Lucid dreaming as a method for living otherwise[1]

Sueños lúcidos como método para vivir de otra manera

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Resumen: Esta contribución explora el sueño lúcido como un método excéntrico para contar una historia diferente sobre la patologización de la narcolepsia. La narcolepsia se ha diagnosticado erróneamente como un trastorno psiquiátrico. El punto de confusión más notorio son las alucinaciones y los sueños vívidos. Este artículo está particularmente interesado en las formas en que la combinación inusual de actividad de sueño alucinatorio y la conciencia reflexiva, permite recuperar el control de la propia realidad. Es decir, una herramienta metodológica agencial y excéntrica para vivir de otra

Abstract: This contribution explores lucid dreaming as an eccentric method for telling a different story of the pathologization of narcolepsy. Narcolepsy has been frequently misdiagnosed as a psychiatric disorder. The most conspicuous point of confusion is hallucinations and vivid dreams. This article is particularly interested in the ways in which the unusual combination of hallucinatory and lucid dream activity and wake-like reflective awareness allows to regain control of one's reality and ownership. By introducing one of the authors' personal experiences with narcolepsy and hallucinations and following Lisa Blackman's (2012, 2014) and Grace Cho's

manera. Al presentar las experiencias personales de una de las autoras con sus alucinaciones, y siguiendo el trabajo Lisa Blackman (2012, 2014) y Grace Cho (2008) sobre los estados conscientes no ordinarios, presentamos el sueño lúcido como un método que ofrece artes particulares para la vida (Tsing, 2007) en mundos que a veces son imposible o aterradores de habitar. El sueño lúcido abre una ventana para explorar formas de cuidado no humanas (Barad, 2012; Bellacasa, 2017; Dokumaci, 2017) que toman forma en mundos sobrenaturales, y que ofrecen supervivencia para quienes habitan mundos oníricos que aterrorizan y un mundo real que patologiza.

Palabras clave: Narcolepsia, sueños lúcidos, alucinaciones, cuidado no humano, monstruos nocturnos.

(2008) work on non-ordinary conscious states, this article examines lucid dreaming as a method that offers a particular art of living in dream-worlds that are sometimes impossible or terrifying to inhabit. Lucid dreaming opens up a window to explore non-human forms of care (Barad, 2012; Bellacasa, 2017; Dokumaci, 2017) that take place in unearthly worlds, which offer survival for those who inhabit a dream-world that terrifies them and a real-world that pathologizes.

Keywords: Narcolepsy, Lucid dreaming, Hallucination, non-human care, night monsters.

1. INTRODUCTION

This contribution explores lucid dreaming as an eccentric method for telling a different story of the medical pathologization of narcolepsy by offering a counter narrative far removed from the pathological diagnosis itself. Narcolepsy has been frequently misdiagnosed —especially by psychiatrists— as a psychiatric disorder. The most conspicuous points of confusion are hallucinations and vivid dreams. This article is particularly interested in the ways in which the unusual combination of hallucinatory dream activity and self-awareness while dreaming allow to regain control of one's reality and ownership. That is, an agential method for living otherwise.

Although, to situate our research, we will start with pointing to the key scholars who have shaped our own thinking, most of the knowledge presented here comes from the autobiographical texts written against the background of one of the author experience with narcolepsy. Consequently, this article is written in more than one voice. Conny and I have decided to present a collaborative work that includes a small photographic exercise, which allows us to get a glimpse of the world of her hallucinations. A world in which she has learned to take control of herself and her condition. Her lucid dreaming recount will be presented here as a creative force that assembles new forms of perception, selfhood and reality, interpersonal experience, and embodiment of

her disability. On my side, the only goal I have is to narrate an affective academic expression of what I have come to understand of her hallucinations and lucid dreaming experience, but I also want to resist the tendency toward creating a piece of work whose politics remain at the level of a mere simplistic representation about her condition.

This article is divided into four sections. The first section introduces narcolepsy as a medical condition and Conny's personal recount of her narcoleptic experiences. In the second section, we follow Lisa Blackman's (2001, 2010, 2012, and 2014) and Grace Cho's (2008) work on non-ordinary conscious states, introducing hallucinations as an affective dimension of human − nonhuman entanglements that, given the affective quality of the encounter, facilitate lucid dreaming. The third part explores lucid dreaming as a method that offers particular arts of living in worlds that are sometimes impossible or terrifying to inhabit. Finally, we elaborate on this to introduce non-human forms of care (Dokumaci, 2002; Barad, 2012; Bellacasa, 2017;) that take form in unearthly worlds, which offer survival skills for those who inhabit the in-between-ness of a dream-world that terrifies them and a real-world that pathologizes them.

To explore lucid dreaming as a methodological tool is, by no means, to situate Conny's experience as the only reality of how narcolepsy is lived by those who share her condition, but to meditate on the ways in which certain disorders are immediately relegated under the rubric of what Lisa Blackman (2019) calls "weird science." As such, this article draws on insights gained from affect studies, science studies, philosophy and cultural theory fields.

2. WHAT IS NARCOLEPSY?

Narcolepsy is a rare neurological disorder marked by excessive daytime sleepiness. It is usually accompanied by other symptoms such as sleep paralysis, vivid dreams, sudden episodes of muscle weakness (cataplexy), and hallucinations while falling asleep (hypnagogic state) or waking up from sleep (hypnopompic state). The cause of narcolepsy is still unknown, although researchers have found out that the neuropeptide hypocretin seems to be linked to the condition. Hypocretin is a substance that appears to be relevant for sleep-regulation and studies show that most patients with narcolepsy cannot build this substance, possibly due to a genetic defect. Narcolepsy can be treated but not cured.

