My Staircase Became a Forest—What is Happening to Me? Charles Bonnet Syndrome and Hallucinations in the Blind

Authors: Jeffry Ricker, PhD and Dean Colston, PhD

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> *As he rose from the sofa and began to walk across the living room to the stairs, the 63-year-old man noticed that he was surrounded by a forest of bushes and small trees. The man, who was completely blind, knew that the plants were not really there, but he still found them difficult to ignore. He navigated through the dense foliage and made his way to the bottom of the stairs. Looking up, he saw that his way was blocked by more plants growing to the top. (Personal narrative)*

This man's experience represents some of the characteristic features of Charles Bonnet syndrome (CBS). One of the most important features is the presence of visual hallucinations (perceptions in the absence of sensory input) in people who are visually impaired or who have a sudden change in vision. Medical experts have found that the visual deficits are often the result of diabetic retinopathy, macular degeneration, glaucoma, or cataracts.

CBS is not a mental health condition. It is a neurological condition. CBS can result from damage at any point in the pathway from the eyes to the visual areas of the brain. People with CBS typically have full or some partial insight into the unreal nature of the hallucinations. In this article, we answer the following questions. What do we know about CBS? Who is most likely to experience CBS hallucinations? Are the hallucinations disturbing or distracting? Can the symptoms be reduced?

How Was CBS First Identified?

Charles Bonnet (pronounced, *Bah-nay*) was an entomologist, botanist, and natural philosopher who, in 1760, reported a case of an elderly blind man who had "visions" of people, animals, and inanimate objects that appeared suddenly in February of 1758 and lasted for over seven months (Draaisma, 2009; Sacks, 2012; Whitaker & Turgeon, 2007). Some years later, Bonnet revealed that the case was of his grandfather, Charles Lullin, who experienced his visions when he was 89 years old. Bonnet described some of these hallucinations:

> I know a respectable man, full of health, … judgment and memory, who, in full alertness and independently of all impression from the outside, sees from time to time before him, faces of men and women, of birds, of coaches, of houses etc. (Bonnet, 1760, as cited in Whitaker & Turgeon, 2007, p. 198)

In 1936, Georges De Morsier coined the term *Charles Bonnet* Syndrome to refer to a similar collection of characteristics (Draaisma, 2009). Since that time, CBS has not been defined consistently. This is one reason why research on the epidemiology of CBS has resulted in inconsistent and, sometimes, contradictory claims.

What Exactly is CBS?

Since 1936, almost all definitions of CBS have included the following characteristics:

- the presence of complex visual hallucinations: partially or fully formed objects such as faces, animals, buildings, flowers, etc.;
- the absence of nonvisual (i.e., auditory, tactile, gustatory, olfactory, or somatic) hallucinations, such as hearing voices or smelling a foul odor;
- the realization that one is hallucinating (referred to as *insight*);
- normal cognition (no dementia, delirium, or altered state of awareness, such as what occurs in light sleep);
- visual impairment (complete blindness, reduced visual acuity, or visual field deficits).

Various authors add other characteristics to this definition when deciding who to include and exclude from their research:

- In the past, some authors did not include simple visual hallucinations, such as floating spots, geometric patterns, and swirling colors (American Psychiatric Association [APA], 2013; Jones, Ditzel-Finn, Enoch, & Moosajee, 2021). Most

authors now accept that simple hallucinations should be included in the definition of CBS.

- De Morsier defined CBS as a condition that occurred in the elderly. Many researchers, therefore, specified a lower age limit, e.g., 50 years and above (Tan, Lim, Ho, Yeo, & Au Eong, 2004). Although some researchers still consider CBS to be limited to older adults, there now is good evidence that the syndrome can occur at any age, including in children (Schwartz & Vahgei, 1998).
- The best research uses medical (e.g., psychiatric, toxicological, and neurological) examinations that rule out behaviors, conditions, and disorders associated with hallucinations, such as alcohol withdrawal, stimulant abuse, psychotic disorders, epilepsy, Lewy Body dementia, and narcolepsy (Pelak, 2021).

