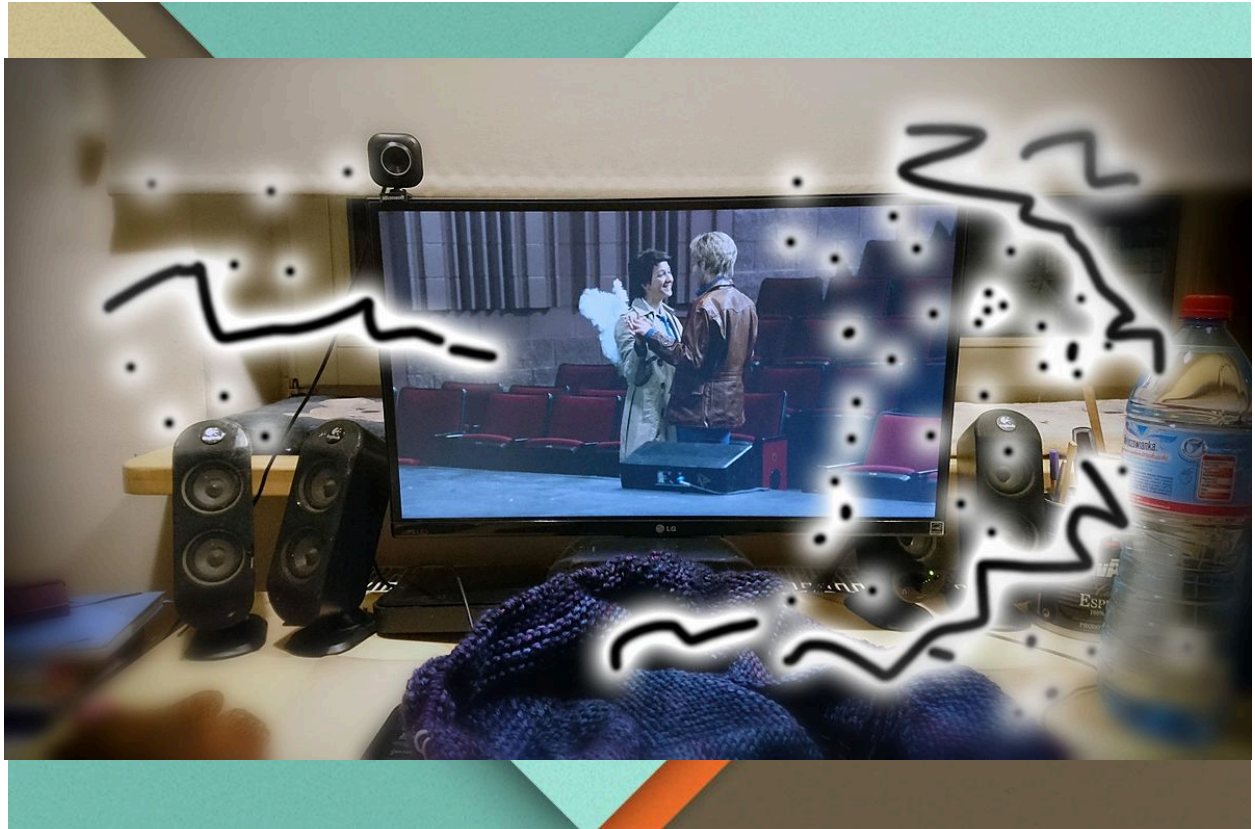




# Destigmatizing Hallucinations

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[Description of Header Image: An artistic representation of the second most common type of visual migraine aura experience (jagged lines and dots), superimposed over a mundane scene of a computer monitor showing a movie, surrounded by household items like a speaker and water bottle.]

## Hallucinations & Stigma: Why is this resource necessary?

Efforts to destigmatize mental illness often focus on the symptoms or diagnosis of depression and anxiety. While this is a noble and worthy cause, these efforts typically neglect a range of symptoms and diagnoses – from personality disorders to psychosis and much more. This leaves us with a society that is beginning to offer more compassion and understanding for mental health symptoms like profound sadness and worry but continues to pathologize other symptoms, like hallucinations and delusions. This informational packet is intended to take one small step towards destigmatizing the normal human experience of hallucinations by focusing on “nonclinical” hallucinations in people without psychosis, cultural contexts of hallucinations, and the affirmative choice to intentionally create the circumstances needed to experience hallucinations (e.g., through recreational substance use).