Although narcolepsy presents indistinctly in both men and women (narcolepsy affects about 1 out of every 2,000 people), the impact of gender in narcoleptic patients seems to affect the recognition, diagnosis, and treatment for women (Won et al., 2014). Because symptoms of narcolepsy can overlap and be difficult to differentiate clinically from some other psychiatric disorders, many

people with narcolepsy are misdiagnosed (Douglass, 2003; Talih, 2011). Narcoleptic women are often more reluctant to discuss their symptoms, particularly hypnagogic hallucinations and cataplexy experiences, due to fear of being wrongly diagnosed with bipolar disorder or schizophrenia. Consequently, the impact of narcolepsy on women has remained occluded, disqualified and problematic.

Narcolepsy was first described and named by Westphal and Gélineau respectively. Gélineau originally described narcolepsy as a disease with an organic cause, a 'névrose rare', a rare form of neurosis (Fortuyn et al., 2011). The relevance of Gélineau's description of narcolepsy is that he situated it as a 'morbus sui generis' ('disease of its own kind'), that is, a disease in itself (Droogleever Fortuyn, 2011). However, since the disorder had undeniable emotional triggers (cataplexy) and psychiatric-like expressions (hallucinations) similar to those of hysteria, the psychiatric view dominated scientific thinking about narcolepsy — not necessarily to the benefit of patients and particularly women—. Since the first clinical reports of cataplexy (Germany, 1877) and narcolepsy (France, 1880), clinicians have reported numerous cases of narcolepsy with prominent hypnagogic hallucinations that were mistakenly diagnosed as schizophrenia or female hysteria[2] (Douglass, 2003).

The involvement of psychiatry with narcolepsy split it up in a primary disease and a secondary syndrome due to hysteria, nervousness, anxiety, and sexual forwardness. Due to this alleged relation to hysteria, Gélineau proposed to fit narcolepsy "in Charcot's classification of hysterical stages, even adding a subtype: "'état narcoleptique'" (Droogleever Fortuyn, 2011, p. 117). Perhaps one of the most haunting photographs of a misunderstood and misinterpreted narcoleptic patient was taken during the 1870s, captured at the infamous Pitié-Salpêtrière Hospital in Paris, France.

Despite its caption, what the photo most likely represents is a young female suffering from narcolepsy type 1, nowadays usually referred to as narcolepsy-cataplexy syndrome. Symptoms would include sudden sleep attacks, abrupt and uncontrollable muscle weakness, often triggered by a strong emotion such as excitement or laughter, episodes of loss of muscle tone when awake, hypnagogic hallucinations, sleep paralysis and disrupted nocturnal sleep. Cataplexy is a symptom almost unique to narcolepsy and always occurs when the person is awake. A person experiencing total cataplexy stays awake and is cognizant of the surrounding but is completely unable to move. Despite growing numbers of scientific studies and an increase of medical literature with

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[2] Hysteria was the term used until at least the middle of the 20th century to describe a person, generally women, who responded in a way that seemed disproportionately emotional or irrational to a certain situation. The term hysteria itself stems from the Greek *hystera*, which means 'uterus', since ancient thinkers believed that a woman's uterus could move spontaneously and randomly through diverse parts of the body, often resulting in different symptoms according to where it was finally allocated (Cherry, 2020; Tasca et al., 2012).

a clearer differential diagnosis of narcolepsy-cataplexy, the frequency of misdiagnosed cases — psychiatric diseases (31%), depression (20%), insomnia (20%), and obstructive sleep apnea (13%) — makes narcoleptic patients, articularly adolescent women, reluctant to go to consultation.

Image 1. A female patient with hysteria- induced narcolepsy at the Pitié- Salpêtrière Hospital in Paris, France (Image: Albert Londe/News Dog Media)

Conny is familiar with the sentiment of rejection to medical diagnosis. As I show her the photo of the misdiagnosed female patient with hysteria-induced narcolepsy at the Pitié-Salpêtrière Hospital, she looks at me and tells me,

> *This was one of my more recurrent nightmares when I was young. I was afraid of being hospitalized, tied up to a bed. I was afraid that something was really wrong with me. Especially hallucinating "people," seeing someone next to me or in my room, who was actually not there, was terrifying. That is why I did not say anything during my adolescence. I knew I was different but I did not want people to think I was crazy.*

I kiss her softly in the back of the head, as she continues to look at the photograph as if the girl in the picture was her. Her words remind me of Oliver Sacks' (2012) description of a night-mare: an "overpowering fear and its physiological accompaniments [that] can even be fatal" (p. 445). But it is precisely this sentiment of fatality we want to put into question in this article,

because Conny has found in her hallucinations and lucid dreaming methodological tools to find other forms of understanding herself, beyond the pathological, psychiatric, clinical stories that claim to know better about her condition.

2.1 Conny's story

"I was diagnosed with narcolepsy when I was 25, although I had symptoms since puberty. The symptoms had been escalating for a few years, but at that point I was falling asleep in class and in the middle of exams. I had to run directly to the bathroom to sleep for a few minutes or to scratch my back until the point of bleeding, to keep myself focused. So I started thinking, "Okay, maybe this isn't normal." At that time (this was the late 1990s), not much information or access to information about narcolepsy was available. In fact, due to my symptoms (extreme daytime sleepiness, lack of attention, hallucinations), my parents' first reaction was to believe I had a drug addiction while the doctors mentioned terms such as depression, paranoia, schizophrenia and autism.

Diagnosis came by my own recommendation. I was doing research about my symptoms and I came upon an article about insomnia. Almost at the end of it, the author mentioned an associated sleeping disorder with the same symptoms, but opposite causalities, called narcolepsy. I read it and I knew it immediately. I went directly to the doctor requesting specific tests (multiple sleep latency test or - MSLT). I had mixed feelings when I got the diagnosis. It felt validating to a certain extent (in front of my family and friends), because for years I had known there was something wrong with me. I was tired all day. When I was diagnosed, I felt relieved. All these things were not actually my fault, but it was also big, life-changing news to wrap my head around. How am I going to deal with this diagnosis if narcolepsy has no cure?

