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REVIEW

Filling in the Blind Spot: Integrating Charles Bonnet Syndrome Screening in Ophthalmology

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Purpose: Charles Bonnet Syndrome (CBS) is an underdiagnosed condition affecting patients with significant vision loss who experience complex visual hallucinations while maintaining cognitive insight. This scoping review aims to synthesize existing literature on CBS prevalence, risk factors, and screening practices, and to propose a standardized, clinically implementable screening workflow for ophthalmologists.

Patients and Methods: We conducted a structured literature search across four databases (PubMed, Embase, Web of Science, Scopus) using keywords related to CBS, visual impairment, screening, and diagnosis. Inclusion criteria encompassed peer-reviewed studies involving patients with vision loss that reported the use of screening tools, diagnostic criteria, or clinical assessments of CBS. Excluded were case reports with fewer than five patients, articles lacking full text or peer review, and those focused primarily on psychiatric or neurologic hallucinations. We identified 1,582 articles, with 89 studies meeting the final inclusion criteria.

Results: CBS prevalence ranged from 2% to 30%, depending on the underlying ocular condition and screening method used. Age-related macular degeneration showed the highest association. Few studies utilized validated screening tools though the QR-SCB and NEVHI instruments demonstrated clinical utility. Barriers to diagnosis included patient reluctance to report symptoms and clinician unfamiliarity. We developed a pragmatic clinical model incorporating risk stratification, direct questioning, validated tools, and functional assessment to improve detection in ophthalmology clinics.

Conclusion: CBS remains underdiagnosed despite its significant psychosocial burden. A structured screening approach may increase diagnostic accuracy and support timely intervention. The proposed model offers ophthalmologists a practical pathway to integrate CBS assessment into routine care.

Keywords: visual perception disorders, low vision, hallucinations, clinical assessment tools, elderly patients, diagnostic algorithms

Introduction

Charles Bonnet Syndrome (CBS) is an ophthalmic condition characterized by complex visual hallucinations in patients with significant visual impairments, but otherwise preserved cognitive function and insight.[1,2] It was initially recognized by the Swiss naturalist Charles Bonnet, who was attempting to describe the condition in his grandfather Charles Lullin. Today, CBS remains a fascinating yet underrecognized phenomenon in clinical practice.[1,2] Patients often report vivid hallucinations of people, animals, or geometric patterns.[1,3] Interestingly, patients with CBS retain complete insight about the hallucinations, which makes this syndrome distinct from other neurologic or psychiatric conditions that may cause visual hallucinations.

With an increasingly aging population, the incidence of conditions that may lead to CBS is expected to increase. Some of these include age-related macular degeneration (AMD), diabetic retinopathy (DR), and glaucoma.[4] Therefore, there is a growing patient population that may be at risk of developing CBS in the future.[2,3] Some studies have reported the prevalence of CBS to be from 11.8% to as high as 17.7% among patients with retinal diseases, low vision, and glaucoma, and it can be as high as 24.6% among visual rehabilitation patients.[5] Additionally, the true prevalence of the disorder is likely underestimated due to underreporting. Many patients are reluctant to admit to having symptoms of the

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disorder due to fear of psychiatric labeling,[2,3,6] and clinicians may fail to recognize the etiology of these symptoms during routine care.[6] As a result, CBS is frequently misdiagnosed or missed entirely, preventing patients from receiving education and resources that could substantially improve quality of life.[6,7]

Despite being recognized for over two centuries, there is no universally accepted diagnostic definition of CBS. However, inclusion in the 11th revision of the International Classification of Diseases (ICD-11) could potentially help standardize the diagnosis among clinicians.[3,6–8] While hallucinations and vision loss are common requirements for diagnosis, there is considerable disagreement as to the content of the hallucinations and the degree of vision loss required for diagnosis.[8] The lack of standardization affects both the quality of clinical care and efforts to research the impact and management of CBS.

Misdiagnosis of CBS as a psychiatric disorder can lead to inappropriate consultations or treatments, which can potentially expose patients to untoward adverse effects, especially in older patients who are more likely to have predisposing conditions.[2,3] Failure to recognize this disease can lead to patients with decreased quality of life, feelings of isolation, increased burden of visual impairment, and potentially psychiatric sequelae from distressing hallucinations.-[2,7] It is essential for clinicians to identify and manage this syndrome early and adopt a systematic approach for the education and management of this condition.

The aims of this study are to examine the literature using a structured approach and create a systematic, practical approach that can be used in ophthalmology clinics to screen for CBS based on current practices and available evidence. We first examined the literature and determined groups most at risk for CBS. Then, we examined the literature for clinical approaches and validated tools that are commonly used in clinical research. Finally, we identified barriers to diagnosis and potentially solutions offered by previous authors. A standardized method of screening and identification is vital to improving patient outcomes, particularly given the wide heterogeneity in prevalence estimates and diagnostic thresholds across the literature.

Materials and Methods

We performed a structured review of multiple databases. Use of Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines was considered, however the multiplicity of the questions we aimed to answer would not fit well in a Patient/Population/Problem, Intervention, Comparison, and Outcome (PICO) framework, and we expected significant heterogeneity in the type of studies that would be useful for this review. We therefore decided to create a proprietary approach better suited to our study aims while still retaining a rigorous methodology. Studies were screened for their suitability of inclusion based on inclusion and exclusion criteria devised by our research team. Inclusion criteria focused on studies of CBS and populations at risk due to vision-impairing ocular conditions, particularly AMD, glaucoma, DR, and other major causes of low vision. Articles deemed relevant included studies that utilized or examined screening tools or diagnostic methods, epidemiology, and potential risk factors, as well as those focusing on clinical management and diagnosis. Article types that were included were systematic reviews, meta-analyses, relevant narrative reviews, observational studies where patients were either screened for CBS or involved patients with previously diagnosed CBS, clinical trials, and case series with five or more patients. Included articles were either peer-reviewed manuscripts or validated abstracts that were published in English.

Exclusion criteria included studies focusing on hallucinations primarily related to psychiatric or neurological etiologies, studies where CBS was only mentioned incidentally, studies that focused on non-visual hallucinations, studies that focused mainly on treatment, studies that did not have a full text or abstract, studies that were not peer-reviewed articles, or case reports and case series that included less than 5 patients. The decision to remove non-English language studies was made on the basis of feasibility, given that accurate translation of full-text articles in multiple languages was beyond the scope of our resources.

Databases that were searched included PubMed, Embase, Web of Science, and Scopus using the following search terms that can be found in Box 1:

A total of 1,582 records were found on initial search (PubMed N = 276, Scopus N = 368, Web of Science N = 218, and Embase N = 720) and added to a Zotero database. These databases were selected given their exhaustiveness and the ability to download search results in a format compatible with Zotero. Duplicate studies were then removed manually (N

BOX 1 Search Terms

((“Charles Bonnet Syndrome”))
AND ((“screening” OR “diagnosis” OR “clinical assessment” OR “diagnostic criteria”)
OR (“prevalence” OR “epidemiology” OR “risk factors” OR “vision impairment” OR “AMD” OR “glaucoma” OR “retinal disease”)
OR (“routine screening” OR “clinical practice” OR “ophthalmology clinics” OR “standardized screening”))

= 749), and subsequently English language studies were also removed (N = 115). A total of 718 papers remained for title and abstract screening.

Title and abstract review were conducted in two rounds. Two reviewers examined the titles and abstract for each study and made a determination of whether the study fit inclusion or exclusion criteria. Reviewers were blinded to the decision of the other reviewer, and any discordance was resolved by a third reviewer during the second, tie-breaker round. Studies that passed text and abstract review were included in the full-text review (N = 114).

