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SLEEP AND NEUROLOGICAL CONDITIONS (A AVIDAN, SECTION EDITOR)

REM Sleep Behavior Disorder as a Pathway to Dementia: If, When, How, What, and Why Should Physicians Disclose the Diagnosis and Risk for Dementia

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Abstract

Purpose of Review People with isolated REM (rapid eye movement) sleep behavior disorder (iRBD) have a high lifetime risk of developing a neurodegenerative disease, including dementia, but disclosure of this risk remains controversial. Herein, we summarize this controversy and provide guidance on disclosure.

Recent Findings Neurodegeneration risk disclosure in iRBD is controversial because of a long latency to disease onset and a lack of preventative strategies. Balancing the relevant ethical principles of beneficence, nonmaleficence, and autonomy is challenging. Although there are few data on disclosure in iRBD, evidence from discussing risk in other diseases with dementia provides some guidance.

Summary We provide an approach to risk disclosure for patients with iRBD. Patients should be asked if they want to know about future risks. If so, disclosure should be patient centered, focusing on what might happen. Discussion should occur early to give patients time to prepare for the future and consider participating in research.

Keywords REM sleep behavior disorder · Phenoconversion · Neurodegeneration · Disclosure · Ethics · Lewy body dementia · Parkinson's disease

Introduction

Worldwide, nearly 50 million people have dementia with more than 5 million in the USA. By 2050, this number is expected to increase to a staggering 132 million worldwide and nearly 14 million in the USA [1]. Given the high cost of care and lack of available disease preventative strategies, there is an urgent need to identify modifiable risk factors and identify people at risk—prior to disease onset—as disease modifying therapies may be most effective in earlier stages of the diseases. One such population at risk for dementia is composed of people with rapid eye movement (REM) sleep behavior disorder (RBD), a condition that is a prodrome for neurodegenerative disease, particularly α-synucleinopathies, which are characterized by an abnormal accumulation of aggregates of α-synuclein protein in the neurons or glia. Examples include Parkinson's disease (PD), PD with dementia, dementia with Lewy bodies (DLB), which is the third most common cause of dementia worldwide [2, 3], and multiple system atrophy. While RBD remains highly predictive of neuronal degeneration, no disease modifying strategies currently exist. Clinicians, particularly neurologists and sleep clinicians, are familiar with the risk of "phenoconversion" (a transformation over time) from having a diagnosis of isolated REM sleep behavior disorder (iRBD) alone to RBD with the development of clinical manifestations of neurodegenerative disease. Yet many are struggling with the expectation of disclosing the diagnosis of RBD, especially when to disclose the risk of developing a neurodegenerative disease, to whom to disclose this risk, and how much to disclose. Herein, we review RBD, the controversy surrounding disclosure of neurodegenerative disease risk, and methods by which disclosure may be performed. We then provide possible clinical scenarios highlighting the controversy.

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REM Sleep Behavior Disorder

REM sleep, which is particularly associated with dreaming, is characterized physiologically by rapid eye movements, mixed frequency electroencephalographic rhythm, dreaming, and muscle atonia. This normal skeletal muscle paralysis serves a protective purpose by preventing the expression of complex manifestations of movements during dreams in REM sleep. In RBD, the motor atonia is lost, resulting in dream enactment behaviors (DEB) which range from verbal outbursts or simple movements to complex and sometimes violent motor phenomena that can lead to injuries to the patient or the patient's bed partner. The diagnosis of RBD requires the combination of DEB, by history or by observation during a sleep study on video manometry, and confirmation of REM sleep without atonia (RSWA) on polysomnography (PSG) [4]. Dream enactment behavior is not unique to RBD, and the condition may also manifest in people with sleep disordered breathing and periodic leg movements of sleep (pseudo-RBD) [5, 6]. RBD is associated with exposure to antidepressants, especially selective serotonin reuptake inhibitors (SSRIs) and serotonin-norepinephrine reuptake inhibitors (SNRIs) [7]. When no clear cause of the RBD is identified, it is called isolated RBD (iRBD). People with narcolepsy may also experience DEB and have RSWA on PSG testing, but here, the condition is related to an impaired hypocretin system which contributes to the instability of motor regulation during REM sleep, and the co-association is unrelated to neurodegeneration [8].

