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# Negative outcome Charles Bonnet Syndrome

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## ABSTRACT

**Background** Charles Bonnet Syndrome (CBS) is widely considered a transient condition without adverse consequence, questioning the need for treatment. Yet, while this view may be true of the majority of people with CBS, it is recognised that some have negative experiences and outcomes. Here, we attempt to better understand negative outcome CBS and the factors that influence it.

**Methods** 4000 members of the Macular Society were sent a structured questionnaire covering the phenomenology of CBS, its prognosis and impact, symptom reporting, patient knowledge and sources of information.

**Results** 492 people with CBS were identified. Kaplan–Meier analysis suggested 75% had CBS for 5 years or more. Thirty-two per cent had negative outcome. Factors associated with negative outcome were: (1) frequent, fear-inducing, longer-lasting hallucination episodes, (2) one or more daily activities affected, (3) attribution of hallucinations to serious mental illness, (4) not knowing about CBS at the onset of symptoms. Duration of CBS or the type of content hallucinated were not associated with negative outcome.

**Conclusions** CBS is of longer duration than previously suspected with clinically relevant consequences in a third of those affected. Interventions that reduce the frequency, duration or fear of individual hallucination episodes and education prior to hallucination onset may help reduce negative outcome.

an unpleasant or disturbing experience.<sup>5–8</sup> CBS thus covers a spectrum of outcomes, one end celebrated by Bonnet in his description of hallucinations as ‘playthings of the brain’, the other a predominantly negative outcome characterised by distress, stigma and reduced quality of life. Given that this latter group is potentially large (between 16 000 and 100 000 people in the UK based on a ~500 000 population with late AMD<sup>10</sup> and CBS prevalence of 10–60%<sup>11</sup>) it is becoming increasingly important to better understand what factors lead to negative outcome and how people with negative experiences of CBS differ from those that do not find CBS distressing. Furthermore, there is emerging evidence that CBS may not be as transient as traditionally held. One study has reported hallucinations continuing for 4 years or more in 45% of people with CBS,<sup>8</sup> while another found 41% of people with CBS had an estimated minimal average duration of 8 years (minimal as hallucinations were ongoing at the end of the study).<sup>6</sup> It is difficult to dismiss CBS as a clinical irrelevance if it results in troubling symptoms that persist for many years for a large group of people. Here, we set out to re-evaluate the prognosis of CBS, and characterise factors associated with its negative outcome in a large-scale survey of members of the Macular Society, a UK charity for people affected by central vision loss that provides practical and emotional support, campaigns for improvements in services and funds research.

## INTRODUCTION

Charles Bonnet's description of his grandfather's visual hallucinations<sup>1 2</sup> lies at the boundary of what might be considered a ‘clinical’ condition. Bonnet focussed on positive aspects of the experience, such as the pleasure and intellectual curiosity hallucinations gave, and the fact they were not associated with psychological or cognitive problems. His grandfather had significant visual impairment, plausibly related to age-related macular disease (AMD),<sup>3</sup> but there was no suggestion the hallucinations themselves were an illness or that treatment would have been necessary or appropriate. Furthermore, the hallucinations resolved within a few months, so that any problems would have been short-lived. Reawakened interest in Charles Bonnet Syndrome (CBS) has done little to dispel this view with consistent reports that the majority of patients with CBS do not find it troublesome.<sup>4–8</sup> Yet, a sizable minority report a range of negative experiences and outcomes. Compared to patients with the same degree of visual loss without hallucinations, patients with CBS have decreased measures of quality of life and functional ability,<sup>9</sup> and some fear being labelled as having serious mental illness.<sup>7</sup> Around a third find the hallucinations themselves

