

# Delusional Confusion of Dreaming and Reality in Narcolepsy

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**Study Objectives:** We investigated a generally unappreciated feature of the sleep disorder narcolepsy, in which patients mistake the memory of a dream for a real experience and form sustained delusions about significant events.

**Design:** We interviewed patients with narcolepsy and healthy controls to establish the prevalence of this complaint and identify its predictors.

**Setting:** Academic medical centers in Boston, Massachusetts and Leiden, The Netherlands.

**Participants:** Patients (n = 46) with a diagnosis of narcolepsy with cataplexy, and age-matched healthy controls (n = 41).

**Interventions:** N/A.

**Measurements and Results:** "Dream delusions" were surprisingly common in narcolepsy and were often striking in their severity. As opposed to fleeting hypnagogic and hypnopompic hallucinations of the sleep/wake transition, dream delusions were false memories induced by the experience of a vivid dream, which led to false beliefs that could persist for days or weeks.

**Conclusions:** The delusional confusion of dreamed events with reality is a prominent feature of narcolepsy, and suggests the possibility of source memory deficits in this disorder that have not yet been fully characterized.

**Keywords:** Dreaming, memory, narcolepsy

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## INTRODUCTION

Each time we recall an event from the past, we are faced with the dual tasks of identifying the source of the memory and evaluating its veracity. In general, we can accurately determine whether a memory originated in our past experience, as opposed to in our imagination, a dream, a film, or a story. However, this process of source monitoring sometimes goes wrong.<sup>1-3</sup> Minor confusions about the source of a memory are common in the general population, as when we mistake the source of a quotation, misremember the context in which we met an acquaintance, or even believe that we actually experienced an event that we only heard about. Recently, case reports have described more severe examples of memory source confusion in patients suffering from the sleep disorder narcolepsy, in which false accusations of sexual assault occurred when patients mistook a dreamed assault for the memory of an actual event.<sup>4,5</sup> These reports are remarkable in that dream memories were misinterpreted as representing real, highly significant life events, leading to sustained delusions that became the basis for serious actions. Narcolepsy is a disorder of excessive sleepiness, and is not typically associated with psychotic symptoms.<sup>6</sup> The dramatic nature of these case reports led us to undertake the first systematic study of these dream delusions in narcolepsy. In a structured telephone interview, we asked patients with narcolepsy and healthy controls a series of questions about sleep, dreaming, and memory. Our goals were to characterize the

incidence of this phenomenon in patients with narcolepsy, as compared to the general population, and to describe the features of this experience.

## METHODS

### Participants

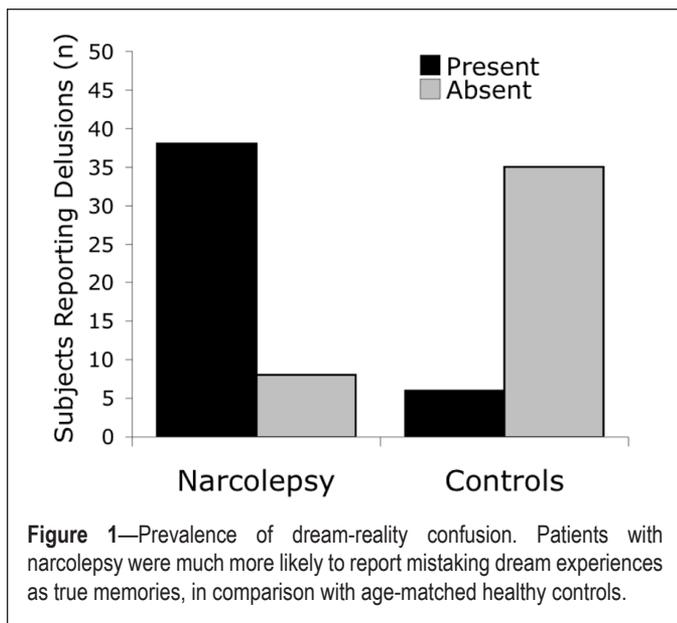
Patients with narcolepsy and age-matched healthy controls were recruited at two collaborating sites: Beth Israel Deaconess Medical Center in Boston, Massachusetts (n = 18), and Leiden University Medical Center in the Netherlands (n = 69). Institutional review boards at both institutions approved this research. Patients (n = 46; age 34.2 ± 10.9 y [SD], 59% female) had a definite diagnosis of narcolepsy with cataplexy for a minimum of 6 mo prior to the study, according to the standards of the International Classification of Sleep Disorders (ICSD-2) Diagnostic and Coding Manual.<sup>7</sup> Diagnoses were confirmed by interview and review of medical records, including clinic notes, overnight sleep studies, multiple sleep latency tests (MSLTs), and HLA testing. At the time of the interviews, patients were under treatment with a variety of medications to manage their narcolepsy, including stimulants (72% of patients; includes modafinil, amphetamine, dextroamphetamine, and methylphenidate), antidepressants (15% of patients; includes tricyclic agents, selective serotonin reuptake inhibitors, serotonin-norepinephrine reuptake inhibitors, and serotonin agonist and reuptake inhibitors), and sodium oxybate (35% of patients). There were no differences in medication usage between those with and without dream delusions (chi-square tests of independence: stimulants: P = 0.82, antidepressants: P = 0.64, sodium oxybate: P = 0.69). Healthy controls were recruited from the general population (n = 41; age 32.7 ± 11.6 y SD, 59% female), and were screened (by self-report) to exclude the presence of any diagnosed sleep

