Charles Bonnet Syndrome

by Richard Harsant FBDO (Hons) CL (Hons) LVA Hon MIADO

Charles Bonnet Syndrome is a phenomenon experienced by some people with low vision. It is understood by low vision practitioners but less so by eyecare practitioners working in many High Street practices. The purpose of the article is to enable such practitioners to help and advise their patients who may experience such phenomena now or in the future.

Charles Bonnet was Swiss. He was a lawyer by profession, but he devoted much of his life to studying philosophy and nature. In 1769 he reported that his 89 year old grandfather (whose vision was deteriorating) had begun to experience visual hallucinations. These might take the form of people, buildings and other everyday objects.

Diagnostic criteria for Charles Bonnet Syndrome (CBS) are generally accepted to be:
- The presence of formed, complex, persistent or repetitive visual hallucinations
- Full or partial retention of insight into the unreal nature of the hallucinations
- Absence of hallucinations in other sensory modalities
- Absence of primary or secondary delusions

In simple terms patients “see” things that are not really there.

Many patients are reticent, embarrassed indeed frightened to discuss this phenomenon with clinicians because they fear they are losing their sanity.

The hallucinations may take the fairly benign forms reported by Bonnet, but some patients report giant spiders and other more alarming objects.

Dispensing opticians working in low vision clinics may be familiar with this syndrome, but patients attending High Street practices may also describe their symptoms. Eyecare practitioners should understand the condition to be able to reassure their patients.

Prevalence
Charles Bonnet Syndrome (CBS) is a problem encountered by about 15% of patients with visual impairment. It is therefore often encountered in Low Vision (LV) clinics in patients who have retinal pathologies, particularly those that affect the macula. Patients’ ethnicity does not appear to affect the prevalence. Most patients will have a macular pathology and Visual Acuity (VA) in the region of 6/60 to 3/60 Snellen.

The role of the low vision practitioner
Many patients will become alarmed and distressed by the symptoms they are experiencing. A common fear is that they may be the precursor to...
dementia, and because of the stigma that still exists about dementia and other similar conditions the patient may be very reticent about discussing them.

Discussion however has been found to be helpful in many cases, and the hallucinations have been reported to reduce in number and frequency following explanation by a practitioner. This may be due to the patient knowing that they are not alone in experiencing them, and reassured that they are harmless.

Many low vision practitioners have an active policy on discussing CBS with patients in the “at risk” group. Doing this may give comfort to patients who are experiencing symptoms, but reticent about discussing them, and also reduce the patient’s anxiety if they experience hallucinations at some future date.

Increasing age is statistically linked to both low vision and to living alone. The effects of CBS on vulnerable patients who may be recently bereaved can be quite devastating.

The role of the low vision practitioner in assisting with the visual rehabilitation of these patients is to enable patients to lead their lives with as high a degree of independence as possible in each individual case.

• Should we tell every patient about it?

• Not everyone will experience CBS, and is it justified to alarm some people who may never experience the symptoms?

In practice we have to use our communication skills and tailor an individual approach in each case.

A patient who has suffered some loss of central vision may initially appear to be adapting well to their impairment and utilising Low Vision Aids (LVA) quite effectively, but then present at a follow up appointment apparently much more withdrawn and possibly not using the LVAs at all effectively. CBS is one possible explanation for this. It is up to individual practitioners how they handle this sort of situation, but one way might be along these lines:

“I don’t know if this has happened to you, but some people with your sort of eye condition find that they tend to see things that they know are not really there, and I want you to be aware of this so you don’t worry if it happens to you. The area of the brain that deals with vision is usually a very active one when we have good vision. It has lots to do, telling us about all that is going on around us. If someone gets the sort of vision problem that you have this area of the brain has much less information to process. In effect it becomes bored and makes things up that aren’t really there.” At this point it is not unusual for the patient to give a big sigh, and say “thank goodness for that. I have had that happen to me, but I didn’t like to tell anyone in case they thought I was going mad!”

**Grieving**

CBS can cause fear and depression in the patients who experience it. The effect may be compounded by the unrelated natural process of grieving that many people have when they experience visual loss. This loss brings an emotional adjustment that people need to make. The partial loss of any of our senses can involve a period of mourning similar to the adjustment we make of the death of a loved one.

The manifestation of the emotional experience will vary greatly from person to person, but it will occur to some extent to all people experiencing significant visual loss, not just those with CBS. It tends to occur according to the following model:

• Shock and denial
• Anger and questioning
• Helplessness, fear and anxiety
• Sadness and grief
• Depression

Opticians are not psychologists: we should deal in the sort of simple explanations mentioned in this article. Some patients will need more support than others. Your local society for the visually impaired or the RNIB should be able to put your patient in touch with an expert counsellor in your area.

Please watch the following clips, and answer the multiple choice questions:

2. Visual Hallucinations - Charles Bonnet Syndrome. The Macular Society, www.youtube.com/watch?v=bn_2KXw387s (note that the link carries an underscore before the ‘2’)
3. Charles Bonnet Syndrome - Living with macular disease. The Macular Society, www.youtube.com/watch?v=_N5uhdwhgRI (note that the link carries an underscore before the ‘N’)
4. http://www.mib.org.uk/livingwithsightloss/copingshotsightloss/emotionalsupport/Pages/emotional_support_counselling.aspx (note that the link carries an underscore between emotional, support, and counselling.)

If you cannot open the YouTube links, go to www.YouTube.com and search for Charles Bonnet Syndrome. Select from the search results.

Alternatively, quick links to the video clips and the article text are available on the ABDO website: http://www.abdo.org.uk/cet/charles-bonnet-syndrome/

Go to ‘CET Online’ as usual to answer the MCQs.

**References**


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Multiple choice questions (MCQs)

Charles Bonnet Syndrome

1. Which of the following best describes the likely cause of Charles Bonnet syndrome (CBS)?
   a. Conflicting electrical activity in the visual pathway
   b. Severe changes to the retinal receptor ratio in the macula
   c. The early onset of dementia
   d. The brain using stored images to fill gaps caused by the lack of information from the retina

2. Which statement is true regarding CBS?
   a. About 80-85% of patients with significant visual loss are unlikely to experience hallucinations
   b. Afro-caribbean patients are statistically more likely to experience CBS
   c. Medical treatment is best started as soon as the condition is diagnosed
   d. Some patients report being able to hear as well as see hallucinations

3. Which of these actions is unlikely to stop or reduce hallucinations in CBS?
   a. Reaching out to touch the image
   b. Pre-determined eye movements
   c. Increasing existing medication
   d. Changing ambient lighting conditions

   a. are the result of stroke activity in the visual pathway
   b. are early signs of dementia
   c. can be explained as a disorder of the mind
   d. are a normal response to a loss of vision

5. Which statement is false?
   a. Patients whose general health, memory and judgement are unimpaired are unlikely to suffer hallucinations
   b. About half of those reporting simple geometrical patterns will go on to experience more complex images
   c. Hallucinations can appear suddenly and last several hours
   d. Sufferers of Parkinson’s disease experience similar hallucinations but without loss of vision

6. Which statement is true?
   a. Macular disease becomes manifest when patients reach the age of about 65-70
   b. Hallucinations may appear in vivid colours
   c. There is evidence to show that having the likely causes of CBS explained causes an increase in the frequency of hallucinations
   d. Patients presenting with hallucinations must be referred to a specialist clinic