Isolated RBD is associated with a high risk of developing a neurodegenerative disease, most commonly DLB and PD. Several studies have shown a high long-term rate of phenoconversion to neurodegenerative disease. Two large cohorts showed that among people with a mean age of 62 years, median latency from onset of RBD to the diagnosis of neurodegenerative disease was 11 years (range 2–24 years). Often, the diagnosis of RBD is made years after the onset, so the latency from RBD diagnosis to neurodegenerative disease diagnosis is shorter. These cohorts combined reported median time to phenoconversion of 7.5 years after RBD diagnosis, with a rate of 33.1% at 5 years, 75.7% at 10 years, and 90.9% at 14 years [9, 10]. Recently, a large international cohort with a mean age of 66 years reported similar data, with an 8-year latency from RBD evaluation to the diagnosis of neurodegenerative disease. They found an annual phenoconversion rate to any neurodegenerative disease of 6.25%, with phenocoversion occurring in 31.3% at 5 years, 60.2% at 10 years, and 73.5% at 12 years [11••]. Older age predicted sooner phenoconversion. The majority (78–82.5%) of the patients in these cohorts were male, which may limit prediction in women [9, 10], though sex did not appear to alter the phenoconversion rate [11••]. Still, the older age and predominantly male sex in these studies limit our ability to predict phenoconversion in younger people and in women. About 94% of RBD patients who develop neurodegenerative disease have an α-synucleinopathy, with DLB being the most common pathologic diagnosis [12]. Conversion to PD but not dementia can be predicted by the severity of RSWA [13].

Several other factors that are also linked to a prodromal state can improve the prediction of neurodegeneration. These include symptomatic orthostatic hypotension, olfactory dysfunction (by standardized testing), erectile dysfunction, hypersomnia, constipation, urinary dysfunction (typically urge incontinence), cognitive dysfunction, history of depression, diabetes, physical inactivity, and severity of RSWA [14–16]. Neuroimaging findings with predictive value include abnormal presynaptic tracer uptake (at least 2 standard deviations below the mean) on dopamine transporter SPECT or PET imaging and hyperechogenicity on ultrasound of the substantia nigra [17]. Among these factors, abnormal dopamine transporter imaging is by far the strongest predictor of phenoconversion. Treatments are available to reduce the frequency and severity of disruptive nocturnal behaviors and injury, including safety strategies and medications such as melatonin and clonazepam. However, at present time, there are no available strategies to mitigate the risk of neurodegeneration.

Understanding this risk is further complicated by isolated RSWA, in which RSWA is identified on PSG without clearly documented historical or videographic evidence of DEB. Many people with iRBD, particularly those who sleep alone, are unaware of the DEB, further complicating how a clinician may "message" the diagnosis of isolated RSWA [18]. Yet recent data suggest that isolated RSWA on polysomnography is a risk factor for the development of RBD, indicating that isolated RSWA is a milder form that may progress over time. In particular, one study showed that among 14 patients with isolated RSWA follow for a mean of 8.6 years, 1 patient developed iRBD [19]. Given the risk from iRBD, isolated RSWA may even be a precursor for neurodegeneration occurring even earlier than iRBD, but this finding needs further examination. While antidepressant use increases the likelihood of RBD diagnosis by 5-fold, whether antidepressant-induced RBD definitively predicts neurodegeneration is still under review [20, 21]. These issues make consideration of prognostication particularly challenging in this setting. The subsequent discussion refers to patients in whom the diagnosis of iRBD is unrelated to antidepressants and narcolepsy.

Disclosure of Neurodegeneration Risk in iRBD

A major area of controversy in the management of iRBD is whether disclosure of the future risk of neurodegenerative disease should even take place. Not all clinicians, for a variety of reasons, disclose this risk to patients. One retrospective study of records in a sleep clinic showed that only 47% of

patients had documentation of having received prognostic counseling, though such counseling may have been provided but not documented [22•]. A recent study surveyed sleep specialists on disclosure. Among the 44 out of 70 clinicians queried, nearly all counseled patients, though only 15.9% disclosed a high risk. The authors proposed a patient-centered and detailed approach to disclosure [23•]. Still, there are no current guidelines about how to disclose, when to disclose, and what to disclose, as there are no data available on the attitudes and preferences of patients with RBD to discussions about risk. Several problems have led to the controversy over providing disclosure as detailed subsequently. A summary of arguments for full disclosure and for watchful waiting approaches are provided in Table 1.