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disorder. There were no differences across study sites in participant age, sex, habitual sleep schedule, dream recall, or incidence of reported confusion (see supplemental Table S1 for participant demographics).

#### Interview Procedures

Participants completed a ~30-min structured telephone interview in which they were asked a series of questions pertaining to sleep, dreaming, and memory. The full text of the interview script is provided in the Supplemental Methods section. Following questions about their habitual sleep schedule and dream experiences, participants were asked, “Have you ever had the experience of being unsure whether something was real, or if it was from a dream?” Delusional episodes were defined as incidents in which a fully awake participant was uncertain if a memory was dreamed or real, or was convinced that a memory was real, only later to discover that it was actually dreamed. To be included, a delusional episode was required to clearly persist into the waking state. Fleeting feelings of confusion during the transition to wakefulness were excluded because brief confusion is a well-known consequence of the hypnagogic and hypnopompic hallucinations characterizing narcolepsy. For purposes of analysis, participants were categorized as a “Yes” for having dream delusions if they claimed to have experiences that met this definition, and were able to provide at least one detailed example of an instance when this had occurred.

To compare general features of dreaming between patients with narcolepsy and healthy controls, participants also rated the frequency, emotionality, and intensity of their typical dream experiences on a five-point scale.

At the conclusion of the interview, two standardized questionnaires were verbally administered—the Boundary Questionnaire and the Prospective-Retrospective Memory Questionnaire (PRMQ). Ernest Hartmann’s Boundary Questionnaire<sup>8,9</sup> assesses the personality construct of psychological boundaries. A “thin” boundary score (higher values) is associated with frequent and intense dreaming, as well as high interest in dreams, and the report of unusual sleep experiences such as

sleep paralysis and sleep related hallucinations, both of which are features of narcolepsy. We administered the 18-item short form of the Boundary Questionnaire.<sup>8</sup> The PRMQ<sup>10,11</sup> assesses subjective complaints of difficulties in remembering to carry out intentions (prospective memory), and in remembering the events of the recent past (retrospective memory). Seventeen participants who reported dream/reality confusions meeting our criteria additionally reported to the laboratory for a face-to-face interview in which they described the qualities of these experiences in greater detail.