## METHODS

Four thousand members of the Macular Society were selected at random from the membership database (database n=10 847 after excluding members surveyed the previous year) using campaign management software (NFP CARE, Advance computer software group). Those selected were sent a structured questionnaire in October 2012 covering CBS: demographics, risk factors, phenomenology, duration/prognosis, (using items derived from the Institute of Psychiatry Visual Hallucinations Interview<sup>8</sup>) impact on daily living and wellbeing, reporting of symptoms and sources of information (see online supplementary material for questionnaire content). Questionnaires were returned by post. Members unable to read the questionnaire were offered support in completing it by telephone. The study was approved by the King's College London, Psychiatry, Nursing and Midwifery Research Ethics subcommittee (PMN/11/12-64). All participants gave informed consent. Categorical variables were compared using  $\chi^2$  tests with Bonferroni correction where appropriate. Continuous variables were examined using analysis of variance (ANOVA) models. Duration of CBS was calculated from the month/year of CBS onset and



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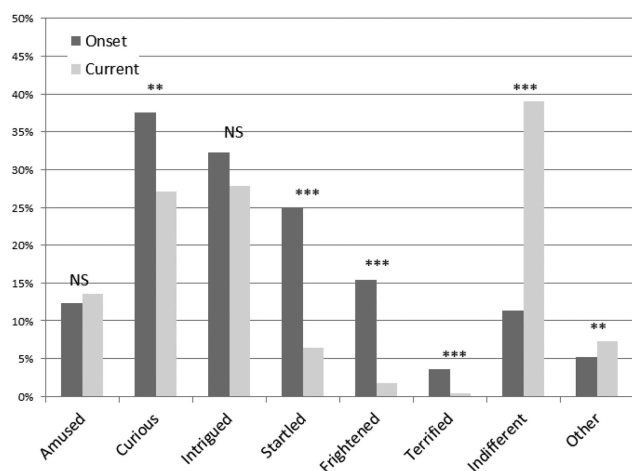
month/year of last hallucination, with a resolution of 3 months, and analysed using the Kaplan-Meier method,<sup>12</sup> with cessation of hallucinations as the outcome event of interest. To avoid inflating the estimate of duration through rounding error, if no month was specified for month/year of onset, the end of the year was used.

## RESULTS

A total of 1254 surveys were returned by members who reported a diagnosis of macular disease (31% of questionnaires sent). Of these, 39% (n=492) had experienced hallucinations of patterns (63%), faces (39%), objects (39%), figures (36%) and animals (22%) and had been told they had, or judged themselves to have had, CBS. Typical hallucinations were of short duration, lasting either minutes (44%) or seconds (34%). When judged at their worst, hallucinations could occur weekly (30%), monthly (21%), daily (22%) or constantly (13%). Figure 1 shows different categories of emotional response (more than one could be selected) at the onset of CBS (dark grey bars) and at the time of the questionnaire (light grey bars). At CBS onset, 38% reported one or more of responses: startling, terrifying and frightening (pooled as 'fear-inducing'), reducing to 8% at the time of the questionnaire. Forty-six per cent reported that CBS had an effect on daily activities, selecting responses: television watching (24%), moving about (14%), cooking (8%) and sleeping (14%) with free-text answers of: reading, driving and relaxing. Only 7% had not told anyone about CBS. Forty-seven per cent had discussed it with a medical professional with around a third of these selecting responses indicating the professional was unsure or did not know about the diagnosis. Sixty-seven per cent had not heard of CBS at symptom onset and attributed the hallucinations to one or more of responses: sight loss (50%), mental illness (11%), Alzheimer's disease (5%) or unknown (40%) with free text answers: side-effects of medication, physical illness and real events. Sixty-three per cent were relieved and/or reassured by receiving information on CBS.

## Prognosis of CBS

Figure 2 shows the Kaplan-Meier plot of CBS duration. The method takes into account the fact that many of the participants



**Figure 1** Emotional responses to Charles Bonnet Syndrome hallucinations. Bars indicate % of hallucinators reporting each emotion. Dark grey indicates emotions at the onset of symptoms, light grey at the time of the questionnaire.  $\chi^2$  corrected for multiple comparisons \*\*\*  $p_{\text{corr}} < 0.001$ ; \*\*  $p_{\text{corr}} < 0.01$ ; NS  $p_{\text{corr}} > 0.05$ .