Full-text review was conducted by extraction of the following details from each study: study title, DOI, authors, publication year, study type, sample size, patient population, CBS screening tools used (if any), risk factors identified, study design, methods, main findings, and limitations. Data was extracted and compiled on a single excel sheet, along with the vote from the research member who reviewed the study. Decision regarding inclusion was made based upon discussion between research team members. A total of 25 studies were removed, 4 of which did not contain useful information about CBS based on the discretion of our reviewers, 12 of which were editorial articles or case reports, 1 of which was a foreign language article, and 8 of which were duplicates that were discovered on review of the full text.

A total of 89 studies were included in the final review. All studies were compiled and reported in Table 1. This table has been expanded in supplemental Table 1 to contain more information about studies included in this review. Figure 1 provides a graphical illustration of our review.

Results

Prevalence Patterns and Demographic Risk Factors

CBS prevalence varies widely depending on the population, underlying pathology, and diagnostic criteria used. A meta-analysis suggested an average prevalence between 10% and 15% among patients with visual impairment.[36] Generally, the likelihood increases with the severity of visual deficits, increasing age, and social isolation.[12,17] CBS is more frequently reported among women and in older adults (7th–8th decade), likely reflecting the higher prevalence of AMD and glaucoma in this age group.[2,33,51,82] Prevalence for all ophthalmic pathology is 0.4%.[86] Approximately 14–20% of all individuals with a vision impairment will develop CBS, with AMD reported as the most frequently associated ocular pathology. However, prevalence estimates vary considerably depending on the diagnostic criteria applied, underscoring the challenge of establishing a consistent case definition.[28,34]

High-Risk Groups and Condition-Specific Prevalence

CBS most commonly occurs in populations with significant bilateral vision loss but can occur in unilateral visual field loss. Late-stage AMD patients are consistently identified as a high-risk group, with prevalence rates of up to 27% when better-eye visual acuity falls below 20/120 (6/36), while neovascular AMD cohorts demonstrate a prevalence of around 9%.[29,33] Low-vision patients, particularly those over age 40, show an overall prevalence of ~19.7%, with increased risk in patients with a visual acuity below 20/60.[51,92] Patients receiving intravitreal anti-Vascular Endothelial Growth Factor (VEGF) therapy have a reported prevalence of 6.6%, and poor visual acuity and contrast sensitivity identified as key risk factors like all other patient populations.[78] In glaucoma populations, CBS in open-angle glaucoma patients with visual field deficits show prevalence rates ranging from 7.1% to 20.1% depending on the population screened.[77,83] Inherited retinal diseases such as retinitis pigmentosa have been shown to be at risk but specific prevalence at this point have not been reported. Non-ocular pathologies such as visual cortex damage due to strokes have been shown to be a significant risk factor for the development of CBS though prevalence has not been reported or quantified.[20,23,73] Overall, populations

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Table 1 List of Included Studies

#	Study Name	Authors	Date	Country	Study Design
1	Visual Hallucinations and Sensory Delusions in the Elderly[9]	G. E. Berrios, P. Brook	1984	UK	Cohort
2	Visual hallucinations in ophthalmology[10]	H. M. Olbrich, M. P. Engelmeier, D. Pauleikhoff, T. Waubke	1987	Germany	Observational
3	Visual Perceptual Disorders Resembling the Charles Bonnet Syndrome. A Study of 434 Consecutive Patients Referred to a Psychogeriatric Unit[11]	L. Norton-Willson, M. Munir	1987	UK	Retrospective
4	Visual Hallucinations in Patients with Macular Degeneration[12]	S. Holroyd, P. V. Rabins, D. Finkelstein, M. C. Nicholson, G. A. Chase, S. C. Wisniewski	1992	USA	Case-control
5	Visual Symptoms Associated With Choroidal Neovascularization Photopsias and the Charles Bonnet Syndrome[13]	G. C. Brown, R. P. Murphy	1992	USA	Cross-sectional
6	Visual Hallucinations and Mental State[14]	G. Schultz, R. Melzack	1993		
7	Clinical Evaluation of 14 Patients With the Charles Bonnet Syndrome (Isolated Visual Hallucinations)[15]	R. J. Teunisse, F. G. Zitman, D. C. M. Raes	1994	Netherlands	Case series
8	The Charles Bonnet Syndrome: A Large Prospective Study in The Netherlands A Study of the Prevalence of the Charles Bonnet Syndrome and Associated Factors in 500 Patients Attending the University Department of Ophthalmology at Nijmegen[16]	R. J. Teunisse, J. A. M. Cruysberg, A. Verbeek, F. G. Zitman	1995	Netherlands	Prospective
9	The Charles Bonnet Syndrome[17]	A. Fernandez, G. Lichtshein, W. V. R. Vieweg	1997	—	Review
10	Social and Psychological Characteristics of Elderly Visually Handicapped Patients With the Charles Bonnet Syndrome[18]	R. J. Teunisse, J. R. Cruysberg, W. H. Hoefnagels, Y. Kuin, A. L. Verbeek, F. G. Zitman	1999	Netherlands	Case-control
11	Hyperperfusion in the lateral temporal cortex, the striatum and the thalamus during complex visual hallucinations: Single photon emission computed tomography findings in patients with Charles Bonnet Syndrome[19]	N. Adachi, T. Watanabe, H. Matsuda, T. Onuma	2000	Japan	Case series
12	Visual Hallucinations in Patients With Retinal Disease[20]	I. U. Scott, O. D. Schein, W. J. Feuer, M. F. Folstein	2001	USA	Cross-sectional
13	Charles Bonnet Syndrome in Glaucoma Patients With Low Vision[21]	R. Nesher, G. Nesher, E. Epstein, E. Assia	2001	Israel	Cross-sectional

14	Prevalence of photopsias and Charles Bonnet syndrome: evaluation of eighty cases with low vision[22]	S. Tatlıpınar, S. Kadayıfçılar, B. Eldem, P. Türkçüog˘lu	2001	Turkey	Prevalence
15	Tc-99m Ethylcysteinate Dimer Brain SPECT Perfusion Imaging in Ictal Nonepileptic Visual Hallucinations[23]	M. Lorberboym, Y. Lampl, R. Gilad, M. Sadeh	2002	Israel	Case series
16	Complex Visual Hallucinations in the Visually Impaired: The Charles Bonnet Syndrome[7]	G. J. Menon, I. Rahman, S. J. Menon, G. N. Dutton	2003	—	Review
17	Visual hallucinations and Charles Bonnet Syndrome after photodynamic therapy for age related macular degeneration[24]	S. Y. Cohen, A. Bulik, R. Tadayoni, G. Quentel	2003	France	Prospective
18	Charles Bonnet syndrome in Asian patients in a tertiary ophthalmic centre[25]	C. S. H. Tan, V. S. Y. Lim, D. Y. M. Ho, E. Yeo, B. Y. Ng, K. G. Au Eong	2004	Singapore	Prospective
19	The rarity of Charles Bonnet syndrome[26]	Y. Shiraishi, T. Terao, K. Ibi, J. Nakamura, A. Tawara	2004	Japan	Cross-sectional
20	The Possible Role of Vision Rehabilitation in the Treatment of Visual Hallucinations in the Elderly[27]	D. Anderson, L. Pankow, D. Luchins	2004	—	Review
21	The Charles Bonnet syndrome: a review of recent research[28]	B. W. Rovner	2006	—	Review
22	Visual Hallucinations in Patients with Age-Related Macular Degeneration (AMD)[29]	S. P. Lannon, M. R. Stevenson, S. T. White, J. F. Logan, A. H. Reinhardt-Rutland, A. J. Jackson	2006	Northern Ireland	Cross-sectional
23	Visual Loss and Visual Hallucinations in Patients with Age-Related Macular Degeneration (Charles Bonnet Syndrome)[30]	E. J. Abbott, G. B. Connor, P. H. Artes, R. V. Abadi	2007	UK	Cross-sectional
28	Six Cases of Charles Bonnet Syndrome Presenting in Neuro-Ophthalmology Clinic[31]	A. Koh, Y. Nakai, M. Shiokawa, R. Higa, K. Shidara, R. Moriyama, M. Wakakura	2007	Japan	Retrospective
24	A semi-structured interview to assess visual hallucinations in older people[32]	U. P. Mosimann, D. Collerton, R. Dudley, T. D. Meyer, G. Graham, J. L. Dean, D. Bearn, A. Killen, L. Dickinson, M. P. Clarke, I. G. Mckeith	2008	UK	Pilot
25	Charles Bonnet Syndrome in Age-Related Macular Degeneration: The Nature and Frequency of Images in Subjects with End-Stage Disease[33]	J. C. Khan, H. Shahid, D. A. Thurlby, J. R. W. Yates, A. T. Moore, S. S. Bhattacharya, A. C. Bird, P. Bishop, P. Black, Z. Butt, D. Clayton, N. E. Day, C. E., A. Fitt, D. W. Flanagan, A. Glenn, S. Harding, C. Jakeman, C. Jones, R. Lamb, A. Lottery, V. Moffat, C. Moorman, A. Nicholas, R. J. Pushpanathan, E. Redmond, T. Rimmer	2008	UK	Case-control
26	Vision Rehabilitation and Charles Bonnet Syndrome[34]	K. E. Crumbliss, M. J. Taussig, W. M. Jay	2008	USA	Prospective

