

Prevalence of visual hallucinations in a national low vision client population

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ABSTRACT • RÉSUMÉ

Purpose: To evaluate the prevalence of visual hallucinations (Charles Bonnet syndrome) in a national population undergoing vision rehabilitation.

Study Design: Cross-sectional survey.

Participants: Participants were 2565 new clients older than 40 years attending a Canadian National Institute for the Blind (CNIB) vision rehabilitation clinic.

Methods: Participants were asked the following question: “Many people who come to CNIB tell us that they see things they know are not there. Some see patterns or shapes. Others see images of people or animals. Have you ever experienced this?” Responses were cross-tabulated on the basis of age, sex, eye disease, visual acuity, and whether the clients lived alone. Multivariable logistic regression was used to analyze the responses.

Results: Overall, 18.8% of people surveyed indicated that they had experienced hallucinations. In the multivariable model, females showed higher odds of hallucinations than males did (odds ratio [OR] 1.32, 95% CI 1.06–1.64, $p = 0.02$). Clients with greater vision loss had higher chances of experiencing hallucinations than those with the lowest level of vision loss (OR 1.49, 95% CI 1.19–1.88, $p = 0.0005$). There was no significant difference in the chances of experiencing hallucinations between people with age-related macular degeneration, diabetic retinopathy, and glaucoma, or in older versus younger respondents. People who did not live alone had higher chances of experiencing hallucinations than those who lived alone (OR 1.54, 95% CI 1.19–1.98, $p = 0.0009$).

Conclusions: Visual hallucinations are experienced by approximately 1 in 5 patients with vision loss caused by any eye disease, warranting greater awareness of the phenomenon among all vision health professionals and their patients.

Objectif : Évaluer la prévalence d'hallucinations visuelles (syndrome Charles-Bonnet) dans une population nationale participant à un programme de réadaptation visuelle.

Nature de l'étude : Étude transversale.

Participants : 2565 nouveaux clients de 40 ans et plus participant à une clinique de réadaptation visuelle de l'INCA.

Méthodes : Nous avons posé la question suivante aux participants : « Un grand nombre de personnes qui viennent nous voir à l'INCA nous disent qu'elles voient des choses qu'elles savent qui ne sont pas là. Certains voient des formes ou des silhouettes, d'autres, des images de personnes ou d'animaux. Cela vous est-il déjà arrivé? » Nous avons croisé les réponses en fonction de l'âge, du sexe, de la maladie des yeux et de l'acuité visuelle des participants, et du fait qu'ils vivaient seuls ou non. Nous avons analysé les réponses en utilisant la méthode de la régression logistique multivariable.

Résultats : Au total, 18,8 % des participants ont indiqué qu'ils avaient déjà eu des hallucinations. Selon le modèle multivariable, les femmes étaient plus sujettes aux hallucinations que les hommes (rapport de cotes [odds ratio - OR] de 1,32; intervalle de confiance [IC] de 95 %; 1,06 - 1,64, $p = 0,02$). Les clients ayant une grande perte de vision étaient plus sujets aux hallucinations que les personnes ayant une faible perte de vision (OR de 1,49; IC de 95 %; 1,19 - 1,88, $p = 0,0005$). Nous n'avons pas constaté de différence significative quant à la probabilité d'avoir des hallucinations entre les personnes atteintes de dégénérescence maculaire liée à l'âge, de rétinopathie diabétique ou de glaucome, ni entre les participants jeunes ou âgés. Les personnes qui habitaient avec d'autres étaient plus susceptibles d'avoir des hallucinations que celles qui vivaient seules (OR de 1,54; IC de 95 %; 1,19 - 1,98, $p = 0,0009$).

Conclusions : Comme environ une personne sur cinq ayant subi une perte de vision à cause d'une maladie de l'œil a des hallucinations visuelles, les professionnels de la vue et leurs patients devraient être plus sensibilisés à ce phénomène.

Charles Bonnet syndrome (CBS), the experience of complex visual hallucinations in people with vision loss and no psychological disorder,^{1,2} was first described by Charles Bonnet in 1760. Although more than 2 and a half centuries have elapsed since then, awareness of the condition by many health professionals and the community in general remains quite low, probably as a result of the reluctance on the part of people experiencing hallucinations to tell anyone for fear of being labelled mentally ill.³

Reported prevalence rates of CBS vary widely, and it is difficult to compare prevalence between studies and eye diseases. One of the reasons for this is the inconsistency of diagnostic criteria for CBS.² Another reason is the inconsistency of the questions used in various studies to determine whether an individual has experienced visual hallucinations. Because many people are reluctant to admit that they are having hallucinations, it is important that questions on prevalence be as nonthreatening as possible.