#### RESULTS

Dream delusions were extremely common in narcolepsy. Overall, 83% of patients with narcolepsy reported that they had confused dreams with reality, compared to only 15% of healthy controls ( $\chi^2 = 40.1$ ,  $P < 10^{-10}$ ; Figure 1). The severity of these delusions was striking. One man, after dreaming that a young girl had drowned in a nearby lake, asked his wife to turn on the local news in full expectation that the event would be covered. Another patient experienced sexual dreams of being unfaithful to her husband. She believed this had actually happened and felt guilty about it until she chanced to meet the ‘lover’ from her dreams and realized they had not seen each other in years, and had not been romantically involved. Several patients dreamed that their parents, children, or pets had died, believing that this was true (one patient even made a phone call about funeral arrangements) until shocked with evidence to the contrary, when the presumed deceased suddenly reappeared. Although not all examples were this dramatic, such extreme scenarios were not uncommon.

All patients with narcolepsy reporting dream delusions provided multiple examples of such occurrences. Two thirds of patients (65%) who completed the follow-up interview reported experiencing dream delusions at least once a week, and all but two (95%) had the experience at least once a month. In contrast, of the six control participants who reported delusions, only two (5% of all control subjects) had experienced this more than once in their lives.

The classic hypnagogic and hypnopompic hallucinations of narcolepsy are fleeting images and feelings linked to the current environment, and patients recognize the hallucinatory nature of the experience within seconds of awakening. In contrast, the experiences reported here were much longer lasting, persisting into stable wakefulness. In follow-up interviews (see Methods), patients reported that although some delusions resolved within minutes after awakening, they often persisted for hours, days, or even weeks.

In line with prior literature,<sup>12,13</sup> narcolepsy patients rated their dreams as substantially more vivid ( $t_{83} = 3.79$ ;  $P = 0.0003$ ) and more emotional ( $t_{82} = 5.25$ ;  $P < 10^{-6}$ ) than the age-matched healthy controls. They also reported recalling dreams more frequently than healthy controls ( $t_{84} = 3.16$ ;  $P = 0.002$ ), and scored higher on the BQ than healthy controls (indicating that patients had “thinner” boundaries;  $t_{85} = 1.98$ ;  $P = 0.05$ ). However, we found no evidence that dream delusions were related to an abnormal quantity or quality of dream experience in narcolepsy. Within the narcolepsy sample, neither BQ scores nor any other measure of dreaming differentiated between those who did and did not experience confusions (all  $P > 0.1$ ).

Although prior research has largely failed to find objective memory dysfunction in narcolepsy,<sup>14-16</sup> subjective complaints of memory difficulty are common.<sup>17</sup> Here, narcolepsy patients scored higher than healthy controls on the PRMQ for both retrospective memory problems ( $t_{85} = 3.71$ ,  $P = 0.0004$ ) and prospective memory problems (difficulties in remembering to carry out intentions;  $t_{85} = 4.20$ ,  $P = 0.00007$ ; see supplemental Figure S1). However, memory impairment as measured by the PRMQ did not discriminate between narcolepsy patients with and without dream delusions.

## DISCUSSION

Our data reveal an underappreciated problem with memory in narcolepsy, in which patients are prone to delusionally believe that dreamed events actually occurred. These “dream delusions” are a special case of memory source confusion, a well-described phenomenon in which the origin of a particular memory is misattributed.<sup>2</sup> The conflation of dream experiences with actual events has previously been described in healthy controls.<sup>18,19</sup> However, in this sample of patients with narcolepsy, the incidence and severity of dream delusions was striking, and far greater than that seen in healthy controls. These observations suggest that something about the pathophysiology of narcolepsy leads to a profound confusion of memory source. Although the mechanism of dream delusions cannot be determined at this time, several possibilities present themselves.

First, on the phenomenological level, our observations confirm previous reports of frequent and intense dreaming in narcolepsy.<sup>12,13</sup> Thus, it is possible that patients mistake dream experiences for real events because the vividness of their dreams prevents the use of perceptual realism as a cue in discriminating the dreamed from reality. Our data did not provide support for this hypothesis, as dream vividness ratings did not discriminate between patients with and without delusions. However, the possibility that these delusions are caused by an abnormal intensity of dream experience in narcolepsy certainly cannot be ruled out.