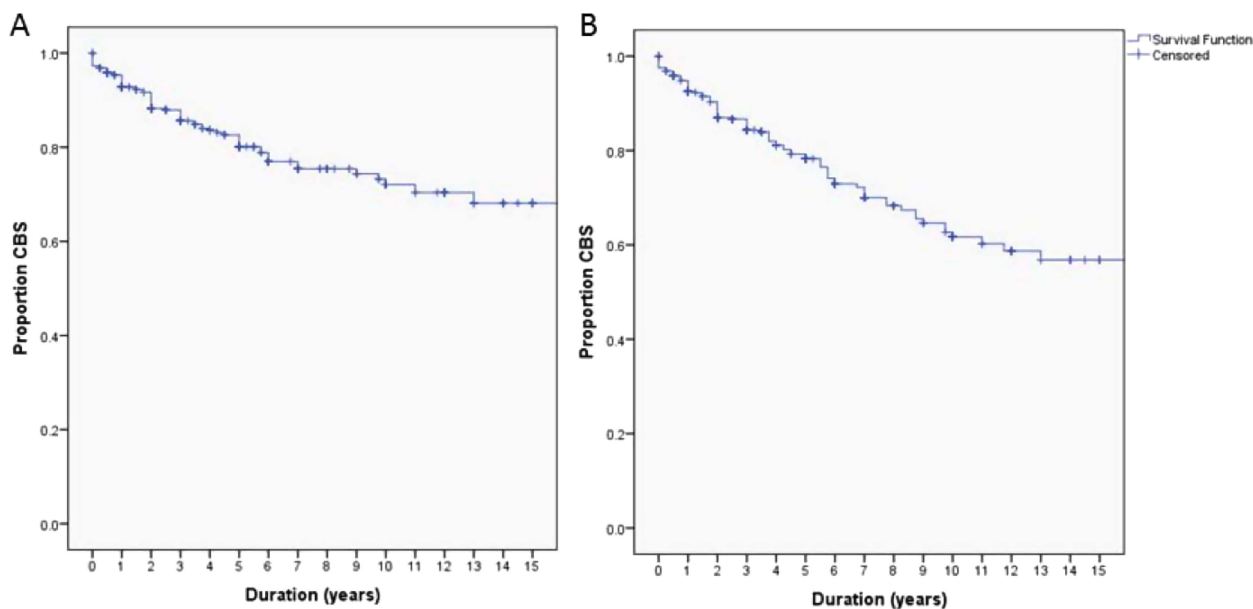
were still having hallucinations at the time of the survey, so that the duration of their CBS is unknown (censored data). However, the large sample size meant that ~100 CBS resolution events were available from which to estimate the duration (survival) function. Two measures of symptom resolution were used. One was derived from the questionnaire item asking whether CBS had stopped or was on-going at the time of the questionnaire (figure 2A). Using this measure, 88% of the sample (95% CI 85% to 92%) had CBS for 2 years or more, resolving in only 25% at 9 years. We recognised that it might be difficult to judge whether CBS has resolved if hallucinations only occur infrequently (eg, every 6 months). We therefore repeated the analysis applying an arbitrary definition of resolution as having no hallucinations in the 3 months prior to the questionnaire (figure 2B). The prognosis at 2 years was the same using this definition (87% with ongoing CBS; 95% CI 83% to 90%) but the time for 25% to resolve reduced to 5.75 years.