Table 1—Functional vision codes

| Acuity Code | Visual Acuity with Correction (Best Eye), Maximum to Minimum |
|---|---|
| 0 | 20/20 (6/6) to 20/69 (6/17) |
| 1 | 20/70 (6/18) to 20/199 (6/59) |
| 2 | 20/200 (6/60) to 20/399 (3/59) |
| 3 | 20/400 (3/60 or 6/120) to 20/1199 (1/59) or counting fingers \geq 3 feet |
| 4 | 20/1200 (1/60) to light perception or counting fingers $<$ 3 feet or hand movements |
| 5 | No light perception |
| Visual Field Code | Central Fields (in Degrees) |
| 2 | 20–11 |
| 3 | 10–6 |
| 4 | 5–1 |
| 5 | No light perception |
| The highest of the acuity code and the visual field code is assigned to the patient as their vision code. | |

Furthermore, inclusion criteria in the various prevalence studies vary considerably, particularly with respect to the inclusion of subjects with lower levels of vision loss.

CBS has been reported in people experiencing vision loss as a result of all major eye diseases^{2–4}—in particular, age-related macular degeneration (AMD), diabetic retinopathy, and glaucoma. There are, however, very few studies in which the prevalence of CBS has been documented in all 3 diseases in a single cohort. There are also very few studies on the prevalence of CBS in people undergoing vision rehabilitation. For these reasons, we undertook an assessment of the prevalence of CBS in new clients undergoing a low vision assessment at Canadian National Institute for the Blind (CNIB).

Table 2—Prevalence of hallucinations by subgroup

| | Number (%) | % With Hallucinations |
|--|------------|-----------------------|
| Total new clients | 2565 (100) | 18.8 |
| Age, y | | |
| 40–80 | 1048 (41) | 16.9 |
| 81+ | 1517 (59) | 20.2 |
| Sex | | |
| Female | 1612 (63) | 20.1 |
| Male | 892 (35) | 16.8 |
| Missing | 61 (2) | 14.8 |
| Vision code | | |
| 0 | 799 (31) | 15.4 |
| 1 | 613 (24) | 19.6 |
| 2 | 708 (28) | 21.3 |
| 3+ | 445 (17) | 20 |
| Eye disease | | |
| AMD | 1562 (61) | 19.9 |
| Glaucoma | 315 (12) | 18.7 |
| Diabetic retinopathy | 168 (7) | 17.3 |
| Other eye disease | 520 (20) | 16.2 |
| Living situation | | |
| Alone | 635 (25) | 17 |
| Not Alone | 1234 (48) | 22.4 |
| Missing | 696 (27) | 14.2 |
| AMD, age-related macular degeneration. | | |

Table 3—Multivariable logistic regression model

| | Odds Ratio (95% CI) | p |
|--|---------------------|--------|
| Age \geq 81 y vs age 40–80 y | 1.16 (0.93–1.46) | 0.19 |
| Female vs male | 1.32 (1.06–1.64) | 0.02 |
| Vision code 1+ vs vision code 0 | 1.49 (1.19–1.88) | 0.0005 |
| Glaucoma vs AMD | 0.92 (0.67–1.26) | 0.60 |
| Diabetic retinopathy vs AMD | 0.87 (0.56–1.35) | 0.53 |
| Other eye disease vs AMD | 0.85 (0.64–1.13) | 0.26 |
| Not living alone vs alone | 1.54 (1.19–1.98) | 0.0009 |
| AMD, age-related macular degeneration. | | |
| *Those who did not provide information on sex or living situation were not significantly different from their respective reference categories. | | |

METHODS

All people over the age of 40 years with various levels of vision loss who attended a CNIB low vision rehabilitation clinic for the first time from July to December 2013 were asked the following question by CNIB low vision specialists as part of their assessment: “Many people who come to CNIB tell us that they see things they know are not there. Some see patterns or shapes. Others see images of people or animals. Have you ever experienced this?” This question was previously reported in a study by Jackson et al.⁵ on the prevalence of CBS in glaucoma.

The responses were cross-tabulated on the basis of age; sex; eye disease; visual acuity of the client as defined by the vision code used by CNIB to characterize overall functional vision (Table 1)⁶; and living situation, that is, whether the client lived alone or with other people. Visual acuity and visual field information were provided by the client’s ophthalmologist or optometrist.

A multivariable logistic regression model was used to analyze the responses to determine whether any observed differences were significant. Vision codes 1, 2, and 3+ had similar odds ratios relative to vision code 0 and were therefore pooled into 1 category for simplicity. Missing values for sex and living situation were accommodated in the model as separate categories.

RESULTS

Out of a total of 2721 clients over the age of 40 years undergoing a low vision assessment over the period of the study, 2565 new clients answered the question supplied earlier. An analysis of their responses showed that 18.8% of this group overall reported that they experienced hallucinations. The prevalence of hallucinations experienced by each subgroup is shown in Table 2. When adjusted for the variables in the model (Table 3), sex, vision code, and living situation showed significant differences, whereas there was no difference in the likelihood of reporting hallucinations between subjects with AMD, glaucoma, diabetic retinopathy, and other eye diseases. There was also no difference in the likelihood of reporting hallucinations between subjects over the age of 80 years compared with those aged 40–80 years.

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