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Table 1 (Continued).

#	Study Name	Authors	Date	Country	Study Design
27	Butterflies and black lacy patterns: the prevalence and characteristics of Charles Bonnet hallucinations in an Australian population[35]	M. Vukicevic, K. Fitzmaurice	2008	Australia	Cross-sectional
29	Charles Bonnet syndrome: a review[36]	A. P. Schadlu, R. Schadlu, J. B. Shepherd III	2009	—	Review
30	Perceived Color of Hallucinations in the Charles Bonnet Syndrome Is Related to Residual Color Contrast Sensitivity[37]	S. A. Madill, G. Lascaratos, G. B. Arden, D. H. Ffytche, A. Princess	2009	UK	Case series
31	Neuroimaging studies in patients with Charles Bonnet Syndrome[38]	H. Kazui, R. Ishii, T. Yoshida, K. Ikezawa, M. Takaya, H. Tokunaga, T. Tanaka, M. Takeda	2009	—	Review
32	Visual hallucinations in eye disease[39]	D. H. Ffytche	2009	—	Review
33	An examination of the relationship between low vision and Charles Bonnet syndrome[40]	G. Gilmour, C. Schreiber, C. Ewing	2009	Canada	Prospective
34	Charles Bonnet Syndrome: A Review of the Literature[2]	L. O'Farrell, S. Lewis, A. Mckenzie, L. Jones	2010	—	Review
35	Clinical Phenomenology and Mortality in Charles Bonnet Syndrome[41]	M. I. Lapid, M. C. Burton, M. T. Chang, T. A. Rummans, S. S. Cha, J. A. Leavitt, B. F. Boeve	2012	USA	Retrospective
36	The prevalence and clinical characteristics of Charles Bonnet Syndrome in Danish patients with neovascular age-related macular degeneration[42]	A. Singh, T. L. Sørensen	2012	Denmark	Prevalence
37	The prevalence and clinical characteristics of Charles Bonnet syndrome in Chinese patients[43]	Y. Hou, Y. Zhang	2012	China	Cross-sectional
38	Charles Bonnet syndrome: a literature review into diagnostic criteria, treatment and implications for nursing practice[3]	D. F. Hughes	2013	—	Review
39	Low awareness of the Charles Bonnet syndrome in patients attending a retinal clinic[44]	A. Singh, Y. Subhi, T. L. Sørensen	2014	Denmark	Cross-sectional
40	Prevalence and clinical characteristics of Charles Bonnet syndrome in Madrid, Spain[45]	E. Santos-Bueso, F. Sáenz-Francés, M. Serrador-García, J. Porta-Etessam, J. M. Martínez-De-La-Casa, J. García-Feijoo, J. García-Sánchez	2014	Spain	Prevalence
41	Negative outcome Charles Bonnet Syndrome[46]	T. M. Cox, D. H. Ffytche	2014	UK	Cross-sectional

42	Charles Bonnet syndrome: characteristics of its visual hallucinations and differential diagnosis Síndrome de Charles Bonnet: características[47]	T. C. Vale, L. C. Fernandes, P. Caramelli	2014	Brazil	Case series
43	Charles Bonnet Syndrome in Advanced Retinitis Pigmentosa[48]	F. O'Hare, S. A. Bentley, Z. Wu, R. H. Guymer, C. D. Luu, L. N. Ayton	2015	Australia	Cross-sectional
44	Charles Bonnet syndrome in older adults with age-related macular degeneration: Its relationship to depression and mild cognitive impairment[49]	H. Boxerman, W. Wittich, O. Overbury	2015	Canada	Cross-sectional
45	Hallucinations Experienced by Visually Impaired: Charles Bonnet Syndrome[50]	L. Pang	2016	—	Review
46	The Prevalence and Characteristics of Charles Bonnet Syndrome in Turkish Patients with Retinal Disease[51]	S. Nalcaci, O. Ilim, Z. Oztas, C. Akkin, A. Acarer, F. Afrashi, J. Mentes	2016	Turkey	Prevalence
47	Prevalence of visual hallucinations in a national low vision client population[52]	K. D. Gordon	2016	Canada	Cross-sectional
48	Charles Bonnet's syndrome: not only a condition of the elderly[53]	H. M. Elflein, M. Rudy, K. Lorenz, K. A. Ponto, A. Scheurich, S. Pitz	2016	Germany	Prospective
49	The Charles-Bonnet syndrome in patients with neovascular age-related macular degeneration - could proton inhibitor pumps play a role?[54]	J. E. Leandro; J. Beato; A. C. Pedrosa; J. Pinheiro-Costa; M. Alberto Falcão; F. Falcão-Reis; Â. M. Carneiro	2017	—	Prevalence
50	The role of the retina in visual hallucinations: A review of the literature and implications for psychosis[55]	F. Bernardin, R. Schwan, L. Lalanne, F. Ligier, K. Angioi-Duprez, T. Schwitzer, V. Laprévote	2017	—	Review
51	Cognitive impairment and Charles Bonnet syndrome: a prospective study[56]	G. Russell, R. Harper, H. Allen, R. Baldwin, A. Burns	2018	UK	Prospective Cohort
52	Visual acuity and contrast sensitivity are two important factors affecting vision-related quality of life in advanced age-related macular degeneration[57]	M. Roh, A. Selivanova, H. J. Shin, J. W. Miller, M. L. Jackson	2018	USA	Retrospective
53	Looking at Charles Bonnet Syndrome: Prevalence and Experiences of Patients Attending a Vision Rehabilitation Clinic[58]	L. M. Ord, A. Henderson, R. M. Christiansen	2018	USA	Retrospective
54	Hallucinatory experiences in visually impaired individuals: Charles Bonnet syndrome - implications for research and clinical practice[59]	D. Jurišić, I. Sesar, I. Ćavar, A. Sesar, M. Živković, M. Ćurković	2018	—	Review

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Table 1 (Continued).