First, there is no current consensus on disclosure, likely stemming from the observation that in patients with iRBD, latency from the onset of RBD to the onset of neurodegeneration is highly variable and may be as long as a decade in 60–75% of patients [9, 11••]. Providers can face this situation of uncertain prediction in other situations. There are other situations like that of iRBD where there is a lack of consensus. For example, one model of disclosure for future risk of disease is in predicting the risk of Alzheimer's disease based on biomarkers or genetics. Yet, even with positive biomarkers that have high accuracy, one observes a 10–15% rate of false positives and false negatives [26]. Another model is the discussion of risk conferred by a low-penetrant gene for PD [24], in which there is a higher risk than those without the gene but considerable uncertainty. Although people with iRBD may succumb to another illness or cause before developing a neurodegenerative disease, nearly all patients followed across multiple cohorts have developed a neurodegenerative condition (clinically or by autopsy, if done), depending on the duration of follow-up [9]. A complicating factor is that there is an inherently limited prediction due to the variable latency—even decades long—to develop the disease. Although this alone is not a compelling reason to withhold disclosure, it does need to be considered, particularly in patients who may be at lower risk. An argument that opponents of full disclosure may hold is the risk of unnecessary anxiety that a clinician may precipitate for a condition that may develop in a decade or longer, if at all.

Second, a major concern about full disclosure is the absence of available disease-delaying treatment for dementia. In contrast, for disorders where risk can be reduced or mitigated, such as mastectomy for women with the *BRCA* gene, counseling is consistently provided [27]. In the absence of unique interventions to modify disease risk, there is a concern that full disclosure may lead to unnecessary worry or anxiety. Counter to this, a recent study on disclosing abnormal amyloid imaging, a biomarker of Alzheimer's disease risk, to cognitively healthy older adults did not find a short-term effect on depression or anxiety symptoms or suicidal ideation [28]. However, this study excluded from disclosure those with moderate to severe depression or anxiety symptoms or history of suicidal ideation [28], and these are the patients who may have the most severe adverse outcomes from disclosure. In those at risk for Alzheimer's disease, about 20% in one study indicated a desire to pursue physician-assisted death if they become cognitively impaired [29]. Furthermore, disclosing the risk of a terminal illness without treatment is uncomfortable for many clinicians. Even a dementia diagnosis, which is not terminal and can be managed, is often withheld from patients in the clinical setting, as clinicians may not feel comfortable in handling such conversations [30]. The counterargument, in favor of disclosure, holds that the clinician's discomfort is not an adequate justification for withholding information that may be important for decision making [24]. Furthermore, disclosure of the diagnosis of iRBD and its risk would empower patients and loved ones to gain an understanding of the disease and ultimately be able to undertake informed decision making and in pursuing care, including enrolling in future neuroprotective clinical trials that might alter its course. Awareness of the disease and its risk allows

Table 1 Summary of arguments supporting "full disclosure" versus "watchful waiting" approaches to neurodegeneration risk disclosure with iRBD [24, 25]

"Full disclosure"	"Watchful waiting"
• Patients have a right to know about their clinical condition.	• Patients may experience anxiety, hopelessness, and stigma with disclosure of impending neurodegenerative disease.
• Disclosure preserves patient participation in shared decision making.	• There is a long latency and variable short-term prediction for phenoconversion.
• Disclosure maintains trust and transparency in the clinician–patient relationship.	• There are no available disease modifying therapies.
• Patients can prepare for the future (advance care planning, finances, life goals).	• There is still much unknown about risk in patients taking commonly used antidepressants associated with RBD symptoms.
• Patients are able to enroll in future trials on potential disease modifying strategies.	
• Patients may undergo monitoring for early diagnosis of neurodegenerative disease.	

for early diagnosis and participation in research, which may lead to better prognostication, understanding of the pathophysiology, and ultimately the development of disease modifying therapies. It also respects the principles of transparency when clinicians invite patient to actively participate in their care by sharing their data and augmenting opportunities to track the condition, especially as some of the neurodegenerative symptoms eventually manifest themselves.