Alternatively, dream delusions may be just one manifestation of a more general memory deficit in this disorder. Consistent with this possibility, we found evidence of subjective memory difficulties in narcolepsy, as assessed by the PRMQ. Again, however, this measure did not discriminate between patients with and without delusions. To our knowledge, no prior study has examined any form of memory source confusion in narcolepsy. Thus, it cannot be said at this time whether the delusions observed here are specific to dreaming, or whether patients with narcolepsy might be equally prone to confuse the origin of other memories; for example, mistaking imagined events or stories they have heard as personal experiences. Future studies using standard source monitoring tasks in patients with narcolepsy should be able to better determine the specificity of this complaint.

Finally, dream delusions could result from an abnormality of memory encoding specific to the sleep state. The failure to discriminate memories formed during sleep from waking life experiences could be a direct consequence of the well-described neural mechanisms of narcolepsy. Narcolepsy is caused by destruction of orexin/hypocretin neurons in the

lateral hypothalamus. Normally, the orexin system helps stabilize wake/sleep states, and loss of the orexin neurons results in “state dissociation” characterized by frequent transitions between states and the intrusion of aspects of rapid eye movement sleep into waking.<sup>20</sup> Because monoaminergic and cholinergic neurons involved in the control of sleep states are major targets of the orexin neurons, we speculate that abnormal activity in these neurons during sleep could alter the encoding of dream content in long-term memory stores, leading to its misattribution as waking memory. Disruption of sleep neuro-modulation, for example, could cause features of wakefulness to blend into rapid eye movement sleep, strengthening the typically poor memory encoding during this state.

Although the underlying mechanism of dream delusions is unknown, it is clear that many people with narcolepsy have a surprising and intense difficulty distinguishing the dreamed from reality. In concert, these patients perceive themselves as having more general difficulties with both retrospective and prospective memory. These observations highlight the possibility of source memory deficits in narcolepsy that have not yet been fully characterized.

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Drs. Wamsley and Donjacour contributed equally to this work. The authors thank Andrew Olsen for assistance in transcribing interviews and data entry.

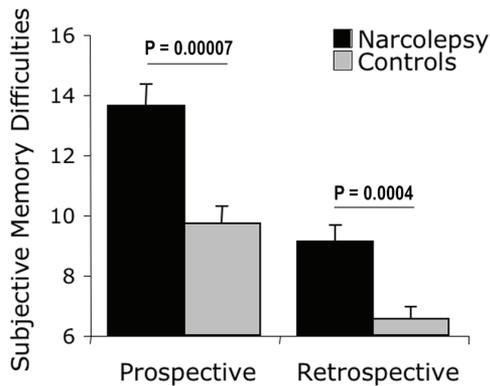
## DISCLOSURE STATEMENT

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**Figure S1**—Prospective and retrospective memory complaint in patients with narcolepsy and control patients. Relative to age-matched control patients, those with narcolepsy reported increased difficulty with both prospective and retrospective memory, as assessed using the Prospective and Retrospective Memory Questionnaire (Smith G, Della Sala S, Logie RH, et al. Prospective and retrospective memory in normal ageing and dementia: a questionnaire study. *Memory*. 2000;8:311-21).

**Table S1**—Patient characteristics at Boston and Leiden study sites

	Boston study site		Leiden study site	
	Patients (n = 11)	Controls (n = 7)	Patients (n = 35)	Controls (n = 34)
Age (y)	36.9 ± 12.5	38.9 ± 10.2	33.4 ± 10.4	31.4 ± 11.6
Bedtime (hh:mm)	11:00 ± 0:29	10:17 ± 1:15	11:09 ± 0:53	11:12 ± 0:48
Dream recall	3.2 ± 1.4	3.0 ± 1.0	3.1 ± 1.0	2.1 ± 1.5
% w/delusions	63%	14%	89%	15%
% female	82%	57%	51%	59%

Means ± standard deviation. Patient characteristics did not differ significantly by study site, with the exception that control patients in the Boston sample had an earlier habitual bedtime than their Leiden counterparts ( $P = 0.02$ ). Bedtimes are participants' typical weekday schedule, as self-reported during the interview. Dream recall was assessed on a five-point self-report scale, with higher numbers indicating that patients report recalling their dreams more frequently (see Supplemental Methods).