#	Study Name	Authors	Date	Country	Study Design
55	Family physician awareness of Charles Bonnet syndrome[60]	K. D. Gordon, T. Felfeli	2018	Canada	Cross-sectional
56	Bonnet's syndrome in ophthalmology: literature review[61]	A. Lindaura, C. Augusto, A. Da Rocha Lucena, M. Lys, C. Augusto, A. G. Matos	2018	—	Review
57	Screening for Charles Bonnet syndrome: Should the definition be reconsidered?[62]	P. Satgunam, R. Sumalini, G. Chittapu, G. Pamarthi, B. Holden	2019	India	Cross-sectional
58	Prevalence of visual hallucinations[63]	S. Marmamula, R. Sumalini, T. K. Reddy, S. M. Brahmanandam, P. Satgunam	2019	India	Cross-sectional
59	The elephant in the room: understanding the pathogenesis of Charles Bonnet syndrome[1]	K. Carpenter, J. K. Jolly, H. Bridge	2019	—	Review
60	Evaluation of the Clinical Features, Management, and Prognoses of Patients With Charles Bonnet Syndrome[64]	H. Buyukgol, F. Ilik, D. H. Ertem	2019	Turkey	Retrospective
61	Charles Bonnet syndrome: development and validation of a screening and multidimensional descriptive questionnaire[65]	S. Cantin, J. Duquette, F. Dutrisac, L. Ponton, M. Courchesne, W. D. A. Cybis, K. Montisci, W. Wittich, M.-C. Wanet-Defalque	2019	Canada	Pilot
62	The Charles Bonnet Syndrome: a Systematic Review of Diagnostic Criteria[66]	A. G. Hamedani, V. S. Pelak	2019	USA	Systematic Review
63	Prevalence of Charles Bonnet syndrome in patients with age-related macular degeneration: systematic review and meta-analysis[67]	S. Niazi, M. K. Nielsen, A. Singh, T. L. Sørensen, Y. Subhi	2020	USA, Canada, UK, Croatia, Denmark, Portugal, Turkey, China, Singapore	Systematic Review and Meta Analysis
64	Prevalence of Charles Bonnet syndrome in patients with glaucoma: a systematic review with meta-analyses[68]	Y. Subhi, D. C. Schmidt, D. Bach-Holm, M. Kolko, A. Singh	2020	Denmark, Sweden	Systematic Review and Meta Analysis
65	Charles Bonnet syndrome: low awareness among patients with glaucoma[69]	S. Molander, D. Peters, A. Singh	2020	Sweden	Cross-sectional
66	Visual hallucinations and sight loss in children and young adults: a retrospective case series of Charles Bonnet syndrome[70]	L. Jones, M. Moosajee	2020	UK	Case series

67	Clinical characteristics of the Charles Bonnet syndrome in patients with neovascular age-related macular degeneration: the importance of early detection[71]	J. E. Leandro, J. Beato, A. C. Pedrosa, J. Pinheiro-Costa, M. Falcão, F. Falcão-Reis, Â. M. Carneiro	2020	Portugal	Cross-sectional
68	An overview of psychological and social factors in Charles Bonnet syndrome[72]	L. Jones, L. Ditzel-Finn, J. Enoch, M. Moosajee	2021	—	Review
69	Charles Bonnet syndrome prevalence in a younger ophthalmology outpatient population[73]	A. Karagöl	2021	Turkey	Cross-sectional
70	How do the blind 'see'? The role of spontaneous brain activity in self-generated perception[74]	A. Hahamy, M. Wilf, B. Rosin, M. Behrmann, R. Malach	2021	UK	Experimental
71	Charles Bonnet syndrome in patients with Stargardt disease: prevalence and risk factors[75]	P. A. Dhooge, R. J. Teunisse, B. Liefers, S. Lambertus, N. M. Bax, C. B. Hoyng, J. R. M. Cruysberg, B. J. Klevering, O. Ids	2021	Netherlands	Prevalence
72	Benefit of psychiatric evaluation on anxiety in patients with Charles Bonnet syndrome[76]	B. Doeller, M. Kratochwil, L. Sifari, N. Hirnschall, O. Findl	2021	Australia	RCT
73	Charles Bonnet Syndrome in Patients with Open-Angle Glaucoma Prevalence and Correlation to Visual Field Loss[77]	D. Peters, M. Stellan, L. Trine, S. Amardeep	2022	Sweden	Cross-sectional
74	The Incidence and Characteristics of Charles Bonnet Syndrome in a Large Cohort of Leber's Hereditary Optic Neuropathy Patients[78]	H. Nguyen, M. Kreimei, E. Mollanji, L. Poincenot, R. Karanjia	2022	Canada	Prospective Cohort
75	Prevalence of Charles Bonnet syndrome among UK visually impaired military veterans and associated impact of visual hallucinations during the COVID-19 pandemic[79]	L. Jones, M. Lee, R. Gomes, M. Moosajee	2022	UK	Cross-sectional
76	Investigation of structural brain changes in Charles Bonnet Syndrome[80]	M. J. Firbank, K. D. Morgan, D. Collerton, G. J. Elder, J. Parikh, K. Olsen, J. Schumacher, D. Ffytche, J. P. Taylor	2022	UK	Cross-sectional
77	Shedding Light on Charles Bonnet Syndrome: AnIn-Depth Analysis in South Gujarat[81]	S. S. Saiyad, H. R. Suthar, M. K. Bhabhor, A. R. Vara, H. R. Suthar	2023	India	Cross-sectional
78	Charles Bonnet syndrome in age-related macular degeneration - prevalence and clinical features in a Portuguese population[82]	M. Portela, P. Arede, M. Picoto, F. Vaz	2023	Portugal	Cross-sectional
79	Impact of Charles Bonnet Syndrome on visually impaired older adults' ability to engage in physical activity: A scoping review[6]	K. Fisher, C. Sanders, E. Stanmore	2023	—	Review
80	Charles Bonnet Syndrome Adversely Affects Vision-Related Quality of Life in Patients with Glaucoma[83]	P. Randeblad, A. Singh, D. Peters	2024	Sweden	Cross-sectional

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Table 1 (Continued).

#	Study Name	Authors	Date	Country	Study Design
81	Prevalence of Charles Bonnet Syndrome (CBS) in patients with vitreoretinal and inherited retinal disease[84]	M. Naik, Y. Bakr, A. Y. Ong, B. Ip, S. M. Downes, P. C. Issa, S. Aslam, J. K. Jolly	2024	UK	Prospective Cohort
82	Emotional well-being in Charles Bonnet syndrome: exploring associations with negative affect, loneliness and quality of life[85]	B. Higgins, D. Taylor, D. Crabb, T. Callaghan	2024	UK	Cross-sectional
83	Epidemiology and phenomenology of the Charles Bonnet syndrome in low-vision patients[86]	S. E G Christoph, K. T. Boden, A. Pütz, K. Januschowski, R. Siegel, B. Seitz, P. Szurman, A. Schulz, K. Heimann	2024	Germany	Cross-sectional
84	Practice patterns in reporting and documentation of Charles Bonnet syndrome: a retrospective review following COVID-19[87]	D. Abdulhussein, L. Jones, H. Dintakurti, M. Moosajee	2024	UK	Retrospective
85	The experiences of visually impaired military veterans with Charles Bonnet syndrome[88]	S. Dave, L. Jones, M. Lee, L. Ditzel-Finn, C. Castle, N. Heinze, J. Potts, M. Moosajee, R. S. M. Gomes	2024	UK	Cross-sectional
86	The prevalence of Charles-Bonnet syndrome in ophthalmic patients: A systematic review and meta-analysis[5]	S. E G Christoph, K. T. Boden, R. Siegel, B. Seitz, P. Szurman, A. Schulz	2024	Germany	Systematic Review and Meta Analysis
87	They are creepy creatures with human-like features': children's experiences of visual hallucinations in Charles Bonnet syndrome-a qualitative study[89]	L. Jones, L. Ditzel-Finn, L. Mcdonald, M. Moosajee	2025	UK	Cross-sectional
88	Visual cortical activity in Charles Bonnet syndrome: testing the deafferentation hypothesis[90]	K. D. Morgan, D. Collerton, M. J. Firbank, J. Schumacher, D. H. Ffytche, J. P. Taylor	2025	UK	Experimental
89	Charles Bonnet syndrome in patients with geographic atrophy secondary to age-related macular degeneration: a cross-sectional study[91]	N. S. Eriksen, N. Mousavi, Y. Subhi, T. L. Sørensen, M. K. Nielsen	2025	Denmark	Cross-sectional