## Negative outcome CBS

While the majority of people with CBS felt it had no real effect on their life (60%), a subset judged it to have a fairly negative (25%) or very negative (8%) effect, and 6% reported a fairly pleasant or very pleasant effect (1%). We collapsed these responses into three outcome valencies: negative (fairly and very negative, n=156), positive (fairly and very pleasant, n=36) and neutral (n=289). Negative outcome was not associated with gender or diagnosis (wet, dry, wet and dry AMD;  $p > 0.05$ ). It was associated with longer-duration hallucination episodes ( $\chi^2 = 38.9$ ,  $p < 0.0001$ ) and more frequent hallucination episodes ( $\chi^2 = 31.7$ ,  $p = 0.0001$ ). There was no difference in mean overall duration of CBS (CBS onset to cessation) for subgroups with negative outcome (mean duration  $2.7 \pm 2.0$  years), positive outcome ( $1.9 \pm 1.3$  years) and neutral outcome ( $3.3 \pm 3.9$  years) ( $F_{2,75} = 0.452$ ;  $p = 0.638$ —censored data excluded). Negative outcome was not associated with a particular type of hallucination content ( $p_{\text{corr}} > 0.05$  for patterns, faces, people, animals and objects). Fear-inducing hallucinations at CBS onset were associated with negative outcome (45% of the subgroup with fear-inducing hallucinations at onset had negative outcome vs 25% of the subgroup without fear-inducing hallucinations;  $\chi^2 = 23.2$ ,  $p_{\text{corr}} = 0.00001$ ). CBS affecting one or more daily activities was associated with negative outcome (52% of the subgroup with an activity affected had negative outcome vs 16% of the subgroup with no activities affected,  $\chi^2 = 75.3$ ,  $p < 0.000001$ ). Attributing CBS to mental illness or, at trend significance, Alzheimer's disease was associated with negative outcome (58% of the subgroup attributing CBS to mental illness had negative outcome vs 30% of the subgroup not attributing CBS to mental illness,  $\chi^2 = 12.0$ ,  $p_{\text{corr}} = 0.01$ ). Attributing CBS to sight loss was not associated with negative outcome ( $\chi^2 = 0.087$ ,  $p_{\text{corr}} > 0.05$ ). Lack of prior knowledge about CBS at symptom onset was associated with negative outcome (25% of the subgroup familiar with CBS at onset had negative outcome vs 35% of the subgroup unfamiliar with CBS at onset;  $\chi^2 = 6.4$ ,  $p = 0.04$ ). There was also a trend association between the quality of information given by medical professional and negative outcome (47% of the subgroup not given a clear account, had negative outcome vs 36% of the subgroup given a clear account;  $\chi^2 = 4.5$ ,  $p = 0.10$ ).

## DISCUSSION

This is the largest phenomenological survey of CBS reported to date, with 492 people identified, compared to an average of 42 people (range 4–150) in previous surveys.<sup>4–9 13–21</sup> The scaling



**Figure 2** Kaplan–Meier plots of Charles Bonnet Syndrome (CBS) duration. (A) The proportion of the sample with CBS each year after onset based on self-report of CBS resolution. The vertical dashes indicate censored observations. (B) The proportion of the sample with CBS each year after onset with CBS resolution defined as an absence of hallucinations in the 3 months prior to the questionnaire.

in sample size allows us to explore issues less amenable to investigation in smaller studies due to their limitations of statistical power. Although our sample is derived from members of a voluntary society, the phenomenology of the hallucinations reported (ie, relative frequency of each content category, distribution of emotional responses, temporal characteristics etc) match those of previous surveys in clinical settings giving us confidence the findings are representative of CBS as a whole.

**How long does CBS continue?**

CBS continued for 5 years or more in 75% of the sample. This seems inconsistent with previous longitudinal studies suggesting 28% recovery at 1 year<sup>22</sup> or an average duration of 18 months.<sup>23</sup> However, the former study relates to resolution over the course of a year without specifying prior duration of CBS, while the latter study does not take into account participants with on-going CBS (censored observations). Our study indicates the typical duration of CBS is far longer than these estimates, and questions the traditional view that CBS is a transient condition. It is possible our estimate is biased by people with shorter-duration CBS choosing not to participate in the survey. However, this seems unlikely, as the estimate of CBS prevalence based on the total number of questionnaires sent (12%) is similar to previous prevalence estimates for ophthalmic populations (~10%)<sup>3</sup> suggesting we were not missing a large proportion of respondents.