The results of research on CBS vary widely for several reasons (Pang, 2016):

1. There is no universal definition of CBS agreed upon by all researchers and clinicians.
2. Related to the first reason, the diagnosis of CBS is made across different disciplines (including optometry, ophthalmology, geriatric medicine, psychology, psychiatry, and neurology) that may use somewhat different diagnostic criteria.
3. It is difficult to get hallucinators to respond honestly because many people fear that they will be given a psychiatric diagnosis if they report their visual hallucinations (O'Brien, Taylor, Ballard, et al., 2020; Pelak, 2021).

What Are Hallucinations?

Hallucinations may be defined as perceptions in the absence of sensory input (APA, 2013; Sacks, 2012). In other words, one sees, hears, tastes, smells, or feels something that seems to exist in the external world but is not really there. Hallucinations, in this sense, differ from imagined sights, sounds, etc., in that they are vivid, involuntary (they intrude upon consciousness) and uncontrollable (they cannot be modified through an act of will).

Hallucinations usually are experienced as external to the person. For example, a hallucinated voice may seem to be located several feet to the left and in front of the hallucinator. However, sometimes, the hallucination may be “heard” internally, like a voice inside of your head. (Fischer & Buchanan, 2021). If the internal voice is vivid, involuntary, and uncontrollable, it seems reasonable to call it a hallucination.

In a similar way, if a vivid vision is experienced as involuntary and uncontrollable, but seems to occur internally (i.e., as if it was projected on a mental movie screen), might we still call this a hallucination? For example, after his eyes were surgically removed, the hallucinations of the man from the opening paragraphs eventually transformed into internal hallucinations (small groups of people dancing). The images were vivid, very colorful, and full of movement, but experienced as internal. Such unusual perceptual experiences have been called “*pseudohallucinations.”* But this term has been criticized for being vague and inconsistently defined (Berrios & Dening, 1996).

Hallucinations also differ from "illusions," which are defined as the misperception of an actual external object or event (APA, 2013). Sacks (2012) provided examples of illusions experienced by “Zelda,” a CBS patient:

> When she looked at me on one occasion, my beard seemed to spread until it covered my entire face and head, and then resumed its proper appearance. Occasionally, looking in a mirror, she might see her own hair rising a foot above her head and have to check with her hand to make sure it was in its usual place. (p. 17)

What are the Causes and Treatments?

Our conscious visual experiences are the result of activity in the visual areas of the cortex (i.e., the outer layers of the brain). Other brain activity that might interfere with visual experience is inhibited. Damage to the visual pathways from the eyes to the cortex, however, may disinhibit these other brain areas, which may cause us to hallucinate (referred to as “release hallucinations") (Burke, 2002).

In addition, damage to the visual pathways prevents information from getting to one or more visual areas of the cortex. These visual areas may produce spontaneous and random activity (Burke, 2002), which may cause us to hallucinate images associated with these visual areas. For example, if spontaneous activity occurs in the facial perception areas, people may hallucinate faces. In other words, the brain starts to create its own phantom images. This is similar to the experience of phantom limbs and phantom limb pain as reported by people after an amputation (Blakeslee & Ramachandran, 1998).

This phenomenon is exactly what we think is occurring in CBS hallucinations.

Interestingly, CBS doesn’t affect people who are born blind. This probably is because the visual areas of the cortex require visual experience in the first years of life in order to develop properly (Siu & Murphy, 2018). But CBS may emerge in those who develop impaired vision after their early years due to an underlying eye condition or complications from eye surgery.

Like the 63-year-old man who knew he was not actually surrounded by foliage, a person with CBS is usually aware that the images are not real. Furthermore, discussions of CBS have often included the claim that nearly all CBS patients either were not bothered by their hallucinations or actually enjoyed them. More recently, however, several studies have found that CBS hallucinations are experienced as disturbing or annoying in 25% to 35% of patients (Cox & Ffytch, 2014; Jones, Ditzel-Finn, Enoch, & Moosajee, 2021). Thus, clinicians have begun to focus on interventions that can reduce the negative effects of CBS hallucinations.