There was a bit of a sorrow element to accepting it. However, I decided that narcolepsy was not going to define who I was or what I could and would do with my life and I started to live my life the best way I could. Of course, there have been difficult situations. People who have used my symptoms against me; managing my social life differently because it was not worth pushing myself to do stuff when I am just too tired and knowing I will pay the consequences the next day. I developed certain habits in order to control my sleeping attacks such as smoking, not eating before an important event, spending my energy on what I love instead of what I have to do, or writing with my left hand – although I am right-handed – to focus my mind and physically challenge my body to stay awake. I have to work really hard to maintain certain conditions and routines in my life that most people take for granted. Sometimes managing the disease feels

like a full-time job, but because the symptoms are invisible, public perception is mostly that narcolepsy must be harmless or even humorous, rather than a serious medical condition, but nobody knows how hard I am working just to keep up.

I am very lucky to have a job that allows me to set my own rhythms. I could not go to college, but instead I found photography. Thanks to my brother, photography became my medicine to keep myself focused and awake. I am a naturally extroverted person, so I never had any problems with making friends. I know I am privileged compared to many other people with narcolepsy; I am fortunate that I come from an understanding and supportive family. I have the money to access the medications I need. I have been able to educate myself about alternative treatments and I have been able to engineer my own daily strategies to navigate through my symptoms. I feel a responsibility to share my story, using what I do best: photography.

Photography helped me to work through my symptoms. It is hard to explain… I guess you can say that photography is such a demanding job, and you have to focus on a ton of different things, and focusing in such a way basically helped me to fight off sleeping attacks. When my mind is absolutely focused on something - or rather many things: the light, the composition of the picture, the adjustments of the camera, etc., I am so clear and awake, that it is really difficult for a sleeping attack to overpower me. For a narcoleptic, it is often really hard to focus on something especially when the mind is not challenged. Photographically representing my experiences with hallucinations and lucid dreaming, and introducing them as methodology, by no means makes me more enlightened or my experiences any less terrifying. What we want to suggest is that there are other forms of understanding hallucinatory experiences and lucid dreaming: using them as a model of thinking offers alternative ways of "knowing," "doing", "caring", and "living" otherwise."

3. HALLUCINATIONS

Complex visual hallucinations (CVHs) are an intriguing phenomenon that occurs in a wide range of organic and psychiatric conditions, as well as in the absence of any demonstrable pathology. In the clinical domain, a visual hallucination (VH) can be described as "a visual percept, experienced when awake, which is not elicited by an external stimulus" (Waters et al., 2014). Complex visual hallucinations are a common symptom in people with narcolepsy, but also experienced by patients with various psychiatric conditions, and therefore may be wrongly diagnosed as delusional psychoses.

VHs occur at the transition from wakefulness to sleep (hypnagogic state) or from sleep to wakefulness (hypnopompic state). Most commonly these

hallucinations take the form of an elaborate, abstract visual interplay of light (monochromatic or colorful) and geometry (flat or three-dimensional), sounds (loud or quiet, hearing music, voices, repetitive words), physical sensations (feelings of floating, falling, leaving one's body) or repetitive actions, also known as the "Tetris effect." Although it is documented that VHs can be an isolated phenomenon or occur within the context of another clinical condition (Waters et al., 2016), VHs in narcolepsy are still part of a disease-model framework, with its corresponding language of deficit and pathology.

In the last decade, clinicians (Iudici et al., 2019; Pierre, 2010; Romme et al., 2009; Romme & Escher, 1989) and cultural researchers (Blackman 2001, 2010, 2012, and 2014; Cho, 2008) have manifested their interest in offering a different approach to the experience, understanding, and labeling of hallucinations, suggesting that there may be important theoretical meaning and characteristics of hallucinations that may have more positive implications for the clinical and social outcome of those who struggle with them. Particularly the phenomenon defined as "hearing voices" has become a quintessential example of the complexity of the relationship between hallucinations and the diagnosis of psychiatric disorders and the risk of automatically categorizing hallucinations as a pathological experience.

One of the most significant cultural theorists exploring this phenomenon is Lisa Blackman. Working collaboratively with the *Hearing Voices Network* (HVN), the author has emphasized on the multifold possibilities of listening to and interacting with voices, arguing against the psychiatric and pathologic presumption of hearing voices as a biochemical disorder. In *Immaterial Bodies,* Blackman (2012a) explores the phenomenon as an affective transfer; that is, "the possibility of articulation or voicing across bodies, human and non- human, separated potentially in both time and space" (p.139). In this context, instead of pathologizing voice-hearing as an anatomical malfunctioning of the brain (that is, e.g. a problem with the capacity for self-monitoring), which generates a lack of cognitive deficit leading to an irrational form of perception experienced as "other", voice-hearing is considered a mode of attention in which "otherness" is nothing but a "threshold phenomena" (*ibid*., p. 20). This suggests "some kind of transport between the self and other, inside and outside, and material and immaterial", that is, a production of relational knowledge based on proximity and connectedness rather than separation and singularity with the world; what I would call a body-mind-world entanglement. Consequently, more than pathological or misperceptions of reality, hearing voices is an affective hallucinational *worlding* phenomenon that can be a tool for opposition and resistance against the power of institutions, discourses, and disciplines that condemn hallucinatory episodes as a psychiatric disorder.

Perhaps the work of Grace Cho *Haunting the Korean Diaspora* (2008) on hearing voices can better exemplify this body-mind-world entanglement. In the

attempt to reconstruct her mother's story about the Korean War, Cho turns to secondary voices — her mother's voices — to reveal something of her mother's story that had never, at least not in a conscious state, been spoken about. Cho's mother was part of a Korean diaspora of women who married military personnel and emigrated to the USA at the end of WWII. Better known as war brides or GI brides, Cho felt that her mother's reluctance to tell her migration story was part of a cultural pattern of shame, secrecy and silence. In order to reconstruct the story of what has been erased by trauma, Cho beautifully develops a "method of seeing and speaking of trauma […] composed of scattered images, affects, and voices" (p. 24). In this research method, ghosts are interlocutors from the past that come to the present to tell us that which has been forgotten.

