pRBD group showed a higher rate of early morning dystonia and higher scores of UPDRS IV and PDSS-2 total scores than the non-pRBD group. The Parkinson's Disease Questionnaire (PDQ-39) domain scores for cognition and emotional well-being were higher in the patients with pRBD-PD compared to PD patients without pRBD. The pRBD group showed higher scores compared with the non-pRBD group on the Parkinson's disease sleep scale-2 (PDSS-2) total and sub-scores (insomnia, distressing dreams) and distressing hallucinations. There were no differences between these two groups with respect to the clinical subtype, disease severity, or motor function.

Another study aimed at understanding the impact of having RBD on multiple non-motor symptoms (NMS) in patients with PD [24]. Eighty-six PD patients were clinically and vPSG evaluated for RBD and assessed for multiple NMS of PD. Seven NMS measures were assessed: cognition, quality of life, fatigue, sleepiness, overall sleep, mood, and overall NMS of PD. RBD was a significant predictor of increased NMS in PD while controlling for dopaminergic therapy and age. The RBD group reported more NMS of depression, fatigue, and overall NMS.

Therefore, there is converging evidence that RBD is a marker of widespread neurodegeneration in PD, with PD-RBD patients vs. PD-without-RBD patients being more severely impaired across motor and non-motor domains, as discussed in Chaps. 5 and 35. The increased levels of PD motor impairment also include axial symptoms, such as postural instability with falls, freezing of gait, and dysarthria. There are increased levels of cognitive impairment (with increased risk for

dementia), visual hallucinations, autonomic dysfunction, and greater impairment in quality-of-life status.

Finally, a study was recently published on quality of life in Korean idiopathic RBD patients [25]. Sixty patients (mean age, 61 years; 36 males, 24 females) had PSG-confirmed RBD and completed a MMSE and the Short-Form 36-Item Health Survey for quality of life. Idiopathic RBD patients were compared with patients with restless legs syndrome, type 2 diabetes mellitus, hypertension, and healthy controls. The total quality-of-life score in idiopathic RBD was significantly lower than that for healthy controls but higher than in the other patient groups. Nevertheless, idiopathic RBD was found to have a significant negative impact on quality of life.

Note Added in Proof: A recent case of antidepressant-induced RBD with major injuries has been published [26]. And in regards to biting during RBD episodes described in section 2.1 and in references [10–12], the differential diagnosis of sleep-related biting has recently been published [27].

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