**Factors influencing negative outcome CBS**

The 32% prevalence of negative outcome in our sample is similar to that described in previous studies.<sup>4 5 21</sup> Since our definition of negative outcome CBS is derived from self-report, without formal measures of psychopathology, well-being, or quality of life, its true clinical significance remains to be determined. However, a higher proportion of the negative outcome CBS subgroup sought medical advice suggesting it has clinical implications (61% of the negative outcome subgroup sought medical advice vs 45% of the neutral or 44% of the positive

subgroup,  $\chi^2=10.3$   $p=0.006$ ). Some of the factors associated with negative outcome were linked to the hallucinations themselves (eg, how long a typical hallucination lasts and whether it induced fear) while others related to knowledge of CBS and quality of information. We explored the relative importance of each hallucination-related and education-related factor as a target for theoretical intervention by calculating the expected reduction in negative outcome for each intervention (table 1). There was a clear advantage for interventions targeting hallucination-related factors over education-related factors. This may reflect the fact that Macular Society members were well informed at baseline, with only 13% unfamiliar with CBS prior to the questionnaire. In comparison, 71% of the clinical sample reported by Abbott *et al*<sup>20</sup> had no knowledge of CBS prior to their study. It is thus likely that information about CBS prior to symptom onset will have a greater impact on negative outcome in the wider clinical population than found here. Replicating

**Table 1** Reduction in proportion of negative outcome CBS from base rate (32%) using hypothetical interventions indicated

Treatment category	Theoretical treatment target	% Reduction in negative outcome
Hallucination-related	Reduction of duration of hallucination episodes to seconds	44
	Reduction of hallucination frequency to monthly	47
	Resolution of fearful emotional responses	24
	No limitation of activities	52
Education-related	CBS awareness at symptom onset	20
	No attribution of CBS to mental illness	6
	Improved clarity of explanation	2

CBS, Charles Bonnet Syndrome.

findings of a previous study,<sup>24</sup> less than half of those with CBS sought medical advice. This low rate of advice-seeking sets a limit on the ability to reduce negative outcome by targeted training of medical professionals.

An unexpected finding was the lack of association between overall duration of CBS and negative outcome. This may reflect a habituation to CBS over time, as supported by the reduction in fear-inducing hallucinations from symptom onset to the time of the questionnaire. Consistent with previous reports,<sup>4 23</sup> some participants suggested the frequency and duration of individual hallucination episodes reduced with time so that they no longer considered them a problem. For other participants, hallucinations ceased for a period but returned with subsequent progression of their macular disease. Such observations highlight the difficulty in defining when CBS resolves and question the relevance of CBS cessation as an endpoint for clinical trials.

## CONCLUSIONS

What are the clinical implications of the findings? It is clear that CBS can no longer be considered a homogeneous, transient condition. For most people with CBS, symptoms continue for many years with negative consequences in around a third. This changes CBS from a symptom that can be largely ignored by clinical services to one that needs further characterisation to identify those with negative outcome and offer appropriate interventions. The low priority given to CBS research to date means there is currently an absence of evidence as to what treatments might be effective. Our study suggests an alternative treatment goal to cessation of hallucinations might be to target negative outcome, reducing the duration, frequency, fear association and interference with activities of ongoing hallucinations to result in a more benign form of CBS. The findings also suggest negative outcome might be preventable, and the need for trials to examine the effectiveness of information/psychoeducation prior to the onset of hallucinations. The era of CBS as an incidental curiosity has ended; for those with negative outcome, CBS now lies unequivocally within the clinical domain.

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**Contributors** DHF designed and supervised the study, its analysis and preparation of the manuscript. TMC analysed the data and drafted the manuscript.

**Competing interests** DHF is supported by NIHR programme grant RP-PG-0610-10100: Towards an evidence-based clinical management of visual hallucinations.

**Ethics approval** King's College London, Psychiatry, Nursing and Midwifery Research Ethics subcommittee (PMN/11/12-64).

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## MACULAR SOCIETY QUESTIONNAIRE

We are surveying our members to find out more about how one particular, common side-effect of sight loss can affect people. The condition is called Charles Bonnet Syndrome and it causes a person to experience visual hallucinations so they see things which are not there. These might appear as patterns, faces (sometimes distorted), people, plants, trees, animals or other objects. The Syndrome is not a mental illness; it is a normal response of the brain to the loss of visual stimulation to the areas which normally process what we see. If you do not have Charles Bonnet Syndrome we are still interested in what you know about it and have indicated which questions we would like you to answer.