What interests us about Cho's and Blackman's approach to hearing voices is twofold. On the one hand, we are intrigued by their acknowledgement of the problems associated with mental illness as a model of thinking that offers productive possibilities (Cho, 2018). Both, Blackman and Cho, have developed methodological tools for researching non-ordinary or understudied conscious states traditionally classified as "weird science". This term is often used to refer "to phenomena, practices, experiences and entities, which have been associated or linked with the paranormal or supernatural" (Blackman, 2019, p. 5) and which may include a plethora of diverse subjects such as "mediumship, electronic voice phenomena, magical beliefs, lucid dreaming, deathbed visions, miracle cures, paranormal beliefs, false memory, telepathy, near-death states, haunted experiences, hypnosis, the placebo effect and so forth" or altered states of consciousness (*ibid*). Using ethnography incorporating voice-hearers' narratives, both authors indulge us with a felt, bodily, lived experience methodology to relate the consciously unspeakable. Cho's and Blackman's works come handy for us since they open a methodological path to analyze other "weird phenomena" that, although not related to trauma necessarily, are related to the embodied experience and the transformation of reality.

On the other hand, both authors rely on the affective dimension of the hallucinatory phenomenon to highlight the body "open-ended in-between-ness" (Gregg et al., 2010), which thoroughly entangle the psychic, bodily and symbolic that characterizes this phenomenon. Narcoleptic people have something to contribute to the affective experience of being and living in the in-between-ness. There is an affective dimension to the in-between-ness of the temporary inability to move and being on the edge of sleep when everything feels more fluid and things have a more free-associative quality. In this state of-in-between-ness, perceptions of the boundaries between subjectivity and objectivity, dreaming and reality, and virtuality and physicality are continuously challenged by "entangled processes that meet, enfold, invigorate and pass" […] through […] "the porous and permeable borders and boundaries between the

self and other, the human and non-human and nature and culture" (Blackman, 2014. p. 309). Conny's state of in-between-ness affords an affective dimension wherein human and non-human encounters manifest in specific ways. In her case, the non-human is represented by an "it" or "thing" having distinctive appearances and particular traits: usually taking the form of "monsters", they appear under certain conditions and have their own agenda – sometimes to scare, to hurt, to intimidate. However, after many years of profound interconnectedness and proximity, Conny has learned to displace her feelings of fear, distress, dread, terror, confusion and anxiety towards them and replace these feeling with more generative ones that enable her to face her monsters and to create epistemic and ontic spaces for a better livability both in dreams and reality.

3.1 Conny's hallucinations

"I feel pain. Although it is no pain in the traditional sense of the word. Not pain so much as an excruciating and energetic sense of disarray. This is how it always begins – the feeling of lessening spreading all over my body. A high-wave vibration drilling my eyes, my face, my brain. An accumulation of a million images per second. A slow-motion feeling meticulously spreading across my environment, shrinking it. I feel this overwhelming vibration running through my veins, stopping in my muscles, which have been paralyzed. I feel pain, a disorienting yet familiar feeling. *A déjà vu*.

I have been in this transitional in-between-state countless times, and yet I never know what is coming. Reality intrudes my brain's dream state. Am I sleeping? Am I awake? The space becomes an incongruent recompilation of high-pitched sounds and different shapes that sometimes fit together. Monochromatic moving pieces falling into place on an invisible layout at the edges of my visual field. An illusory slow-motion puzzle, a mental Tetris game.
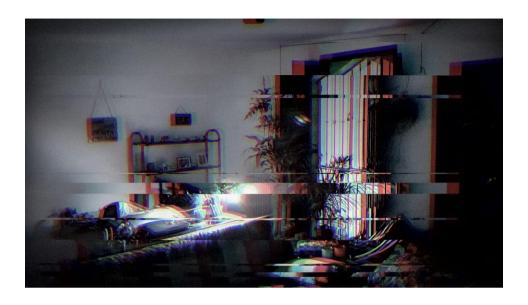
Image 2. Optical field in a hypnagogic state: Monochromatic visual interplay of light (Image: Cornelia Schoenmann)

This is the entry point of some unusual visitors. They might look like witches, monsters, a shadowy figure, a demon sitting on my chest or standing right next to the bed, or creatures with no face at all. No matter what they look like, these creatures leave me terrified and seemingly trapped in my body, unable to move as they weigh down on me. They like to appear in the incongruous corners of brain, where my dream-state intersects with my conscious mind, projecting themselves as hallucinations and nightmares into the real world —my world. A world that is ethereal, elusive, and reminiscent. A world characterized by vivid dreams, hallucinations, nightmares, feelings, and creativity which I encounter every time just before falling asleep.

My hypnagogic hallucinations are part of my half-waking state where subjective images, swiftly or slowly, take over my reality and present themselves as incongruous and terrifying pictures. Hypnagogia is not a dream, but it shares with dreaming its visual nature. It is closer to a schizophrenic hallucination, except that in a hypnagogic state, the hallucination is dream-based. I am very good at knowing when I am hallucinating; however, these images do not lose their disturbance, uneasiness, and awkwardness. I normally do not speak openly about my hallucinations, how they make me feel afraid for hearing or seeing things that are not there and how sometimes, even when I am fully awake, these images are so difficult to shake away from real life. Hallucinations evoke jocularity, innuendo, surprise, disbelief. In the worst case,

people look at me in fear after I tell them what I see in my dreams. Sometimes this look scares me more than the creatures that dwell in my hallucinations.

Image 3. Dark faceless creatures. (Image: Cornelia Schoenmann)

I am in a room and someone is knocking at the door. I cannot move. I hear more voices. I cannot understand what they are saying. I cannot move. I am afraid. Suddenly, there are black silhouettes around me; saying things, moving. I cannot see their faces. I can only describe them as dead. Or at least, this is the feeling I get from them. And this image, this feeling repeats itself many times before I start to feel panicked and suffocate because I cannot even control my own breathing. I try to speak or scream but it comes out as a whisper. I am frozen with fear. I try to wake myself up, but it never works. I'm always stuck "in it" until my body decides when it will let me wake up.