### Disclaimer

This should not be interpreted as a claim that depression and anxiety are no longer stigmatized conditions. The author’s personal observation is that it is only the mildest manifestations of anxiety and depression that have even seen the most negligible reduction in stigma. For example, depression seems to be destigmatized only to the degree that the least empathetic observer can identify an adequate ‘cause’ (e.g., a limited range of grief/loss for a limited time), and anxiety seems to be similarly destigmatized only to the degree that the least empathetic person can identify with an easily identified ‘cause.’ Severe depression that causes difficulty with performing responsibilities like parenting, socializing in neuronormative ways, or personal hygiene, or that contributes to self-harm or suicidal ideation or completion continues to be highly stigmatized. Anxiety conditions like OCD remain misunderstood and stigmatized by the general public.

Regardless, the author has focused this particular informational packet on so-called “nonclinical” hallucinations. It can also be noted that severe depression can be accompanied by hallucinations in some cases, and thus, destigmatizing hallucinations can help destigmatize anxiety and depression.

Finally, this informational packet is not intended to be exhaustive. The subject of hallucinations and the complete variety and range of experiences is too vast a subject to cover in a resource like this.

It could be argued that by focusing on hallucinatory experiences outside of the diagnostic realm of psychosis, schizophrenia, and mood disorders, these most highly stigmatized conditions are othered and allowed to stand as a reservoir for stigma. This is a valid criticism. However, this resource is not offered as if any singular resource will, on its



own, successfully end stigma. Instead, it is offered as a modest tool for therapists to learn or relearn and reflect. It is this active reflection that the author hopes music therapists will take steps towards dismantling ableism and challenging stigma.

The author will also share their own experiences with hallucinations in the hope of challenging ableist stereotypes that “therapists don’t have hallucinations,” and in particular to remind any therapist or therapy student/intern reading this that if you have had hallucinations, or if you continue to have them, that you are not alone and you are a welcome member of our professional community. Hearing voices does not mean you cannot be a therapist. Perceiving things that are “not there” does not mean you are inadequate, unworthy, or incapable. To the contrary – our profession needs people who can understand on a personal level what it can be like to navigate a world where your sensory system allows you to experience things others do not.

## What is Stigma?

According to the Merriam-Webster Dictionary, stigma is “a set of negative and unfair beliefs that a society or group of people have about something” or “a mark of shame or discredit.” It comes from Latin and Greek words that describe a permanent mark on the skin or a scar or wound that identifies or stains the person’s character.

Stigma towards mental illness makes it more difficult for people to access treatment for their problems – whether because a person is hesitant to ask for help, to be open and honest about what they are going through, or to otherwise seek social support, or because society declines to offer this help through a scarcity of care, underfunding of services, putting services behind a paywall, or creating other barriers to accessing care. Stigma also exists within the mental healthcare system, in institutional ways that are reflected through government and business policies, but also through the interpersonal interactions of individual clinicians who hold derogatory beliefs about mental illness.

## A Note on Disability Simulations

Disability simulations attempt to reduce the stigma of specific disabilities by simulating the disability in nondisabled people. These simulations have been attempted in regard to hallucinations and schizophrenia, but like other disability simulations, have shown poor efficacy. Ando, et al.’s (2011) systematic review of the literature found that while simulating hallucinations in people without schizophrenia increased empathy for people with schizophrenia, it also increased the desire for social distance from people with schizophrenia. It is clear that the work of deconstructing ableism against people with schizophrenia, people who hear voices, and people who experience hallucinations is more complicated work than a simulation of psychiatric symptoms that can be “turned on” and “turned off.”

## What are Hallucinations?

Hallucinations are sensory experiences that seem as if they are real and come from the external world but are actually produced by the brain and nervous system. Hallucinations can involve any sense – including vision, hearing, smell, taste, and touch. A person may or may not know that what they are perceiving is “unreal” or that other people cannot perceive it.

Hallucinations are different from illusions or misinterpretations. For example, if you see a coat hanging on the doorframe, you might think at first glance that there is a person standing there. This is not a hallucination because the coat is real.