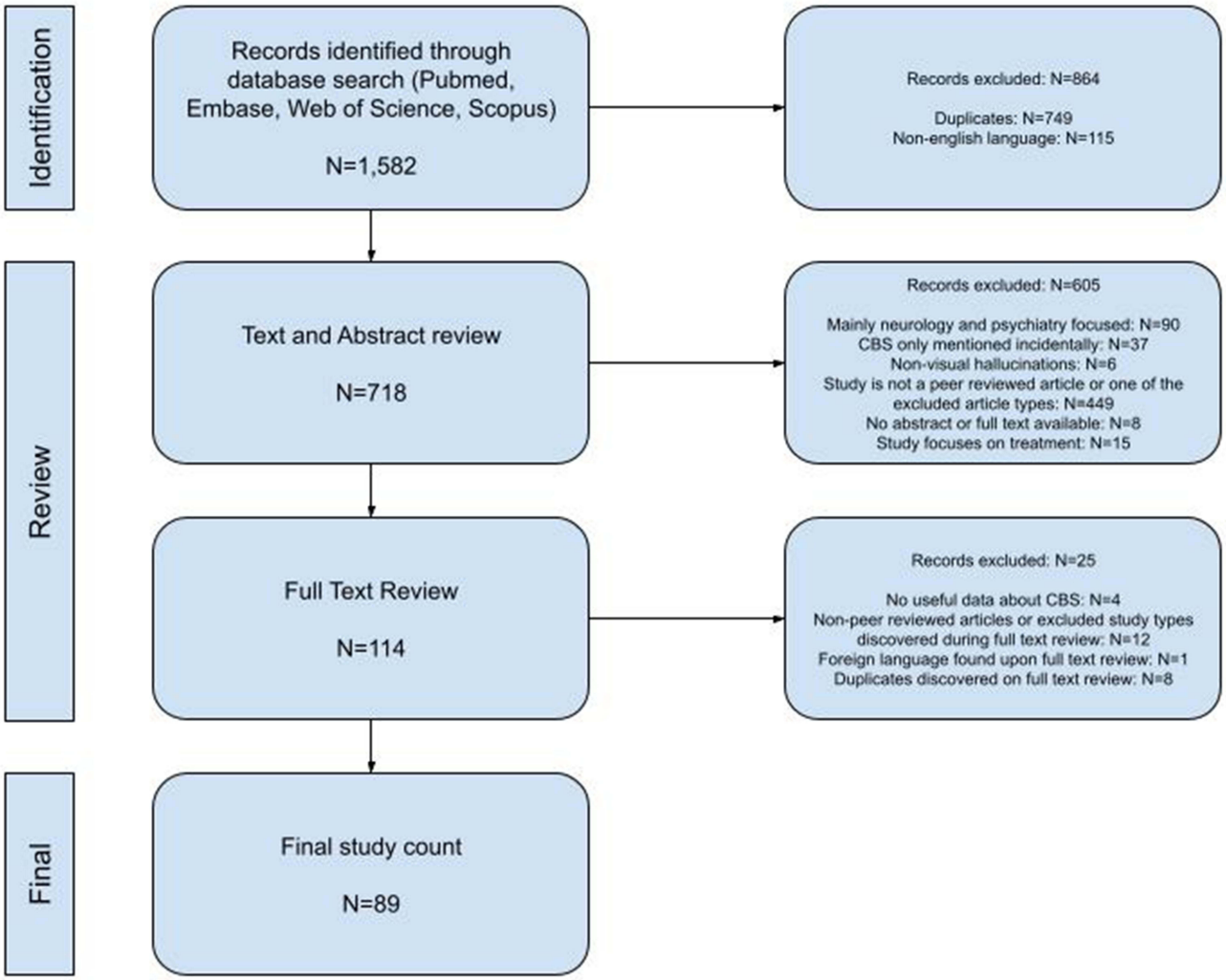

Figure 1 Study selection flowchart for the structured review of Charles Bonnet Syndrome (CBS). A total of 1,582 records were identified through database searches (PubMed, Embase, Web of Science, Scopus). After removing duplicates and non-English articles, 718 records remained for title and abstract screening. Of these, 605 were excluded based on predefined criteria, including irrelevance to CBS, non-visual hallucinations, and lack of peer review. A full-text review was conducted on 114 articles, with an additional 24 excluded due to inadequate data, non-peer-reviewed status, or duplication. A final total of 89 studies were included in the structured review.

at risk include patients with bilateral visual field/acuity loss such as AMD (Dry and neovascular), advanced glaucoma, DR, strokes, and congenital retinal conditions.

Condition-Specific Associations and Risk Profiles

Age-Related Macular Degeneration: The Primary Risk Group

Among the ocular pathologies linked to CBS, AMD has been most extensively studied, with reported prevalence ranging from 10% to 30%.[2,29] Several studies report a prevalence of CBS in AMD patients ranging from 10% to 30%.[33,49,82] With patients showing end stage AMD, geographic atrophy, or neovascular AMD showing increased susceptibility to CBS.[91]

Studies investigating the relationship between visual acuity and the risk of developing CBS in patients with AMD have resulted in mixed findings. With some studies reporting that diminished visual acuity or visual field loss either independently or combined does not reliably predict the likelihood of developing CBS.[12] Other studies show that specific visual acuity thresholds may be associated with increased risk. Khan et al's case–control study showed that visual acuity worse than 20/120 in the better seeing eye was significantly associated with an increased risk of CBS (OR 3.5).[33] Other studies have shown that bilateral visual acuity of 20/60 is also associated with an increased risk of CBS.[82]

Glaucoma: Underrecognized but Clinically Relevant Risk

CBS has been less frequently reported in glaucoma compared to AMD. Reported prevalence of CBS in glaucoma patients was reported to be between 2% and 5%.[46]

Diabetic Retinopathy: CBS Risk in Bilateral Central Vision Loss

Patients with diabetic retinopathy (DR) can develop CBS, especially if patients have bilateral vision deficits. Overall prevalence was lower than in AMD, prevalence was between 2% and 10%, with an increased risk of CBS with macular edema and neovascularization leading to central vision loss.[16,78]

Other Etiologies: Retinal, Optic, and Cortical Pathways to CBS

CBS has also been reported in association with optic neuropathies, retinal detachments, and inherited retinal diseases such as retinitis pigmentosa.[93] Strokes leading to cortical visual impairment have also been documented as a cause of CBS, and data on prevalence in this population are limited.[20,67,92] The main feature across all these other conditions is significant loss of visual input to the visual cortex, while most bilateral optic neuropathies have been shown to have monocular CBS. Table 2 presents a summary of these CBS prevalence results.