The feeling of being paralyzed is an inherent fear for many people who hallucinate and has been interpreted differently around the world. From friends I have learned about diverse cultural explanations of this sensation. In Italy, for example, people have mentioned the *Pandafeche*, a figure described as a malevolent witch dressed in white, with demonic eyes and a long and pointed muzzle, with which she causes wounds, or as a terrifying giant cat present during the sleep paralysis (see Jalal et al., 2015). In Mexico, *presencias* are

malicious spirits that terrorize the world of dreams as well as the "real world." In Egypt, a wide held belief is that sleep paralysis is caused by the *Jinn*, a spirit-like creature rooted within Islamic tradition (see Jalal et al., 2014). I also know about the *segatelel*, a menacing dwarflike creature feared by indigenous people in South Africa, or the *karabasan* in Turkey, known as evil spirits or demons that cause fearful dreams.

Like many other people with my condition, I am also particularly influenced by Western medicine, and I had been led to define my experiences in (mostly) negative terms — as unpleasant or even horrific, frequently associated with anxiety, depression, fear, paranoia, sleep disruption, and even suicidality. Usually, most narcoleptics want to avoid hallucinatory experiences because of the distress and terror they evoke. However, behind fear, there are other powerful resources for self-exploration and personal agency. It is true that the majority of people diagnosed as psychotic seem to have little or no ability to influence their hallucinations (and their invasive, abusive, or violent effects). After having these nightmares and hallucinations for many years, I have started to control them; or at least, the feeling of being afraid. When I see things or people moving around me, when I have the feeling of being threatened by someone/something I cannot see, when I start to feel afraid, to feel anguish and suffering, I know I am lucid dreaming. Lucid dreaming has the potential to provide dream-states far removed from the pathological phenomenon of hallucinations and much closer to what I call "practices of experimentation".

I like to refer to lucid dreaming as a practice of experimentation because it functions as a sort of reality-producing device that incorporates practices that change the coordinates of what is possible. As the dreamworld is very specific for each individual, our dreams are a unique site of the imaginary that offers specific practices of experiments and knowledge production. This knowledge, in contrast to the pathological explanations, offers a much more interesting site of creativity with alternative living possibilities and new forms to investigate the ways in which we may be colonized by certain ways of thinking about relationality with different worlds.

Lucid dreaming is a practice and technique that allows me to experiment with certain aspects of my dreams, helping me to integrate and incorporate psychic and physical experiences of fear into a more benign setting. The plot of the dream can remain the same, but when I am feeling distressed, small changes in the plot such as moving things or pushing people away, can change my "attitude" towards the dream. Suddenly, I can find patterns to realize I am hallucinating. I can even give myself some clues inside my dreams to orient myself, to become calm and re-gain self-control, and most of the time, I am able to relate differently with the most terrifying creatures coming in contact with me while I am dreaming. Lucid dreaming is a technique that allows me to re-gain some control of my own nightmares and, as a result, experiment with new forms

of companionship and experience of selfhood with those creatures that scare me the most. Lucid dreaming is a method of learning to cultivate, interpret, and create dream-state niches that afford epistemic resources and arts of living particularly when my hallucinations permeate or influence both my dreaming and my waking worlds."

4. LUCID DREAMING

Lucid dreaming involves conscious awareness of dreaming while you are still asleep. In a lucid dream state "the dream is still a dream, but the person is able to distance himself from the ongoing imagery and may even be successful in attenuating its emotional impact" (Voss & Voss, 2014, p. 25). Lucid dreams differ from vivid dreams since the dreamer usually knows that the dream is not reality but just a highly realistic version of it; a dream that literally mimics reality, and when you wake up you are able to recall every last excruciating detail. When the content of this type of dream can be controlled to a certain extend by the subject, a lucid dream is experienced.

In recent years, there appears to be a growing interest in the neuroscience of lucid dreaming (Rak et al., 2015; Stumbrys et al., 2012), not just in the academic field, but also in the general public, as indicated not only by web searches and Google trends (e.g. "how to become a lucid dreamer", "lucid dreaming techniques"), but also by the success of popular books (Johnson, 2017; Tuccillo et al., 2013;) and movies, which directly or indirectly explore the topic of lucid dreaming (e.g. *My Own Private Idaho*, 1991; *Deuce Bigalow: Male Gigolo*, 1999; I*nception*, 2010; *Ode to Joy*, 2019). Some studies have addressed the (potential) application of lucid dreaming as a technique to overcome nightmares (Abramovitch, 1995; Brylowski, 1990; Schädlich & Erlacher, 2012; Zadra & Pihl, 1997) and the contribution of lucid dreams when engaging with creative tasks (Stumbrys & Daniels, 2010; Stumbrys et al., 2012). Although a variety of applications of lucid dreams exists, few of them investigate its implications on narcoleptic individuals.

The study *Increased Lucid Dreaming Frequency in Narcolepsy* (2015) shows reliable data that confirms that in 70% of the studied cases, dream lucidity provided relief during nightmares. Despite the findings, the authors highlight that "increased lucid dreaming frequency in narcolepsy patients might be considered as an under recognized opportunity for a systematic therapy of narcolepsy-related nightmare symptoms: patients could be instructed to use dream lucidity to confront fearful dream elements in nightmares and, in turn, change the course of the dream plot" (Rak et al., 2015, p. 790). However, until now, the utilization of lucid dreaming as a method of experimenting at the edges of consciousness has not yet been addressed in any study. We want to fill this gap by showing how lucid dreaming, as a methodological approach, opens up

more speculative, inventive, and creative ways of engaging with worlds that extend beyond us and can create alternative conditions for living otherwise.