**SUPPLEMENTAL METHODS**

**Script for Telephone Interview**

“First I’ll ask some questions about your usual sleep habits...”

1. On average when do you go to bed on workdays?
2. When do you get up on workdays?
3. On average when do you go to bed on weekends (off days)?
4. When do you get up on weekends (off days)?
5. How many times do you usually wake up at night?
6. What is the main reason for waking up?

“Now I will continue with some questions about dreaming...”

1. “Do you typically remember your dreams?”
  - If yes**, “How often do you recall your dreams?”  
Rarely/once a month/once a week/a few times a week/almost every night
  - If no**, “Have you ever remembered a dream?” (Try to find out whether this person really never recalls)
2. “On a scale of 1 to 5, how visually vivid are your dream experiences, where 1 means that your dreams have little to no visual imagery, and 5 means that your dreams are as vivid as your waking life experiences?”
3. “On a scale of 1 to 5, how emotional are your dream experiences, where 1 means that you do not typically have any emotions in your dreams, and 5 means that your dream emotions are as powerful as the strongest feelings you have had in real life?”
4. “Sometimes people have the experience of being uncertain whether something really happened, or whether they just dreamed it. In fact, people sometimes mistakenly think, for a period of time, that something from their dream was actually real. Have you ever had the experience of being unsure whether something was real, or if it was from a dream?”

**If yes**, “Can you give an example of when this has happened to you?”

**If no**, go to the next Q

5. “What about the reverse experience—have you ever thought that something was from a dream, only to find out it was actually real?”

**If yes**, “Can you give at least one example of when this has happened to you?”

**If no**, go to the next Q

6. On a scale of 1 to 5, how interested would you say you are in your dreams (in terms of how much you think about them, talk about them, write them down, or find them to be intriguing experiences)? On this scale, 1 would mean not at all interested and 5 would mean very interested. What would your score be?

“Now I’ll be asking you a few questions about your memory...”

Prospective/Retrospective Memory Questionnaire (Smith et al., *Memory*, 2000)

“The following questions are about minor memory mistakes that everyone makes from time to time, although some of them happen more often than others. We would like you to tell us how often these things happen to you.”

[Administer PMRQ]

“Finally, I would like to ask you a series of questions relating to your personality, likes, and dislikes. I will read you a series of statements, and for each statement you should consider how well that statement describes you. You will then rate each statement on a scale of 0 to 4, where 0 means “not at all true about me” and 4 means “very true about me”. Is that clear? Do you

have any questions before we begin with the statements?... Remember, 4 means 'very true of me', and 0 means 'not at all true of me'."

[Administer Boundary Questionnaire & Conclude Interview]