Reversing vision loss (e.g., by cataract removal) can eliminate the hallucinations of CBS. Furthermore, the frequency or duration of hallucinations can be reduced by increasing light levels, blinking or moving one’s eyes back and forth, or increasing

external stimulation (e.g., conversing with others). Their negative psychological effects often are the result of fears about mental illness, such as psychosis or dementia. In this case, joining support groups for people with vision loss or seeking the guidance of experts can be helpful. Most of all, it is important to seek treatment for any vision disorders.

How Many People Have CBS?

CBS probably is more common than is often reported. There are three reasons why this is believed by many researchers.

First, as noted earlier, many patients do not report these hallucinations out of fear of being stigmatized as mentally unstable.

Second, physicians may unintentionally overlook this condition or may misdiagnose the patient.

Third, there is much variability in the diagnostic criteria used by different researchers. Hamedani and Pelak (2019) analyzed 33 research studies on the epidemiology of CBS. They found that researchers often were not careful to exclude participants who might be suffering from other neurologic or psychiatric disorders that also are characterized by visual hallucinations. For example, researchers often failed to use procedures that effectively excluded participants with nonvisual hallucinations, delusions, or cognitive impairments. Furthermore, CBS researchers have asserted that vision loss caused by damage or disease of the eye is unnecessary for the development of hallucinations.

Instead, researchers argue that CBS hallucinations can develop after injury to any part of the visual pathway, and that visual acuity need not be reduced: However, many research studies failed to specify diagnostic criteria that would allow for the inclusion of participants to test these assertions. For example, the majority of studies required vision loss; and most involved eye disease (only 6% included participants with damage to the cortex) (Hamedani & Pelak, 2019).

How Common is CBS in Different Cultures?

In western societies, the prevalence of CBS varies widely depending on the patient population. The prevalence ranges between about 10% and 65% (Teunisse, Cruysberg, Verbeek, & Zitman,1995), but most estimates range between about 10% and 15% (Pelak, 2021).

Social isolation and loneliness are thought to predispose people toward the experience of CBS hallucinations (Jones, Ditzel-Finn, Enoch, & Moosajee, 2021). If this is true, one would predict that the prevalence of CBS would be lower in communal cultures, such as those found throughout many Asian countries. Some evidence supports this prediction. A study performed in Singapore found that only 0.4% of patients experienced hallucinations consistent with a diagnosis of CBS (Tan, Lim, Ho, Yeo, Ng, & Au Eong, 2004). A study performed in Japan reported an essentially equivalent prevalence of

0.5% (Shiraishi, Terao, Ibi, Nakamura, & Tawara, 2004). This large difference in the prevalence of CBS between Western and Asian societies might be due to decreased social isolation and loneliness in Asian cultures, but other factors, such as differences in how hallucinations are viewed in the different cultures, also need to be considered. For example, it is possible that Asian participants are much less likely to admit to having hallucinations.

Conclusion

Altogether, CBS is a common ophthalmologic condition that involves visual hallucinations. Currently, there is no established medical cure for CBS. It is not a mental health issue or a symptom of another disease, but it is a direct result of physical damage to the visual pathway. Most of all, more research into Charles Bonnet syndrome is needed to help clinicians and the public better understand this condition. Perhaps of most importance is the need to develop specific diagnostic criteria that are used by all researchers. Finally, investigators need to answer the question of why some people are affected negatively by their hallucinations whereas others are not. This may help clinicians develop more specific and effective interventions.

About the Authors

Jeffry Ricker, PhD
Dr. Ricker was trained as a researcher in the biological sciences and as a researcher and clinician in the psychological sciences. He taught genetics and academic psychology for thirty years, and now is transitioning to medical communication. He is blind and advocates for the development of accessible technology, software, and web design.

Dean Colston, PhD
With over 30 years' experience in the medical industry, health insurance, higher education, and blindness advocacy organizations, Dr. Dean is an adult educator and medical communicator. A former university professor, department chair, and dean of faculty, Dr. Dean continues to be passionate about breaking down health and medical topics into digestible content for his readers. Currently, he is the Director of Social Media & Health Communications at A Flock of Scientists, LLC.

His passion for accessibility, equality, and opportunities for people who are blind or visually impaired hits close to home. Dean's mother was blind by 40 years old. In addition, he has been legally blind since 2012 and has had vision challenges his entire life.

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