Table 2 Summary of CBS Prevalence, Risk Factors, and Demographic Trends Across Vision-Impaired Populations

Study	Mean Age	Population	Prevalence (%)	At-Risk Groups
Singh et al (2014)[44]	78.5	Low vision patients	—	Older adults with vision loss
Portela et al (2023)[82]	88	AMD patients	—	Late AMD, poor BCVA
Khan et al (2008)[33]	80.3	Late AMD patients	27	Poor better eye VA (<20/120)
Nalcaci et al (2016)[51]	71.7	Low vision clinic attendees	12	VA worse than 20/60
Crumbliss et al (2008)[34]	74.1	Visually impaired individuals	—	Vision loss
Lapid et al (2012)[41]	79.5	Elderly patients	—	Aging with visual impairment
Doeller et al (2021)[76]	79.3	General low vision population	—	Older adults
Karagöl, (2021)[73]	39.4	Young ophthalmology patients	—	Young adults with vision loss
Jurišic et al (2018)[59]	—	Visually impaired individuals	—	Low vision
Subhi et al (2020)[92]	—	Patients ≥40 with low vision	19.7	Low vision aged ≥40
Nguyen et al (2022)[78]	—	Anti-VEGF treated patients	6.6	Poor VA and contrast sensitivity
O'Hare et al (2015)[48]	—	Retinitis pigmentosa patients	—	Advanced RP
Lorberboym et al (2002)[23]	—	Post-stroke CBS patients	—	Stroke with visual cortex damage
Leandro et al (2017)[54]	—	Neovascular AMD patients	9	Late-stage AMD
Dhooge et al (2021)[75]	—	Stargardt disease patients	8.4	Inherited retinal disease
Eriksen et al (2025)[91]	—	Geographic atrophy patients	20.8	Advanced dry AMD
Vukicevic & Fitzmaurice (2008)[35]	~78*	Visually impaired older adults	17.5	Elderly with significant vision loss
Peters et al (2022)[77]	—	OAG patients with vision loss	20.1	Open-angle glaucoma with visual field loss
Randeblad et al (2024)[83]	—	Open-angle glaucoma patients	7.1	Glaucoma with reduced visual function
Teunisse et al (1995)[16]	—	Low-vision patients	11	Severe bilateral vision loss
Scott et al (2001)[20]	—	Patients with retinal disease	—	Neurological comorbidities including stroke

(*Continued*)

Table 2 (Continued).

Study	Mean Age	Population	Prevalence (%)	At-Risk Groups
Christoph et al (2024)[86]	—	Low vision patients	—	Broad CBS epidemiology in low vision
Fisher et al (2023)[6]	—	Visually impaired individuals	—	Quality of life impact in CBS
Tan et al (2004)[25]	—	Asian patients in tertiary care	—	CBS presentation in ethnic subgroups
Teunisse et al (1994)[15]	—	Patients with visual impairment	—	Early CBS characterization across conditions
Boxerman et al (2015)[49]	—	Older adults with AMD	—	CBS prevalence in older AMD populations

Notes: *Age approximated based on cohort description.

Screening Tools and Diagnostic Practices in CBS Research

We have identified two screening tools that are formally validated and used in multiple studies, namely the North-East Visual Hallucination Interview (NEVHI),[32] and the Questionnaire de Repérage du Syndrome de Charles Bonnet (QR-SCB).[65] Additional screening tools found include one created by Vukicevic and Fitzmaurice,[35] which has not been formally validated, and one created by Shirashi et al,[26] which was validated by the study authors, however, is not routinely used in ophthalmologic research and only contains one question specific to CBS. The NEVHI was created by Mosimann et al in 2008 and is a semi-structured interview designed to assess the phenomenology of hallucinations, emotional response of patients, temporal characteristics, and cognitive insight in older patients with visual or cognitive impairment. It has good face, content, and criteria validity with strong inter-rater reliability (Kappa 0.72–0.83), but requires a trained interviewer.[32] The QR-SCB, which was developed by Cantin et al in 2009, is a self-administered, 55-item questionnaire that can be used by low vision patients and offers a structured algorithm for screening. The sensitivity was found to be 1.00 with a sensitivity of 0.77 in the validation study, however it was only validated for use in french-speaking populations and relies on patient self-report which can be affected by the cognitive status of the patient.[65] A major advantage of this approach is that it can be completed without a trained interviewer, enhancing its clinical utility. The original validation of the NEVHI did not provide an estimated elapsed time of the interview; however, the length of administration is likely to cause more disruption to clinic flow than the QR-SCB. The NEVHI consists of 3 sections, the first of which includes 4 binaries, ie yes/no, questions that require patient elaboration. The subsequent two sections include 4 multiple choice questions delineating the temporal aspects of the hallucination, and 9 questions where patients must respond using a 1–5 Likert scale. Providers can be adequately trained to administer this standardized interview, however it would require the patient to be in an appropriate setting, ie a clinic room, for administration. Conversely, the QR-SCB often took between 15 and 45 minutes for administration; however, does not require a trained interviewer, and can be filled out while the patient is waiting to be roomed, provided they have a positive affirmation to the initial screening question. This is less likely to disrupt the clinic flow substantially and is able to be administered even in busy clinics. The characteristics of each of these tools have been characterized graphically in Table 3.

Overall, of these tools, the NEVHI offers the most depth regarding evaluated domains and is great for use in specialist settings or for research, however the brevity of the QR-SCB allows for more rapid assessment and is a more attractive option for clinical settings. It has been previously adapted for use in English-speaking patients.[78,84]

For our investigation into screening and diagnostic methods, we examined observational studies that either prospectively or retrospectively screened patients for CBS. Observational studies that recruited based on patient reported or documented CBS were not used for this portion. Several trends were discovered while reviewing the identified observational studies. The final results were tabulated and added to Table 4. Chief among these includes the considerable heterogeneity in overall screening approach and an underutilization of validated CBS screening tools.

Screening approaches varied among studies with the most popular being structured, non-validated interviews alone (49% of studies 30/61). Customized questionnaires alone were used in 28% of studies (17/61). A combination of customized questionnaires and interviews were used in 5% of studies (3/61). While the majority of studies relied on self-reporting of visual hallucinations or medical history (52%, 32/61), 34% (21/61) used additional tools such as the Mini-

Table 3 Diagnostic Features, Strengths, and Limitations of Validated Charles Bonnet Syndrome Screening Instruments

Tool Name	Developers	Year	Format	Domains	Validation	Reliability	Strengths	Limitations
NEVHI (North-East Visual Hallucinations Interview)[32]	Mosimann et al	2008	Semi-structured interview (requires trained interviewer)	Hallucination presence, type, timing, emotion, cognition	Mosimann et al, 2008	No sensitivity/specificity reported; κ = 0.72–0.83; α = 0.71; strong face and criterion validity; <6% off-topic responses	In-depth assessment; includes emotional/cognitive features; validated in older adults with vision/cognitive impairment	Requires trained staff; time-intensive with 3 sections and open-ended responses
QR-SCB (Questionnaire de Repérage du Syndrome de Charles Bonnet)[65]	Cantin et al	2019	Self- or verbally administered questionnaire	Hallucination features, psychological impact, etiology, coping, context, timing, support	Cantin et al, 2019	Sensitivity 100%, specificity 77%; validated by clinician judgment	High sensitivity; simple administration; algorithmic scoring	Initially French-only; less detailed than interviews

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Table 4 Summary of Studies Assessing Charles Bonnet Syndrome: Diagnostic Criteria, Screening Tools, and Hallucinatory Domains