Hallucinations are also different than internal sensory experiences, such as internal visual imagery or audiation (the imagination of sound or “hearing music in your head”). Hallucinations seem to be real, external sensory experiences. For example, an auditory hallucination may seem to come from a specific location outside the person’s head.

Hallucinations can occur due to a wide range of neurological phenomena and diagnostic labels, including epilepsy and seizure disorders, migraine, schizophrenia, mood disorders, fever and illness, degenerative brain diseases, traumatic brain injury, bereavement, prescribed medications, and recreational drug use. The hallucinatory experiences resulting from these diverse causes cover an enormous range of types of hallucinations.

While schizophrenia is commonly described as the “most common” cause of hallucinations, there is an enormous range of human experiences that can cause hallucinations outside of schizophrenia.

For example, over their lifetime, the author has experienced many types of hallucinations, from childhood to adulthood, without the stereotypical use of psychedelic drugs or qualifying for a diagnosis like schizophrenia or psychosis. Some of these experiences will be described later.

## Hallucinations Always Have a Cultural Context

Hallucinations are sensory experiences that occur within a human being’s cultural context because hallucinations are often described as “unreal” experiences, but culture defines what is seen as real. Many cultures accept some variation of the “supernatural,” which can strongly influence how a hallucination is both experienced and interpreted by others.

Larøi et al. (2014) take an ethnographic approach to studying hallucinations. They point out that three different groups in the Amazon may each use the hallucinogenic



substance ayahuasca but understand these hallucinatory experiences in three different ways – as providing guidance, access to an alternate reality, or access to true reality (while normal human day-to-day life is seen as the hallucination). Hallucinations commonly play a positive role in religious ritual and expression, with or without the use of psychoactive substances. Larøi et al. (2014) also discuss how local culture influences not only the content of hallucinations but also how debilitating these hallucinations are when they are recurrent. It is a fascinating study worth reading in its totality and is publicly available with no paywall (see references section for a link).

## Prevalence

It is difficult to claim precisely how common it is to experience hallucinations. Stigma can prevent people from admitting they experience hallucinations. The author experienced this personally as a child, as described later.

“Nonclinical” hallucinations in the “general population,” or hallucinations from people who are not labeled with schizophrenia or psychosis, are less likely to be distressing or unpleasant, are more likely to be brief, and occur less frequently; hallucinations associated with psychosis and schizophrenia occur more frequently and are more likely to contain distressing content (Larøi et al., 2014).

Larøi et al. (2014) describe how 10-15% or more of the general population has reported having hallucinatory experiences. Hallucinations that occur while transitioning from wakefulness directly into REM sleep may occur in up to 37% of people (Teeple et al., 2009)!

## A Digression? Hallucinations & Recreational Substance Use

Estimating the lifetime prevalence of any hallucinatory experience can be difficult to estimate, in part due to expanding access to and use of hallucinogens or psychedelic drugs that can promote hallucinatory experiences. Many people will not admit to using psychedelic drugs out of fear of legal consequences. Therapists should be cognizant of how common it is to be offered psychedelics on social media through automated spambots that market hallucinogens as mental health treatments, that psilocybin (“magic mushrooms”) grow naturally in many parts of the world (including the author’s hometown of Houston, Texas) and can be grown indoors with similar setups as one grows culinary mushrooms. In some jurisdictions, some hallucinogenic drugs are decriminalized or legalized for recreational use.

Your clients may have had experiences with hallucinogenic drugs in recreational settings. It is important to cultivate a positive therapeutic relationship with unconditional

positive regard so that your client can be open with you about these experiences, as they can impact your client's progress in diverse ways.

## Case Studies – Positive Outcomes

When your client trusts you, they may admit to using hallucinogenic drugs in ways they feel have benefitted them. It can be helpful for some clients to explore what they feel were positive outcomes of recreational drug use in therapy, and therapists should be hesitant to jump immediately into the role of the cop by exclusively emphasizing the danger, illegality or criminality, and disapproval of substance use. Your client is familiar with these narratives, and you will not be offering a new perspective by defaulting to this position.