### Script for Follow-Up Interview

1. "As we discussed during our phone conversation, we are interested in learning more about instances when people are confused about whether something was dreamed, or whether it really happened. To begin, I would like to ask you to describe some examples of when this has happened to you?"
  - i. » If participant does not provide much detail, prompt them by saying "Is there anything else that you can remember about that experience?"/"Are there other examples that you can remember?"
2. People have different types of memories. Some memories are about things that happened at a particular time and place. For example, you might remember the experience of a particular birthday celebration, or a particular summer vacation. But we also have memories about general pieces of information. For example, you remember the capital of your state, the location of your favorite restaurant, and the date of your birth. [Here, if the participant seems to not understand what you mean, provide further explanation]
  - i. When you have these confusions, would you say that they are normally about specific things/events that happened, or about general information? Both? Can you tell me some more about this? Can you give me some examples?
3. [Begin with open-ended questions]: When do these instances of confusion tend to occur?
4. [Follow-up with asking participant about each of these different times:]
  - a. Upon awakening in the morning?
  - b. Following daytime naps?
  - c. When drowsy?
  - d. Following sleep attacks?
  - e. Following cataplexy?
  - f. Following sleep deprivation?
  - g. While sleeping in a strange place?
5. When you have these dream/reality confusions, do they tend to be about things that are personally important to you (example: an argument with a spouse, getting a raise at work)? Or do they tend to be about things that are trivial/unimportant (example: a casual phone conversation with a friend, or maybe something you saw on television)?
6. Have these experiences disrupted your daily life, causing you distress, or interfering with your work or personal life?
  - i. » If yes, "can you give an example?"
    1. If participant does not provide much detail, prompt them by saying "is there anything else that you can remember about that experience?"
  - ii. » If yes, "On a scale from 1 to 10, how disruptive to your life have these experiences been (where 1 is "not disruptive at all" and 10 "severely impairing my life")?"
7. [begin with open-ended question]: "How often do these confusions occur?"
8. [Follow-up with asking participant to select from these options:]
  - a. at least once per week?
  - b. at least once per month?
  - c. at least once per year?
  - d. less than one time per year?
9. Sometimes people remember their dreams as soon as they wake up, but other times a dream might not come to mind until something happens during the day that causes the memory to "pop" into your head. For example, you might remember dreaming about your friend only when you see them later in the day. When you get confused about whether something was dreamed or real, is the dream memory involved something that is in your mind as soon as you wake up, or is it something that just "pops into your head" later in the day?"
10. [Begin with open-ended question]: "For how long have these confusions been happening?"
11. [Follow-up with asking participant to select from these options:]
  - a. For how many years?
  - b. Since childhood?
  - c. At what age can you first remember this happening?
  - d. If you can remember, did this start happening before or after you first had symptoms of narcolepsy?
12. Have these confusions changed across time? Have they become more/less frequent? Or more/less severe? Have they changed in other ways?
  - i. » If yes, "If you can remember, when did these changes occur?"
13. Dreams can sometimes be vague and fuzzy -- but other times they can seem as crisp and detailed as if they were actually happening. When you have dream/reality confusions, are they normally associated with a particularly vivid and/or realistic dream?
  - i. On a scale of 1 to 10, how vivid would you say the dreams are that you have been confused about, where 1 is "fuzzy and vague" and 10 is "as vivid as if it were really happening" ?
14. Do your confusions tend to be about particularly emotional dreams?
  - i. On a scale of 1 to 10, how emotional would you say these dreams that you become confused about are, where 1 is "no emotional at all", and 10 is "extremely intense emotion, comparable to the most intense emotions I have experienced in waking life"?
15. "The next few questions are about actions you might have taken after these instances of confusion have occurred..."
  - a. "Have you ever taken action to try to resolve your confusion? For example, maybe you have asked someone else to confirm whether an event really happened or not, or maybe you have checked your diary or your email in order to confirm whether something really happened?"
    - i. » If yes, what exactly did you do?

1. [If participant does not provide much detail, prompt them by saying “is there anything else that you can remember about that experience?”]
  - b. Have you taken action on that something dreamed was real? For example, maybe you have brought up something from a dream in conversation with a friend, as if it were real?
    - i. » If yes, what exactly did you do?
      1. [If participant does not provide much detail, prompt them by saying “is there anything else that you can remember about that experience?”]
  - c. If you eventually decided that the information/event was dreamed, what was it that led you to decide this?
  - d. If you eventually decided the information/event was dreamed, how long did it take you to figure this out and come to a conclusion?
16. Has someone else ever claimed that something you’ve said that happened didn’t really happen?
- i. » If yes, “can you describe some examples of when this has happened to you?”
    1. » If participant does not provide much detail, prompt them by saying “is there anything else that you can remember about that experience?”
17. Have these confusions all been resolved at this point? Or are there some things about which you are still unsure if they were dreamed or real?
18. Have you ever experienced the opposite—a situation where you thought that you had dreamed something, but later realized that it had actually happened? [Here, if the participant seems to not understand what you mean, provide further explanation]
- i. » If yes, can you describe some examples of when this has happened to you?
    1. » If participant does not provide much detail, prompt them by saying: “is there anything else that you can remember about that experience?”
  - ii. » If yes, how often does this/did this happen to you?
    - a. at least once per week?
    - b. at least once per month?
    - c. at least once per year?
    - d. less than one time per year?
19. Is there anything else remarkable or important about these experiences that you would like to share with us?