When referring to lucid dreaming as a method, we mean a specific approach of narcoleptic individuals to work through certain thoughts, dreams, and imageries. By offering an auto-ethnographically grounded account of Conny's lucid dreams, we do not present them as merely immaterial fantasies or abstractions, but as directly constitutive of Conny's embodied experiences and responses to the contingency of visible and invisible worlds. Bearing this in mind, we aim to develop alternative approaches and sensibilities that take lucid dreaming in narcoleptic individuals as a possibility that demands new practices and methodologies of attention, experimentation, creation, fabulation, and speculation. In this regard, the speculative stance has become part of the disability studies to formulate new possibilities in the unpredictability of those whose physical symptoms fluctuate widely or with mentally "unexplained mysteries, oddities, 'strange stuff' or challenges to established thinking" (Blackman, 2019, p. 5). The importance of the speculative resides in providing alternative ways of thinking, imagining, and narrating the ontological indeterminacy of what it means to be a "sick person" opening up the possibility for more inventive and creative ways of research science.

Feminist philosopher Isabelle Stengers (2011) argues that speculative thinking brings nothing other than "a struggle against probabilities" (p. 17) which constitutes a plurality of modes of importance. Here, "importance" is a proposition intended to provoke thought about the production of what matters, in terms of the transformation of experience. For Stengers, experience is linked to the speculative as an "experimental adventure" (p. 18) — that is, an experimental mode of thinking that does not stand outside of experience. Consequently, speculation is an approximation to experiencing as an experimental adventure that opens up other possible trajectories where reality is "always already entangled with the 'not-yet', the 'yet-to-come', the 'what-if', the 'already-here', that is, with a sense of the (im)possible" (Wilkie et al., 2017, p. 8). Following Stengers' argument, lucid dreaming is therefore closely related to what Conny and Lisa Blackman (2012) call "practice(s) of experimentation", that is "inventive strategies for producing particular forms of entanglement" (p. 144).

> *The concept of experimentation as simply revealing or disclosing entities or phenomena that pre-exist the experimental setting is one that ignores or elides the complex processes of mediation that allow phenomena to take form. We might think of practices of experimentation as inventive strategies for producing particular forms of entanglement. This is in line with work taken up across the sciences and humanities, which approaches experimentation as performative, and where the technical framing of an experimental event provides the setting for dynamic processes of enactment to take form. (Blackman, 2012, p. 144)*

If we follow Blackman's and Stengers' line of thought that "reality", "truth" and "fiction" are already entangled in the realm of experience/experimentation, then, just as the phenomenon of hearing voices enables us to examine the complex brain-body-world entanglements, lucid dreaming mediates the boundaries between subjectivity and objectivity, dreaming and reality, and virtuality and physicality in complex ways. For a narcoleptic patient, lucid dreaming is a way to entangle the uncertain and fluid nature of a dream world and the blurred sense of reality. It is a method to experiment with the duality of dream/reality with profound interconnectedness with the human and the non-human as well as a non-human 'agency' that enhances the power of humans to direct their own life. This is a relationship that demands a narrative method for a different sense of co-presence, interaction, and interlocking understandings and practices of *living-with* entities inhabiting the dream-world; a method for a different storytelling about *living-with* frighteningly unearthly creatures.

Perhaps no author has been more persisting in her invitation of the potential of storytelling than Donna Haraway. Haraway (2008, 2016, and 2019) has used storytelling to build a methodological relationship between science and fiction (or science-fiction), as an epistemological way to challenge the understanding of what matters as science and how it takes form. As Haraway (2019) reminds us with reference to Marilyn Strathern, the creation of hypothetical worlds where it matters what stories tell stories and where "It matters what thoughts think thoughts, what stories tell stories, what knowledges know knowledges" (Haraway, 2019, p. 5). As such, the importance of the stories we tell is quintessential to our understanding of the world since telling stories is a very material process, a form of *worlding* itself.

Through *worlding,* we learn to *become-with,* to *live-with* other creatures, Haraway argues; it means to promiscuously encounter "microbes, plants, animals, humans and nonhumans, and sometimes even machines" (Haraway, 2016, p. 169). We would add here also the encounter with frighteningly unearthly creatures; those who appear at the boundary between subjectivity and objectivity, dreaming and reality, virtuality and physicality. That is beings that one "meets" during lucid dreaming.

Lucid dreaming is our particular speculative approach to the relationship between science and storytelling. It conveys a generative friction between dreaming (concepts and ideas) and its narrative (storytelling and fiction). Following Anna Tsing's (2005) definition of the term, we purposely use the word "friction" here, referring to "the awkward, unequal, unstable, and creative qualities of interconnection across difference" (p. 4). Lucid dreams are frictional encounters and interactions between the real and the unreal that push stories in new directions. Lucid dreaming frictional/speculative features allow us to momentarily wonder about how encounters with frightening creatures such as

ghosts, witches, beasts and other monsters of the natural and supernatural worlds could look like. In the following section we want to explore how exactly living with unearthly creatures as companions allows one to live otherwise.

4.1 Dreaming with monsters: living and caring otherwise

In what follows, we approach Conny's hallucinations and lucid dreaming as fundamental encounters that incite new ways of living in different worlds — worlds that entangle social modes of existence, practices, and care stories. We outline lucid dreaming as a highly affectual event that radically provides an affirmative life moment through different affective dream states, including those of a "negative" register. By examining Conny's hallucinations and nightmares, we show how Conny's personal practice of experimentation with lucid dreaming opens up for her a possibility for being in the world otherwise. To be able to analyze Conny's lucid dreaming, we build our argument around the account of two specific dreams. The first dream episode has to do with trepidation and anxiety while the second introduces an event of terror and impossibility. Both dreams have at their center Conny's encounter with a frighteningly unearthly creature. However, both dream episodes have also to do with care and love, and with being receptive to the frightening other. Like any dream experience, they are only representations; they never show the full picture. Conny's recount of her dreams is only a partial grasp of them, and there is always something that will escape from the range of her awareness. Thus, we would like to invite the reader to join in the fleeting experience of what is impossible to empirically determine (Pyyry & Aiava, 2020). To speculate what is possible rather than what is probable. By presenting here Conny's dream stories we offer you, the reader, the experience of sensing/feeling them, since even if lucid dreaming is not part of our verbal/mental capacity or our own experience, these dreams are not a far-fetched possibility to happen in our own dream worlds. Although the two dreams vary significantly from each other in terms of their content and plot, we argue that they speak of similar emotional landscapes: landscapes of care and enchantment that offer Conny the possibility of being in the "real" world otherwise.