➤ Client: Donna, mid-20s, in treatment for eating disorder

Donna reported using psilocybin recreationally with friends. Donna did not ingest enough mushrooms to experience dramatic or overt hallucinations, but she reported “seeing things differently.” When Donna stepped away to use the restroom, she looked at herself in the mirror. She reports being struck by her beauty for the first time in her life. She reported, “I really saw myself for the first time.” Donna felt released from dysmorphia and instead of seeing her physical flaws, began to notice things about herself that she found “beautiful.” Donna reported feeling like she was “beautiful on the inside,” and impressed by what her body was capable of. Donna reported that this insight remained after the effects of the drug wore off, and she continued to feel positive about herself in both her physical appearance and internal character.

➤ Client: Don, an adolescent in a dual diagnosis treatment program (substance use & depression/anxiety)

Don reported using psilocybin with two friends. As the night progressed, Don's peers were more engaged with each other and Don felt left out and rejected. Don lived nearby and decided to walk home. When Don got home, he reported feeling overcome by sadness and began weeping. Don reported that prior to this, he seldom cried and “didn't have feelings.” Don said he cried for a long time, and then he went to his mother. He talked to her about feeling lonely and rejected. Don's mother comforted him.

Don reported that even though he cried and felt sad, he felt it was a deeply healing experience because it allowed him to feel and express his emotions, connect with his mother, and receive support. Don reported that he was continuing to draw on his relationship with

his mother and that the incident helped her to understand him and helped him to understand that his mother would always love and support him.

Key takeaways from these anecdotes include the clients being in safe and socially supportive environments that enabled positive breakthroughs. When the therapist expressed concern, for example, for Don walking at night by himself while under the influence, Don shrugged these concerns off due to “living in a safe neighborhood.” For these clients, experiences with hallucinatory substances helped them to meet their goals.

## Case Study – A Negative Outcome

Just as with prescribed medications, positive outcomes are not inevitable. Other people may have less positive experiences.

### ➤ Dean, mid-30s, in treatment for anxiety/depression

Dean was confident and capable with a military background and perfectionist standards. While Dean was early in treatment, he received a message on social media offering to sell him psilocybin. The seller made claims that psilocybin is an effective mental health treatment that improves a variety of symptoms. Dean had never used drugs before but purchased and consumed the psilocybin.

When Dean presented to group, he appeared quiet (as usual) but notably distressed and distracted. Dean began to express feelings of derealization and what some users refer to as “ego death” or “ego loss,” or the loss of one’s sense of subjective self-identity. Dean was clearly unsettled and distressed by these questions. Dean asked the therapist and group questions like, “How can you know what is real? How do I know if I am real?”

It was not clear if Dean was currently under the influence at the time he asked these questions, as he did not admit to purchasing and using the substances until after the session. The therapist and group members attempted to help Dean process his experiences without knowing about his use of substances. A group member offered spiritual insights from her religious tradition, which Dean did not adhere to, which only seemed to unsettle Dean more.

Dean met briefly with a social worker after the music therapy session, who performed a risk assessment and determined that Dean was safe to take an Uber home if his spouse would be there and remain with him until Dean returned to treatment the following morning. When Dean checked in with the social worker to confirm he

had arrived home safely and his spouse would remain with him, Dean admitted to using psychedelics with the goal of increasing the rate of progress in therapy. Dean verbally committed to returning to treatment the next morning.

However, the next day, Dean instead traveled out of the country for leisure travel with his spouse. Dean did not return to treatment and was discharged Against Medical Advice.

These clinical portraits illustrate how substances that engender hallucinogenic experiences can also provoke strong psychological and emotional experiences. When someone is unsupported in these experiences and does not feel they can truthfully share their experiences with the therapist or key support figures, they can negatively impact treatment outcomes.

Music therapists can adopt an attitude of open-mindedness, non-judgment, and empathy in order to promote the client's ability to seek support within therapeutic settings – even if you disapprove of their choice to use substances. Therapists must express concern for safety issues without condemning the client's character.

Improved therapeutic rapport and group cohesion might have enabled Dean to share his intent to use substances and be more candid about his use of substances after the fact. Had the therapist understood Dean's derealization was a result of recreational drug use, they could have provided helpful psychoeducation, as well as referral to our on-site specialist in substance use, who could have met individually with Dean and provided specialist support in processing his hallucinogenic experiences.

## Other Types & Causes of Hallucinations: A few examples

These are only a few examples of types and causes of hallucinations outside of psychosis and schizophrenia, several of which are quite common in the "general population."