Third, RBD symptoms are not even the presenting complaint for all patients. Another sleep issues such as sleep disordered breathing, periodic limb movements, hypersomnia, or insomnia may be the patient's main issue [25]. Another report showed 11% of RBD cases had a different primary chief complaint. Even if present, many patients are unaware of the dream enactment [25, 31] or attribute it to a "nightmare." History of dream enactment may be elicited during the evaluation, particularly when seeing a sleep clinician. Upon evaluation, it is extremely beneficial to interview the bed partner as they may actually experience insomnia and hypersomnia more so than the patient with RBD. It is not uncommon to encounter patients with DEB who may not exhibit alarm or concern about the nature of their dream enactment behavior, which could lower the clinician's enthusiasm when disclosing a neurodegeneration risk. Although it is unclear if these patients would be interested in prognostication, their bed partners may function as partners in highlighting the burden of disruptive dream enactment on their own sleep and quality of life. Bed partners may be invited to participate as facilitators in confirming the diagnosis of RBD, motivating loved ones to pursue management for RBD, and enhancing their motivation to pursue follow-up with neurologists to monitor for neurodegeneration.

Several ethical principles need to be considered in disclosure: autonomy, beneficence, and nonmaleficence [32]. Beneficence is the principle that clinicians should act in the best interest of patients. Disclosure will provide the patient information to prepare for the future and consider risk-reduction strategies, though none are currently available for neurodegeneration. Nonmaleficence is the related principle that requires that clinicians should do no harm, and disclosing the risk of future disease may lead to anxiety or hopelessness. When disease modifying treatments are available, these two principles are often in line. However, in the case of iRBD, they may be at odds with each other. The principle of autonomy provides that a patient has the right to self-determination, including the right to know about and prepare for potential risks. Patients are the owners of their medical information. However, autonomy in most cases also includes the right not to be informed about risk. Some patients may be interested in dealing with symptoms of iRBD but not interested in future risk. Autonomy is implemented in medicine by informed consent in which patients receive adequate information to be able to make medical decisions. If prognostic information about the risk of neurodegenerative disease is needed for such decisions, it would need to be disclosed unless the patient elected otherwise. Lastly, increasing information on the relationship between RBD and neurodegeneration is available on the internet, so patients are likely to find out the risk themselves. In cases of nondisclosure, learning about the relationship between iRBD and neurodegeneration on one's own may impact the trust between the patient and clinician.

Should There Be Disclosure and Why?

In cases in which disclosure of risk is not clearly related to a preventive benefit and may cause harm through worry about a future circumstance that may never occur, the choice of whether to disclose should be left up to the patient. In a study of patients at high risk of Alzheimer's disease, the vast majority of individuals preferred disclosure but not all [33]. Because the information belongs to the patient, the option of disclosure must be presented (except in the rare circumstance that there is a compelling reason that making this decision would seriously harm the patient) [34]. The discussion about whether the patient wants to know prognostic information requires a patient capable of decision making, should be carried out in a way that preserves disclosure as a choice and not a requirement, and preserves the option of future disclosure. If the patient wants to know, the clinician should determine how much information the patient wants, such as the risk of disease, time frame of risk, types of associated diseases, and disease symptoms, course, and available treatments. The information should be disclosed using the techniques of compassionately breaking bad news [35].

If the patient does not wish to be informed about their condition, information should not be forced upon patients, as this action would violate their autonomy to elect not to know. At a future visit, the clinician can again inquire about the desire to know. If still not desired, the clinician should express their availability to discuss if the patient changes their decision and is interested in more information [24].

The benefits of awareness of neurodegeneration risk give patients time to prepare for a future when the neurodegenerative condition manifests itself, including advance care planning, arranging care, advance directives, wills, retirement planning, insurance, and planned treatments and consideration of research participation [24, 33]. Advance planning ultimately leads to motivation and willingness to pursue disease modifying strategies, when available, and allow for early treatment by preventing or delaying the emergence of neurodegenerative disease. Such planning is best done prior to developing cognitive impairment [24].

Disclosure may have potential risks. Stigmatization, anxiety, hopelessness, and even suicidality have been seen in the discussion of the risk of Alzheimer's disease [26] and Huntington's disease [36], though with the latter there is

clearer risk stratification based on genetics. Such stress also can affect patients' relationships with others. However, withholding disclosure has an additional risk of harming the patient–clinician relationship. With the information available on the internet, patients may need their clinician to put their disorder and risk into context. Furthermore, if patients are unaware of their risk, they may not follow up for monitoring of neurodegeneration.

What Should Be Disclosed?