4.1.1 The eagle, the witch, and the art of caring otherwise

Almost every night I can feel Conny next to me, quivering, screaming, and laughing while sleeping. She is living another life right next to me. Sometimes she wakes me up in the middle of the night. She apologizes and gets out of the room to smoke. Sometimes I ask her what kind of worlds she visits in her dream, the expression of her face tells me the story and I do not have to ask. Since we have decided to collaborate on this article, Conny has been much more

open about sharing her nightly experiences, her dream worlds. Worlds where creatures can make Conny suffer and be afraid, but they are also full of beings that have the ability and power to intervene, to help her, care for her - when I cannot.

Image 4. Flying-with (Image: Cornelia Schoenmann)

I remember this particular dream in which I was being chased by someone. This frightening figure wanted to get something from me, something it considered valuable. I was extremely afraid because I felt I was in great danger. The atmosphere of the dream is hard to communicate: a verbalized memory is a lame interpretation. It was violent, loud, and extremely unsettling; a combination of rage, despair, and energy. A forceful event with the potential to radically shatter me. In this moment of mental breakdown, I suddenly realized I am having a nightmare and that I am hallucinating. This is when I took control of what was happening and I decided to fly away to escape from the situation. While flying, I noticed that I did not know how to turn around. This created a new feeling of terror and anxiety. To escape this feeling, I decided to learn how to fly better and just like that, a huge eagle appeared right in front of me. He was twice my size and had a son, a baby eagle. He decided and began to teach us both how to flight. He threw us outside the nest (where we suddenly were) and the lesson started. Later, when I was back in the nest, the large eagle embraced me with his long wings. Suddenly, everything was black and warm and I woke up. I have not forgotten this feeling because I woke up in peace and confidence in myself

different from I usually do: stressed and scared. The eagle appears to me in moments of stress. This may sound strange but he is like my mentor when I have difficulties with something. I cannot wait to find him in another of my dreams.

When Conny told me this particular dream, her account of this caring event made me reflect on conventional notions of care. Her story made me speculate on how we might think of care when it is provided by the more-than-human, and how we can disclose the subjective and affective relationships that happen during this caring encounter. In another forthcoming article (Mendez de la Brena, 2021), I am researching the far-reaching speculations of care in disability worlds, particularly when care is not possible or not feasible by human contact. Drawing on Arseli Dokumaci (2020) and María Puig de la Bellacasa (2017), I reflect on the space that opens up between a disabled body and the non-human touch that allows other forms of care, not involving human presence. I use the term "caring matter" to refer to this form of care — that is a momentary entanglement with matter, where the body is always-already touched by other beings which give a form of care that humans cannot provide.

Conny's lucid dreaming has opened a window (for me) to speculate on the context of unearthly worlds where care is provided by other than humans. Here, I follow Puig de la Bellacasa's (2017) speculative notion of care, which reveals how, in specific moments of life, other-than-humans are involved in "agential intra-activities that together make 'our' worlds, existences, and doings, and that get earthlings through our interdependent days, taking care of myriad vital processes" (*ibid*., p. 22).. Puig de la Bellacasa invites us to think about different configurations and practices of care and argues that to touch and to be touched puts the question of the reversibility of reciprocity and the circulation of care in more-than-human worlds. Following a similar line of thinking, Karen Barad (2012) suggests that when the human touch is not allowed or possible, "the living and intra-acting in more than human worlds, provide a differentiated 'touch'" […] "the touch of entangled beings (be)coming together-apart" in ways that enable response-ability" (p. 208).   However, it is important to note that although touch necessitates proximity to what (or who) touches us, touch is not always caring or taking place in a caring context *per se.* It can just as well occur in a hostile environment, while vice versa, care can also be present in hostile (non-loving) scenarios and can be provided by the most unexpected or unpleasant actors.

In her unearthly dream-worlds, Conny has been touched by such unpleasant/unexpected actors; the frightening eagle for example is not exactly a loving figure, but his touch nevertheless brings vitality and vibrancy to her, particularly when no other person can fit in that world to provide care. Care, in Conny's world, presents itself as what I call an "affective trans-unearthly touch" which provides her with "vital affordances", allowing the "multiplication of the

conditions of living, exactly when and where those existing conditions least afford living" (Dokumaci, 2017, p. 408). During lucid dreaming, "affective trans-unearthly touch" is a critical, affective, and caring tool for collaborative survival that provides safety, peace, and confidence not just while (lucid) dreaming but also for her daily living.

Conny felt a similar "affective trans-unearthly touch" during another dream with a different visitor. I remember this particular night because we were both lying in bed when, around three in the morning, Conny started talking loudly, almost screaming. At first it was scary because it seemed like she was talking with someone else in our room. After a couple of minutes she started laughing out loud. I did not understand what she was saying because she speaks in German (her mother tongue) in her dreams. The next morning I asked her about her dream and told her that she was laughing loudly and speaking quite a lot during the night. This is what she replied:

> I was high above the roof of a house. Again, I was struggling to fly. In lucid dreams, flying is an energetically demanding performance, you must know. I was there, trying to learn to fly better and this old frightening witch approached me. The event was very discouraging. It was a highly affectual, agonizing and petrifying moment. Usually, when I recognize these feelings in my dreams, I decide to control the narrative of my dream. I decide the way things are going in the dream and then I can change it. So this is what I did last night also, I guess. The witch was really frightening and scaring me, so I decided to change the narrative. I started a discussion with her. I don't remember that I was laughing loudly, but if I was, it was probably during our heated discussion. Suddenly, the witch did not scare me anymore; although I cannot say I was feeling completely comfortable around her. She resisted to be controlled. She looked at me with disdain but at the same time her eyes were full of compassion and wisdom. She said in an enchanting voice: "Do not force it, let it go." I remember I woke up with this advice in my head. I receive these kinds of advice from witches from time to time in my dreams. They are like my personal coaches I would say, not always nice and tender, and sometimes I do not know what to expect from them, but they always provide me with an attitude and some advice for the real world.