### I. Visual Migraine Aura

Many people with migraines report a migraine aura that includes visual hallucinations, and some types of migraine include only visual hallucinations. These hallucinations are often sparkling, silver lines that take on jagged shapes. They may move across the visual field, starting on one side and moving towards the midline. The visual hallucinations of migraines can be differentiated from occipital seizures by the duration and rate of onset. Migraine-associated hallucinations typically come on slowly and build up, lasting 20-30 minutes. Seizures more commonly come on suddenly and last for a few seconds, up to a minute or two. Migraine and seizure

can sometimes be hard to differentiate, especially because one can lead to the other. This is sometimes called “migralepsy” – or a migraine with aura that triggers a seizure.

Visual migraines may or may not occur with other migraine symptoms, like headache or light sensitivity. The author has this type of hallucination, triggered by stress and lack of sleep and/or by certain types of visual stimuli.

Visual triggers are not an uncommon trigger for migraines and seizures for many people. Music therapists should independently learn about common visual triggers (such as flashing lights and contrasting repeating patterns). Unfortunately, this author cannot supply examples without risking triggering a migraine in themselves (or readers). Part of creating an accessible therapy space is reducing the use of migraine-inducing decorations. For example, chevron patterns have become popular decorative themes, but these can cause migraines and seizures, and even people without these conditions may feel disoriented or unwell when exposed to them.

## II. Hypnogogic & Hypnopompic Hallucinations

Hypnogogic and hypnopompic hallucinations are associated with the transition into and out of sleep. They are not uncommon, although may be associated with underlying conditions like narcolepsy or Parkinson’s. In some cases, the content of these hallucinations can be frightening – just like the content of dreams can be frightening. Hypnogogic hallucinations occur in up to 37% of people, and hypnopompic hallucinations in up to 12% (Teeple et al., 2009).

### Hypnogogic Hallucinations

Hypnogogic hallucinations occur as you transition from wakefulness to REM sleep. They are most often visual in nature and consist of colorful, morphing geometric patterns, but could also feature people, animals, or objects. These hallucinations can be auditory and consist of people’s voices, environmental sounds, or even music.

This author often has visual and auditory hypnogogic hallucinations, with the auditory hallucination imitative of sports commentators or even ‘90s dance-pop hits, and the visual hallucinations consisting of colorful geographic images or common everyday objects (It feels like being able to see with your eyes closed because the image stays the same whether your eyes are open or closed!).

Hypnogogic hallucinations can also feel like you are moving when your body is still or feature tastes or smells.

## Hypnopompic Hallucinations

Hypnopompic hallucinations occur as you are waking up and have many shared features with hypnogogic hallucinations.

### III. Idiopathic Childhood Occipital Epilepsy – Gestalt Type

When I was a young child in early elementary school, I often experienced hallucinations of a specific type, although I did not understand them as such. I assumed that everyone occasionally saw what I saw – just like everyone could see an after-image of a bright light when the light is turned off or you look away. These hallucinations looked like stacked emerald green circles, or figure-eights, with bright red spots, and they moved and swirled in a fan-like rotating or spinning gesture. They occurred usually on one side of my vision, lasted for a few seconds or a minute, and then went away. I never noticed any other symptoms, and it didn't bother me in the slightest. I privately named them my "green potatoes with red eyes."

One day, I experienced this hallucination while in the company of my mother. I hadn't had this experience in a while and felt a little excited and happy.

"They're back!" I told her. "The green potatoes with red eyes!" I said this as if I fully expected her to understand what I meant, even though we had never talked about it before. She asked what I meant. I repeated myself, calling them green potatoes with red eyes. She was clearly confused and said, "Well, I don't see green potatoes with red eyes." This would be the first and last time I would ever tell an adult about these images. I understood very clearly that this was not a normal experience I shared with everyone and that there was something weird about it. Since I had no other associated symptoms – no pain, no lapse of consciousness, no tremors or convulsions – I successfully hid these hallucinations until they simply went away.