Study Name	Year	Authors	CBS Screening Tools	Diagnostic Criteria	Domains Assessed	Psychiatric/ Neurologic Diagnoses Exclusion
Visual Hallucinations and Sensory Delusions in the Elderly[9]	1984	G. E. Berrios, P. Brook	Questionnaire	No formal diagnostic criteria used.	1. Content of visual hallucinations. 2. Insight about visual hallucinations. 3. Color of visual hallucinations. 4. Emotional responses to hallucinations. 5. Presence of non-visual hallucinations.	No clear explanation
Visual hallucinations in ophthalmology[10]	1987	H. M. Olbrich, M. P. Engelmeier, D. Pauleikhoff, T. Waubke	Semi-structured interview	Presence of visual hallucinations that could not be described as photopsias with neurologic and psychiatric conditions ruled out.	1. Localization of hallucinations 2. Patterns seen by patient 3. Content of images 4. Frequency of hallucinations 5. Duration of hallucinations 6. Conditions under which hallucinations occur	Psychiatric and neurologic exam along with EEG analysis.
Visual Perceptual Disorders Resembling the Charles Bonnet Syndrome. A Study of 434 Consecutive Patients Referred to a Psychogeriatric Unit[11]	1987	L. Norton-Willson, M. Munir	Semi-structured interview	Presence of visual hallucinations without underlying psychiatric or neurological explanation.	1. Content of hallucinations 2. Color of hallucinations 3. Presence of insight 4. Emotional reaction to hallucinations	Mental status and neurologic exam. Psychological test was administered to rule out dementia
Visual Symptoms Associated With Choroidal Neovascularization Photopsias and the Charles Bonnet Syndrome[13]	1992	G. C. Brown, R. P. Murphy	Semi-structured Interview	Presence of formed visual hallucinations,	1. Presence of photopsias. 2. Subjective descriptions of photopsias. 3. Frequency of photopsias 4.Duration of the photopsias. 5. Laterality of the photopsias. 6. Color of the photopsias. 7. Light conditions that might've triggered the photopsias. 8. Presence of formed visual hallucinations. 9. Characterization of the visual hallucinations.	Excluded patients with a history of psychiatric, neurologic, or ophthalmologic disease that could potentially cause visual hallucinations such as retinal detachment, intracranial tumors, seizure disorders, schizophrenia, and migraines. Thorough ophthalmologic examination with scleral depression was done to rule out any ocular causes. No standardized tools or psychiatric interviews were used.

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Table 4 (Continued).

Study Name	Year	Authors	CBS Screening Tools	Diagnostic Criteria	Domains Assessed	Psychiatric/ Neurologic Diagnoses Exclusion
Visual Hallucinations in Patients With Macular Degeneration[12]	1992	S. Holroyd, P. V. Rabins, D. Finkelstein, M. C. Nicholson, G. A. Chase, S. C. Wisniewski	None	Presence of visual hallucinations	Presence of visual hallucinations	Through structured tools, namely Beck's depression inventory, Telephone Interview for Cognitive Status, and patient history.
Visual Hallucinations and Mental State[14]	1993	G. Schultz, R. Melzack	Semi-structured interview	Presence of visual experiences, including seeing objects or things that appeared "like a mirage."	Content of hallucinations.	Through patient interview and review of patient history
Clinical Evaluation of 14 Patients With the Charles Bonnet Syndrome (Isolated Visual Hallucinations)[15]	1994	R. J. Teunisse, F. G. Zitman, D. C. M. Raes	Semi-structured questionnaire	1. Presence of formed visual hallucinations 2. Full or partial retention of insight 3. Absence of primary or secondary delusions 4. Absence of hallucinations in other modalities	1. Content of hallucinations 2. Duration of hallucinations	Patients were administered the Geriatric Mental State Schedule and a structured questionnaire to delineate of patient met DSM-III criteria. A separate MMSE, psychiatric assessment, and medical record review was also conducted on patients with visual hallucinations to ensure there were no confounding diagnoses.
The Charles Bonnet Syndrome: A Large Prospective Study in The Netherlands[16]	1995	R. Teunisse, J. R. M. Cruysberg, A. Verbeek, and F. G. Zitman	Semi-structured interview	1. Presence of formed and complex, persistent or repetitive visual hallucinations 2. Full or partial retention of insight 3. Absence of delusions 4. Absence of hallucinations in other modalities	1. Presence and type of complex visual hallucinations 2. Hallucination characteristics, including persistence/repetitiveness, insight, and emotional impact	Structured psychiatric evaluation, including standardized diagnostic tools like the GMSS and MMSE as well as an assessment against DSM-III-R criteria for hallucinations and the author's own criteria for CBS, to exclude psychiatric and neurologic conditions.
Social and Psychological Characteristics of Elderly Visually Handicapped Patients With the Charles Bonnet Syndrome[18]	1999	R. J. Teunisse, J. R. Cruysberg, W. H. Hoefnagels, Y. Kuin, A. L. Verbeek, F. G. Zitman	Semi-structured interview	1. Presence of formed and complex, persistent or repetitive visual hallucinations 2. Full or partial retention of insight 3. Absence of delusions 4. Absence of hallucinations in other modalities	1. Presence of complex visual hallucinations 2. Ability to cope with visual hallucinations 3. Impact of visual hallucinations on daily life 4. Psychological impact of visual hallucinations	Diagnostic criteria for CBS required the absence of delusions and hallucinations in other sensory modalities.A psychiatrist used the Dutch-language version of the Geriatric Mental State Schedule to assess whether the CBS diagnostic criteria were met.The study only included "psychologically normal" participants with CBS, and the control group did not have any visual hallucinations.

Visual Hallucinations in Patients With Retinal Disease[20]	2001	I. U. Scott, O. D. Schein, W. J. Feuer, M. F. Folstein	Semi-structured interview	No formal diagnostic criteria used.	1. Form of visual hallucinations 2. Content of visual hallucinations 3. Color of visual hallucinations 4. Definition of visual hallucination edges 5. Location of hallucinations 6. Insight 7. Intensity of hallucinations 8. Frequency of hallucinations 9. Frequency of hallucinations 10. Length of time the patient had hallucinations 11. Duration of hallucinations 12. Condition of patient when hallucinations occured 13. Time of day when hallucinations occur	Not mentioned in the paper.
Charles Bonnet Syndrome in Glaucoma Patients With Low Vision[21]	2001	R. Nesher, G. Nesher, E. Epstein, E. Assia	Semi-structured interview	1. Visual hallucinations were formed, well-defined visual experiences that could not be explained by other visual phenomena. 2. Patient had insight into the unreal nature of the hallucinations. 3. Patients typically did not disclose the hallucinations previously, which suggests they were not distressing or concerning.	1. Size of hallucination 2. Color clarity of hallucination 3. Motion 4. Hallucinatory Content 5. Hallucination frequency 6. Hallucination duration 7. Location in the visual field	Abbreviated version of Mini-Mental State Examination (MMSE) was used to assess the cognitive status of the participants and exclude those with impaired cognition. Collected information about participants' living situation and medication use to screen for potential causes of hallucinations. Clinical evaluation to determine if patient had any neurological conditions that could lead to hallucinations.
Prevalence of photopsias and Charles Bonnet syndrome: evaluation of eighty cases with low vision[22]	2001	S. Tatlıpınar, S. Kadayıfçılar, B. Eldem, P. Türkçüog˘lu	Semi-structured interview	No formal diagnostic criteria were listed in the study	1. Whether the patient had experienced hallucinations in other senses 2. The timing of the visual hallucinations (day vs night) 3. The characteristics of the hallucinations, such as their shape and color	Through clinical judgement and unstructured interviews rather than the use of standardized diagnostic tools.

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Table 4 (Continued).