The patient should be asked about the extent of information desired. The clinician should discuss the potential risks known, including the time frame for risk and the types of associated diseases. Depending on how much the patient wants to know, the clinician can also discuss the specific diseases and their natural history, progression over time, and potential disabilities and invite the patient to participate in the management plan. An individualized risk stratification, depending on the presence or absence of other prodromal risk factors, should be provided. This may provide better precision for the patient and may be important for participation in research [15•]. However, there are limits to the attainable precision based on the available data and the clinical assessment. For example, a 40-year-old woman with iRBD and no other clinical biomarkers of neurodegeneration will have a lower 10-year risk than a 70-year-old-man with olfactory loss. Although the risk of developing a neurodegenerative disease is high, it may take even decades to develop the disease. Furthermore, competing risks may occur. Therefore, disclosure should focus on what might happen rather than what will happen [37]. Parallel examples of other common risk factor–diagnosis correlations familiar to the patient may be provided, such as family history as a risk factor for heart disease or dementia. In the meantime, in addition to the treatment of the symptoms of RBD, clinicians should generally advise patients to follow a healthy lifestyle [25]. Efforts should be made to make the patient aware about ongoing research and, if the patient is interested in participating, how to get involved in research such as cohort studies or potential neuroprotective clinical trials.

When and How Should There Be Disclosure?

Given the risk of dementia, it is critical that disclosure be made while the patient maintains the capacity for decision making. Disclosure early, at the time of or soon after the diagnosis of iRBD, is better to give time to prepare and allow for research. However, the timing and approach to disclosure should be individualized based on the patient's specific situation and involving family or caregivers as desired [38]. Although disclosure may be considered after treatment of RBD symptoms [37], it may take several weeks to months to establish effective symptom control.

Counseling should ideally be performed by a clinician knowledgeable and familiar with iRBD prognostication, such as a sleep specialist or movement disorders specialist, but this does not preclude other clinicians who have knowledge of RBD, its presentation, differential diagnosis, and diagnostic criteria and are familiar with the attribute of phenoconversion and the natural history and physical findings in neurodegenerative conditions. Communication skills are critical given the implications that increased dementia risk has on future identity, self-determination, and stigma [39]. There are several resources available to clinicians on methods of communication of dementia risk (for current examples, see previous studies [40, 41]). Information should be provided in easily understandable terms, e.g., "half or 5 out of 10 patients develop a disease by 11 years" rather than "median latency to disease onset is 11 years." Disclosure may be best performed in person to make it easier for the clinician to maintain rapport, while reading nonverbal cues during the discussion, and facilitate the patient asking questions [42]. However, one study did not find more anxiety or depression resulting from the discussion of the genetic risk of Alzheimer's disease whether it occurred in person or by phone [43]. During the COVID-19 era, when many visits are conducted by telemedicine and when patients prefer to stay at home, particularly when patients have a high risk for infection, it is ideal to conduct the interview with the video on to look for nonverbal cues, aiding the clinician to allow patients time to comprehend the medical information and ask questions. The interview should not be hurried, and clinicians should make themselves available for a follow-up discussion after providing the patient with information and resources.

Regardless, caution should be taken in disclosing risk to those with comorbid psychiatric disease given that the knowledge of risk may exacerbate underlying anxiety or depression. There should be rapport built with the patient. This may be established on the first visit but may take additional visits to develop. Adequate time should be budgeted to provide the necessary information and allow the patient to ask questions. The clinician should ask the patient if they want family members involved in the discussion. A separate visit with their partner and other family members while allowing adequate time to discuss the risks and answer questions may be more feasible.

Disclosure should be patient centered [24]. The clinician should ask the patient about their knowledge of the disease and volunteer to disclose uncertainties. Some patients may already be aware of the increased risk of dementia by reading about their conditions on the internet. Indeed, the diagnosis of "RBD" on a sleep study which is automatically shared with patients merits disclosure of RBD diagnosis as appropriate and consideration of neurodegenerative disease risk, as

withholding disclosure may risk resentment from patients who perceive this as a clinician's withholding clinical data. In addition to the information about the future risk and the associated diseases, the clinician should discuss the long-term goals of care. Patients may not have considered this before and may need to continue the discussion in a subsequent visit. The clinician should review the plan for regular monitoring and referral or treatment if new symptoms arise. Patients should have an adequate follow-up to monitor for the development of neurodegenerative disease, answer questions, and provide updated information on risks. Written handouts are beneficial to provide additional information whether in person or by phone and may lead to better retention [44]. Providers should also consider connecting patients and families with other networks or groups for patient and research advocacy for DLB and PD.