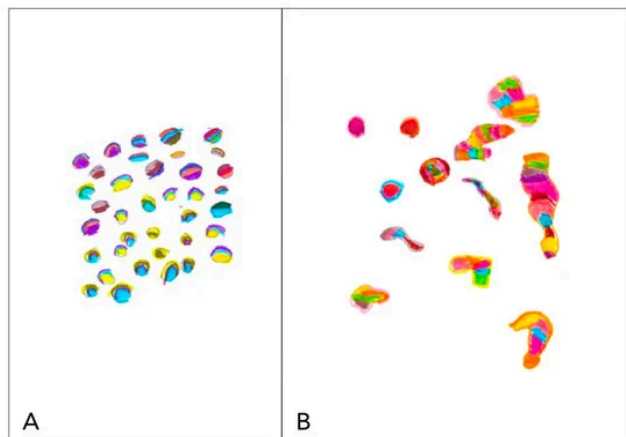
This is the trouble with stigma. My mother was not cruel or mean. She simply reported that she did not see what I saw, and I understood this was just one more thing that made me different than others. Nobody ever asked me if I saw things other people didn't, and I certainly wasn't going to volunteer this information and be made into a freak. As a result, I didn't learn a possible explanation for these experiences until I was an adult seeking answers for a totally different type of visual hallucination.

Gestalt-type idiopathic childhood occipital epilepsy is a type of relatively rare epileptic syndrome in children that primarily features elementary visual hallucinations as a result of a focal seizure in the occipital lobe. These seizures are often brief (usually lasting from a few seconds up to 1-2 minutes), recurring daily or

weekly, and occur during the daytime. The elementary visual hallucinations are typically small, multi-colored circular patterns in the peripheral visual field (D'Agnano et al., 2023) – my “green potatoes with red eyes.”

In some cases, other symptoms may occur – like headache or vomiting. In some children, the hallucinations initially present as “elementary” forms but may progress to more complex ones as the condition changes over months or years.

This form of epilepsy typically first appears in early elementary and moves into remission within several years.



*These examples of elementary visual hallucinations are drawn by the children who experienced them.*

*A – a child with occipital epilepsy without loss of consciousness.*

*B – a child with migraine and aura*

#### IV. Bereavement Hallucinations

Even Europeans/European Americans, who tend towards a more secular worldview and the rejection of the potential to “speak to the dead,” often report hallucinatory experiences associated with their lost loved one during periods of bereavement. People may hear their loved one’s voice, see their image, or feel their touch.

### Key Takeaways

Larøi et al. (2014) suggest some valuable reminders for therapists:

- Positively valuing psychotic hallucinations improves patient’s experiences.
- A clinician is also part of a culture and the factors that affect the clinician’s interpretation of hallucinatory experiences need to be understood in making clinical judgments.
- Clinicians should never assume that the mere report of what seems to be a hallucination is necessarily a symptom of pathology.

## Additional Takeaways

- The way you respond to a child's reports of unusual sensory experiences can determine whether that child ever divulges atypical experiences to adults. Curious, nonjudgmental follow-up questions can help you determine if a referral needs to be made to a neurologist or pediatrician for additional screening or treatment.
- Music therapy students, interns, and professionals can and do experience hallucinations. Do not assume that because clients are not present in professional spaces, you are free to speak of hallucinations and people who have them in stigmatizing ways.
- In addition to some of the "nonclinical" hallucinations described in this resource, music therapists can experience hallucinations due to psychosis, schizophrenia, or other highly stigmatized conditions – in the past and in their current lives. Do not assume that the experience of more pathologized forms of hallucinations means a person cannot be a good music therapist.
- Understand that because hallucinations are a natural and common part of being human, even if you have never hallucinated before, it is something you could experience in the future. Furthermore, it is possible that you could experience a hallucination that is positive and meaningful to you.
- Avoid chevron patterns, especially in high-contrast colors (like black and white), or other examples of repeating, contrasting patterns, as these can be a common seizure or migraine trigger. Likewise, while some find strings of decorative lights ("Christmas lights") to be cheerful, they can make your space inhospitable. While working in classrooms, this author has had to turn off stringed lights or position themselves so as to block the visibility of the lights to prevent a visual migraine (silvery linear hallucinations that move across the visual field). For those who enjoy Christmas trees in therapy spaces, please understand that using string lights is an accessibility problem.

## Additional Reading

*The Collected Schizophrenias*, by Esmé Weijun Wang

*The Protest Psychosis: How Schizophrenia Became a Black Disease*, by Jonathan M. Metz

*Migraine*, by Oliver Sachs

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