

Think sight loss, think Charles Bonnet syndrome

Joanne Best, Pui Y. Liu, Dominic Ffytche, Judith Potts and Mariya Moosajee 

Received: 20 August 2019; revised manuscript accepted: 7 November 2019.

Charles Bonnet syndrome (CBS) was first described in 1760 by the Swiss philosopher Charles Bonnet, whose father was troubled by visual hallucinations after losing his sight. CBS is characterised by visual hallucinations in those with sight loss from any cause, but no contributing psychiatric component or cognitive impairment. It can occur at any age, but it typically affects older people, reflecting the mean age at which common underlying conditions, such as age-related macular degeneration, diabetic retinopathy and glaucoma, cause loss of vision. Patients have insight into the nature of the hallucinations, which range from simple geometric shapes/patterns to complex visualisations of people, objects or landscapes. Also known as visual release hallucinations, CBS is theorised to be a result of de-afferentation of the visual cortex, and studies have revealed cortical hyperexcitability.¹

The reported prevalence ranges from 0.4% to 30% in those with sight loss,² although it is considered to be underreported due to patients' fears of being categorised as mentally ill and a relative lack of awareness among the medical profession.³ There are no recognised successful treatments for CBS, although anticonvulsants and antipsychotics have been trialled.⁴ Patients' experience of their hallucinations varies widely, from indifference to enjoyment or fear. Around one-third report negative sequelae, including stress linked to uncertainty over the origin and meaning of the hallucinations, particularly if patients have not been informed of the sight loss complication.⁵

Raising awareness

In November 2018, Moorfields Eye Hospital NHS Foundation Trust held its first CBS patient day for affected individuals, their carers and key stakeholders, including rehabilitation officers for the visually impaired and the major UK sight loss charities, attracting more than 80 participants. Experts and patients shared their medical knowledge and personal experiences of CBS, with a workshop on techniques to cope with visual hallucinations (Box 1). To evaluate the workshop, seven attendees with CBS completed the National Eye Institute Visual Functioning Questionnaire–25 (NEI VFQ-25) to measure the impact of visual disability and symptoms on generic health domains and repeated the questionnaire 2 months later to establish the effect on quality of life once coping mechanisms were introduced [this study was approved by the National Research Ethics Committee (12/LO/0141) and was conducted in adherence to the tenets of the Declaration of Helsinki; informed written consent was obtained from all participants]. The mean overall composite score was 39.86 at baseline; this increased to 43.20, up by 8.38% ($p=0.407$) 2 months later (a higher score indicated better functioning). Specific domains such as ocular pain yielded a 38.71% ($p<0.05$) increase in score from 55.36 to 76.79, and mental health increased by 23.40% ($p=0.229$) from 41.96 to 51.79 (Figure 1).

Education can help patients feel more in control of CBS, in terms of coping and managing it. The

Ther Adv Ophthalmol

2019, Vol. 11: 1–2

DOI: 10.1177/
2515841419895909

© The Author(s), 2019.
Article reuse guidelines:
sagepub.com/journals-
permissions

Correspondence to:

Mariya Moosajee
Consultant
Ophthalmologist and
Associate Professor, UCL
Institute of Ophthalmology,
11–43 Bath Street, London
EC1V 9EL, UK.
m.moosajee@ucl.ac.uk

Joanne Best
Pui Y. Liu
Barts and The London
School of Medicine and
Dentistry, London, UK

Dominic Ffytche
Institute of Psychiatry,
Psychology and
Neuroscience, King's
College London, London,
UK

Judith Potts
Esme's Umbrella, London,
UK

Mariya Moosajee
Moorfields Eye Hospital
NHS Foundation Trust,
London, UK; Great Ormond
Street Hospital for
Children NHS Foundation
Trust, London, UK; UCL
Institute of Ophthalmology,
London, UK

Box 1. Techniques for minimising or eliminating visual hallucinations secondary to Charles Bonnet syndrome.