Case Scenarios

Case 1 A 65-year-old man comes to the clinic with his partner complaining of vivid dreaming associated with punching and screaming in his sleep for the past 4 years. He reports hitting his partner while dreaming about fending off an attacker in his dream, but his partner has not been significantly injured. He once fell out of the bed while dreaming he was dodging a car. His partner notes that he talks in his sleep a few times per week. He does not take antidepressants. His father had Parkinson's disease. He has difficulty smelling and tasting food for the past 5 years. He does not have any cognitive complaints or orthostatic dizziness, and there is no evidence of Parkinsonism on history or examination.

You ask him if he has heard or read about such problems in sleep, and he has seen some information online about RBD causing dementia. You tell him about the diagnosis of probable RBD and that diagnosis requires polysomnography. You apprise him of the importance of evaluating for RBD because of the risk of injuries from these behaviors and provide instruction on safety precautions. You inform him that RBD, if confirmed, can be associated with future health risk and ask if he wants to know more about that before confirmation of the diagnosis. He states that he wants to wait until the diagnosis is confirmed, and you affirm that you will bring it up at the next visit.

Polysomnography confirms the diagnosis of iRBD, and he returns to the clinic 1 week later. You inform him that he has iRBD. Safety precautions and pharmacologic management are reviewed. You again inform him that iRBD can affect his future health risk and ask if he wants to know more, and if so, if he wants his partner to be part of the discussion, and he responds affirmatively to both questions. You inform him that there is an increased lifetime risk of developing a neurodegenerative disease, including Parkinson's disease, dementia, and others, and inform him about the major symptoms and available symptomatic treatments of each. The available data indicate phenoconversion in approximately 60–75% at 10 years from iRBD diagnosis, with about half of people developing the disease 11 years after iRBD onset. You review factors that can influence risk, such as olfactory loss and family history of Parkinson's disease, but there are limits to how much you can individualize his risk and predict if and when he will develop a disease. You suggest that he consider his long-term health plan should he develop a neurodegenerative disease but state that such planning would be important regardless of the diagnosis of RBD, as one can develop unrelated health problems in the future. The plan will include monitoring him regularly (or referral a neurologist for monitoring) for the development of other risk markers and symptoms of neurodegenerative disease. You report that there are currently no available treatments that reduce the risk of associated neurological disease, but there are research studies examining patients with iRBD to better understand iRBD and its relationship to neurological disease and research aimed at the development of disease modifying treatments, and you can refer him for research participation if he is interested. You provide some written materials about RBD and neurodegenerative disease and recommend that he and his partner write down questions to review at a follow-up visit soon.

Case 2 A 58-year-old woman with a history of mild anxiety presents for evaluation of insomnia. In taking a detailed history, she reports that she has been acting out her dreams for the past 2 years. She woke up her partner punching and screaming a few times. She was diagnosed with pancreatic cancer 4 months ago, and since then, she has been very depressed and having suicidal thoughts. She recently started bupropion with a little benefit. She does not have any other clinical markers of neurodegeneration risk and does not have evidence of olfactory loss or Parkinsonism on history or examination. In addition to addressing insomnia, you inform him of the provisional diagnosis of probable iRBD and discuss safety precautions and that it should be confirmed by polysomnography. You ask her if she knows anything about this condition, and she does not. Given the severity of depression, you withhold further discussion pending polysomnography. She returns 1 week after the sleep study, which confirmed iRBD. Though dream enactment was not her presenting complaint, you also inform her that iRBD can be predictive of future health risks, particularly over 5–15 years, and ask if she wants to know more. She reports feeling too overwhelmed with her cancer diagnosis to consider other problems. Due to concern for provoking further depression and suicidal thoughts and out of respect for her autonomy, you pause further discussion and focus on the management of insomnia and symptomatic treatment of RBD. You plan to monitor her for markers of neurodegeneration and ask again her preference to know the risk when her depression improves.

Conclusion

In summary, several ethical issues surround disclosure of neurodegeneration risk in iRBD related to the long latency to disease, onset, and lack of preventative treatments and that iRBD symptoms may not be the patient's primary sleep complaint. Balancing the benefits and risks of disclosure is challenging, but ultimately disclosure is the patient's choice. We recommend first determining—in a careful compassionate way—the patient's desire to be informed. If present, the clinician should provide disclosure focusing on the care plan, goals of care, life planning, and participation in research. In particular, research is vital to develop preventative strategies that may unravel the ethical dilemmas faced in this setting.

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Declarations

Conflict of Interest The authors have nothing to disclose.

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