That night, a simultaneously material, affective and aesthetic choreography of unearthly companionship took place in Conny's lucid dreaming. A form of enchantment in both of its meanings: as an "act of magic or witchcraft; use of magic; magic power" (Enchantment, Online Etymology Dictionary), and as the sensation to be struck by the extraordinary that lives amid the familiarized and the extraordinary. In her seminal work The Enchantment of Modern Life, Jane Bennett (2001) describes enchantment as

> a state of wonder, and one of the distinctions of this state is the temporary suspension of chronological time and bodily movement. To be enchanted, then,

is to participate in a momentarily immobilizing encounter; it is to be transfixed, spellbound. (*ibid.*, p. 5)

To be enchanted is a state, a feeling, and an affect inspiring experience of being immersed in an uncanny moment, feeling completely and utterly displaced and at the same time feeling engaged with the world. The importance of enchantment is that it is a simultaneous sensation of wonder and disturbance that emerges from an encounter between two sets of active materialities; this encounter or "cross-species encounters", Bennett's term, generates a sensation of "thrill", a "rush" that enables the person to feel "more intensely alive". However, enchantment can also evoke a state of fear, and the sense of wonder associated with a "more unheimlich (uncanny) feeling of being disrupted or torn out of one's default sensory-psychic-intellectual disposition" (Bennett, 2001, p. 5). Consequently, to be enchanted is not always to feel delighted or charmed but, as Cheryl McEwan (2008) argues, to be enchanted also means

> to be faced with something both real and simultaneously weird, mysterious, awesome, and perhaps even dreadful. Enchantment can be a state in which ghosts, spirits, and specters exist within a mélange of other marvels, including magic, myth, monsters, witchcraft, sorcery, voodoo, vampires, and zombies. (p. 30)

Conny's dream does not necessarily fit with Bennett's more optimistic politics and ethics of enchantment. Conny's meeting with the witch did not take place in a context of joy and wonder but was rather embedded in a composition of a range of affective tones: fear, suffering, frustration, wonder, expectation, and jealousy. Conny's enchantment is more about anxiety and fear than fascination and wonder. In her hallucination, Conny is confronted by frightening circumstances beyond our understanding. She is confronted with a world that operates in moments of hesitation, fear, and uncertainty. However, without these moments of frightening confrontation, a "genuine reevaluation of the world could not take place" (Pyyry & Aiava, 2020, p. 11). At such moments, a frightening yet generous touch by an unearthly creature (at times an eagle, at other times a witch) provides Conny with caring relationalities and life lessons that give her an urge for self-care not only through the reception of comforting advice but also because this advice provides her with a feeling of security in the face of the her own fragility in the everyday life world. Conny's eerie experience with the witch is about care that perhaps does not give her a more comforting world, but helps her to feel stronger in that world through self-understanding and self-care.

Conny has learned to talk to witches, eagles, and other monsters of the natural and supernatural worlds and is affected by them. Her lucid dreaming opens up a new world through anxiety and fear, a world that contains a

multitude of creatures that leave her with no choice but to radically change the terrifying events attributing to them new possibilities in order to create something else. Lucid dreaming essentially helps Conny to be receptive to the frightening other and receiving from this other an affirmation of life itself, (through a sense of care and protection), in an encounter that transcends the boundaries between material and non-material, human and non-human, dream and reality, allowing her to regain control of her reality and ownership of herself.

5. CONCLUSIONS

This article aims to simultaneously be a bridge and build a bridge between the ways of knowing about narcolepsy and the effects this condition has on someone living with it, while also making a significant contribution to research methodologies for approaching other forms of care. To this end, we have introduced lucid dreaming as an eccentric research technique that opens up new ways of approaching the study of hallucinations. By presenting Conny's personal experience and her dream-stories we have shown how hallucinations are (admittedly) a symptom of her condition, yet the monsters that dwell in them are not just fragments of the (popular) imaginary, but exist as a rather real part of her life. These hallucinations manifest themselves in specific ways, and for different reasons. Conny's condition/narcolepsy makes her live through and with nightmares and hallucinations with great frequency and in a very different way that most people dream. In her hallucinations, monster-human encounters are almost always scary and frightening. However, after many years of experiencing these creepy encounters, she has challenged herself to look at her condition in new and excitingly different ways.

Conny has used lucid dreaming as a practice of experimentation that allows her to explore the indeterminacy of her dream experience, and thus towards understanding what it means to have monsters in her life. Conny writes about how she has learned to talk about and with the uncanny in a generally understandable way, not trying to prove medicine wrong, but rather to suggest a widening of perspectives on hallucination and the creatures that inhabit it. Lucid dreaming for her is a creative tool for collaborative survival in more-than-human worlds that sometimes seem impossible to inhabit. I propose that the care provided by other-than- human offers an "affective trans-unearthly touch" that perhaps does not make Conny's world more "normal", but which helps her to be in this world feeling cared for and loved and not as if she does not belong. We hope this contribution will be useful in thinking through experimental and eccentric methodological approaches, to decompose the usual interpretations of what we have come to know about narcolepsy, and to open ourselves to new

registers and modalities of attending to "other worlds" that exceed conscious rational thought. By using lucid dreaming as a methodological tool we are speculating on alternative ways of "knowing," "doing", "living" and most of all "caring" otherwise.

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