When the hallucinations start, look from right to left once every 15s without moving your head
Try to touch the hallucination
Stare straight at the hallucination
Turn your head to alternative sides, then move the head towards each shoulder in turn
Walk around the room or to another room
Shine a torch from below your chin in front of (not into) your eyes
Change the light level in your room or the activity you are doing

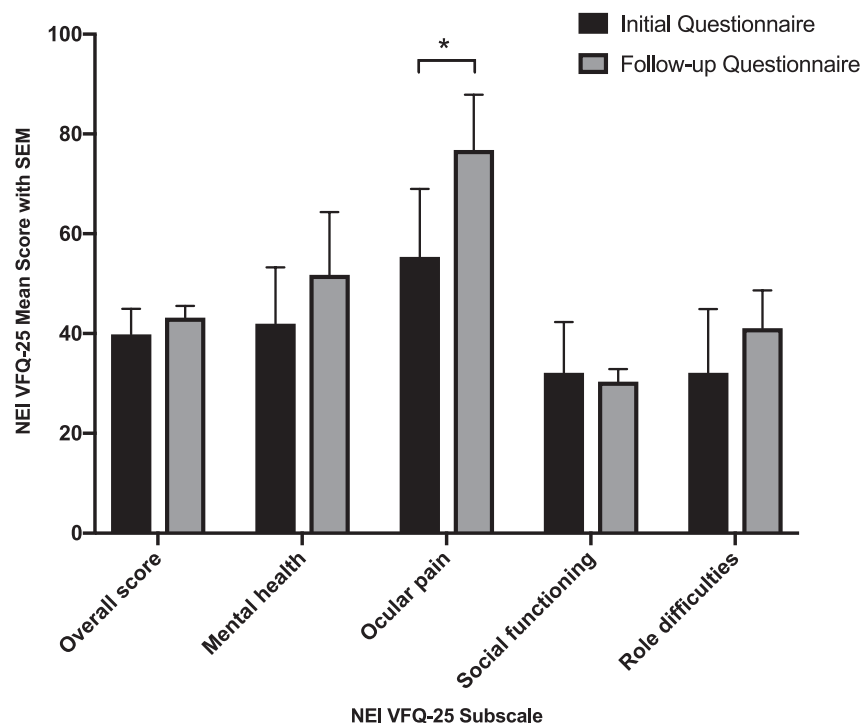


Figure 1. Graph comparing the mean scores (\pm SEM) of different domains of the VFQ-25 before and 2 months after the patient day, $*p < 0.05$.

NEI VFQ-25, National Eye Institute Visual Functioning Questionnaire-25; SEM, standard error of measurement.

National Institute for Health Research (NIHR) SHAPED (Study of HAllucinations in Parkinson's disease, Eye disease, and Dementia) programme is underway to inform the UK National Health Service (NHS) practice and policy in relation to visual hallucinations and produce sets of guidelines for clinicians, patients and carers. Too often, those with sight loss are unaware that they may experience visual hallucinations. Informing patients and following up with coping strategies can have a positive impact on patients' quality of life.

Acknowledgements

We gratefully acknowledge the support of the National Institute for Health Research (NIHR) Biomedical Research Centre based at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology, Esme's Umbrella and the Wellcome Trust.

Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Mariya Moosajee  <https://orcid.org/0000-0003-1688-5360>

References

1. Painter DR, Dwyer MF, Kamke MR, *et al.* Stimulus-driven cortical hyperexcitability in individuals with Charles Bonnet hallucinations. *Curr Biol* 2018; 28: 3475–3480.
2. Pang L. Hallucinations experienced by visually impaired. *Optom Vis Sci* 2016; 93: 1466–1478.
3. Jurisic D, Sesar I, Cavar I, *et al.* Hallucinatory experiences in visually impaired individuals: Charles Bonnet Syndrome – implications for research and clinical practice. *Psychiatr Danub* 2018; 30: 122–128.
4. Vukicevic M and Fitzmaurice K. Butterflies and black lacy patterns: the prevalence and characteristics of Charles Bonnet hallucinations in an Australian population. *Clin Exp Ophthalmol* 2008; 36: 659–665.
5. Cox TM and ffytche DH. Negative outcome Charles Bonnet Syndrome. *Br J Ophthalmol* 2014; 98: 1236–1239.