**Please answer Question 1 to Question 7 even if you do not have Charles Bonnet Syndrome**

**1. How old are you?**

- 18 – 35 years
- 36 – 50 years
- 51 – 65 years
- Over 65 years

**2. Are you male or female?**

- Male
- Female

**3. Do you have macular disease?**

- Yes
- No
- Don't know

**4. How long have you had macular disease? (Duration in months / years)**

**5. What type do you have?**

- Wet
- Dry
- Wet & Dry
- A juvenile form (name)
- Don't know
- Other

**6. Does it affect both eyes?**

- Both
- Left only
- Right only

- Different types in each eye

**7. Do you have Charles Bonnet Syndrome?**

- Yes
- No

**If you do not have Charles Bonnet Syndrome please go to Question 24 and continue the questionnaire.**

**8. What of images did you / do you see? (tick all that apply)**

- Patterns
- Faces
- Figures
- Animals
- Objects

**9. When did the Charles Bonnet Syndrome start? (month / year)**

**10. When was your last hallucination? (month / year)**

**11. Do you consider your hallucinations to have stopped?**

- Yes
- No

**12. How long did / does each hallucination last on average? (tick shortest duration that best describes your typical hallucinations)**

- Seconds
- Minutes
- Hours
- Continuous

**13. At worst, how frequently did / do the typical episodes described in Q12 occur? (tick the frequency that best describes the hallucinations at their worst)**

- Something was occurring all the time
- I had a hallucination almost every hour
- I had a hallucination almost every day
- I had an hallucination most weeks
- I had a hallucination most months

**14. What best describes your reaction to Charles Bonnet Syndrome when it first occurred? (tick all that apply)**

- Amused
- Curious
- Intrigued
- Startled

- Frightened
- Terrified
- Indifferent
- Other

**15. What is your reaction to Charles Bonnet Syndrome now? (tick all that apply)**

- Amused
- Curious
- Intrigued
- Startled
- Frightened
- Terrified
- Indifferent
- Other

**16. What did you think might be the cause when you first experienced Charles Bonnet Syndrome? (tick all that apply)**

- I had been told it might occur
- Thought it must be to do with sight loss
- Thought I might have illness such as Alzheimer's disease
- Thought I might have a mental illness.
- Did not know what to think
- Other

**17. Did / does Charles Bonnet Syndrome interfere with the following abilities? (tick all that apply)**

- Moving about
- Watching television
- Cooking
- Sleeping
- Has no effect
- Other

**18. Charles Bonnet Syndrome had / has the following effect on my life? (tick the one that best applies)**

- A very negative effect
- Fairly negative
- No real effect
- A fairly pleasant effect
- A very pleasant effect

**19. Who have you told about your hallucinations? (tick all that apply)**

- Medical professionals
- Spouse
- Other family
- Friends

- Other people with macular disease
- No one
- Other

**20. What reasons have prevented you from telling people? (tick all that apply)**

- Embarrassed by symptoms
- Feared others would think I was developing a serious illness e.g. Alzheimer's or mental problem
- I don't have anyone close to tell
- I don't discuss my health with other people
- I was not concerned about it
- Other

**21. Did you already know about Charles Bonnet syndrome when you first experienced the hallucinations?**

- Yes
- No

**22. If you have consulted a medical professional, what did they say it was? (tick one that best applies)**

- They gave a clear account of Charles Bonnet Syndrome
- They were unsure or did not know
- They gave a different diagnosis of:

**23. What difference did finding out about Charles Bonnet Syndrome make to your feelings about the hallucinations? (tick all that apply)**

- Reassured
- Relieved
- Confused
- Angry that I hadn't been told about it earlier
- It made no difference
- Other

**24. Had you heard of Charles Bonnet Syndrome before this questionnaire?**

- Yes
- No

**25. How did you find out about it? (tick all that apply)**

- Ophthalmologist
- Eye clinic nurse
- Optometrist
- GP
- Social worker
- Rehabilitation officer



- Sensory awareness team
- Friend or family
- Macular disease society
- Internet research (by self/family/friend)
- Radio, television, newspaper or magazine article
- Other