Study Name	Year	Authors	CBS Screening Tools	Diagnostic Criteria	Domains Assessed	Psychiatric/ Neurologic Diagnoses Exclusion
Visual hallucinations and Charles Bonnet Syndrome after photodynamic therapy for age related macular degeneration[24]	2003	S. Y. Cohen, A. Bulik, R. Tadayoni, G. Quentel	Semi-structured interview	Presence of structured visual hallucinations	1. Description of visual hallucinations 2. Dominant color of hallucinations 3. Time elapsed from photocoagulation to symptom occurrence	Not mentioned
Charles Bonnet syndrome in Asian patients in a tertiary ophthalmic centre[25]	2004	C. S. H. Tan, V. S. Y. Lim, D. Y. M. Ho, E. Yeo, B. Y. Ng, K. G. Au Eong	Questionnaire	1. Presence of complex, formed visual hallucinations 2. Normal insight and mental state examination 3. Absence of delusions or hallucinations in other sensory modalities 4. Exclusion of patients with dementia, psychiatric illness, epilepsy, organic brain lesions, or drug/alcohol dependence	1. Characteristics of the visual hallucinations. 2. Frequency and duration of the hallucinations. 3. Emotional impact and reaction to the hallucinations. 4. Insight and cognitive status.	Patient history and standardized cognitive assessment (MMSE) to screen for and exclude patients with psychiatric or neurological conditions. Conditions screened for include dementia, psychiatric illness, epilepsy, organic brain lesions, and substance abuse. Patients with a history of auditory hallucinations in addition to visual hallucinations were also excluded.
The rarity of Charles Bonnet syndrome[26]	2004	Y. Shiraishi, T. Terao, K. Ibi, J. Nakamura, A. Tawara	Questionnaire, semi-structured interview	1. At least one complex visual hallucination within the past 4 weeks 2. A period between the first and last hallucination exceeding 4 weeks 3. Full or partial retention of insight into the unreal nature of the hallucinations 4. Absence of hallucinations in other sensory modalities 5. Absence of delusionsStates they are using Teunisse et al 1996 criteria	1. Hallucination frequency 2. Time of day of occurrence 3. Duration 4. Laterality of affected eye 5. Influence of eyelids 6. Emotional impact on the patient 7. Content of the hallucinations 8. Insight into the unreal nature of the hallucinations.	Mini International Neuropsychiatric Interview (MINI), was used to screen for and exclude psychiatric disorders that could cause visual hallucinations.
Visual Hallucinations in Patients with Age-Related Macular Degeneration (AMD)[29]	2006	S. P. Lannon, M. R. Stevenson, S. T. White, J. F. Logan, A. H. Reinhardt-Rutland, A. J. Jackson	Questionnaire	1. At least one complex visual hallucination within the past four weeks 2. Period between the first and last hallucination not exceeding four weeks 3. Full or partial retention of insight into the unreal nature of the hallucinations 4. Absence of hallucinations in other sensory modalities 5. Absence of delusions	1. Simple or complex hallucinations. 2. Frequency of hallucinations. 3. Insight into the unreal nature of hallucinations. 4. Emotional impact.	Not mentioned

Visual Loss and Visual Hallucinations in Patients with Age-Related Macular Degeneration (Charles Bonnet Syndrome)[30]	2007	J. Abbott, G. B. Connor, P. H. Artes, R. V. Abadi	Institute of Psychiatry Visual Hallucination Interview	Presence of visual hallucinations were required for inclusion into either the "apparent CBS" and "manifest CBS" group.	1. Whether the hallucinations were exclusively visual, distinguished from other visual phenomena, and coexisted with real perception 2. The level of insight the patient had into the authenticity of the hallucinations, which varied over time 3. The complexity of the hallucinations, categorized as either simple (colored shapes/patterns) or complex (recognizable forms)	A four-point primary inclusion criterion to ensure patients had no cognitive impairment that could contribute to VHs. A secondary two-point criterion to exclude patients with concurrent medications or diagnosed conditions associated with hallucinations or psychosis. Cognitive assessments using the blind and TICS to confirm intact cognition.
Six Cases of Charles Bonnet Syndrome Presenting in Neuro-Ophthalmology Clinic[31]	2007	A. Koh, Y. Nakai, M. Shiokawa, R. Higa, K. Shidara, R. Moriyama, M. Wakakura	None	Presence of visual hallucinations during period of visual impairment.	1. Duration of symptoms 2. Details of visual hallucinations	Not mentioned
Charles Bonnet Syndrome in Age-Related Macular Degeneration: The Nature and Frequency of Images in Subjects with End-Stage Disease[33]	2008	J. C. Khan, H. Shahid, D. A. Thurlby, J. R. W. Yates, A. T. Moore, S. S. Bhattacharya, A. C. Bird, P. Bishop, P. Black, Z. Butt, D. Clayton, N. E. Day, C. E., A. Fitt, D. W. Flanagan, A. Glenn, S. Harding, C. Jakeman, C. Jones, R. Lamb, A. Lottery, V. Moffat, C. Moorman, A. Nicholas, R. J. Pushpanathan, E. Redmond, T. Rimmer	Semi-structured interview	1. Formed and complex visual hallucinations 2. Persistent or repetitive hallucinations 3. Partial or full retention of insight into the unreality of the hallucinations 4. Absence of delusions 5. Absence of hallucinations in other sensory modalities 6. Recurrent hallucinations (not just isolated events) 7. The hallucinations also had to be more complex than simple light phenomena like flashes or pinpricks of light.	1. Formed/complex hallucinations 2. Retention of insight 3. Absence of delusions/ hallucinations in other modalities	Not mentioned
Vision Rehabilitation and Charles Bonnet Syndrome[34]	2008	K. E. Crumbliss, M. J. Taussig, W. M. Jay	Questionnaire	1. Presence of formed and complex visual hallucinations. 2. Retention of insight. 3. Absence of delusions or hallucinations in other modalities.	1. Presence of visual hallucinations 2. Type of hallucinations. 3. Frequency of hallucinations. 4. Onset of visual hallucinations.	MMSE was used to screen for cognitive impairment. MMSE score between groups was compared to ensure they were not significantly different.

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Table 4 (Continued).

Study Name	Year	Authors	CBS Screening Tools	Diagnostic Criteria	Domains Assessed	Psychiatric/ Neurologic Diagnoses Exclusion
Butterflies and black lacy patterns: the prevalence and characteristics of Charles Bonnet hallucinations in an Australian population[35]	2008	M. Vukicevic, K. Fitzmaurice	Questionnaire	1. Vivid, elaborate, and recurrent visual hallucinations 2. Psychologically normal people with clear consciousness and preserved intellectual functioning 3. Insight into the unreal nature of the hallucinations, except in cases where the hallucinations are initially confusing or contain ordinary objects that fit realistically into the surroundings.	1. Characteristics of the visual hallucinations (type, frequency, duration) 2. Emotional impact (stress levels related to the hallucinations) 3. Insight	Unstructured interviews. Excluded if patient had a diagnosed psychiatric disorder, were taking medications that could cause hallucinations, or had hallucinations in other modalities.
Perceived Color of Hallucinations in the Charles Bonnet Syndrome Is Related to Residual Color Contrast Sensitivity[37]	2009	S. A. Madill, G. Lascaratos, G. B. Arden, D. H. Ffytche, A. Princess	Institute of Psychiatry Visual Hallucinations Interview	1. Presence of visual hallucinations 2. Absence of cognitive decline, psychosis, substance abuse, or epilepsy 3. No history of cerebrovascular disease 4. Hallucinations not limited to sleep onset or waking	1. Hallucinatory phenomenology (characteristics of the hallucinations) 2. Descriptive style (how the patient describes the hallucinations)	Excluded patients with evidence of psychiatric or neurological conditions based on clinical judgement and unstructured interviews.
An examination of the relationship between low vision and Charles Bonnet syndrome[40]	2009	G. Gilmour, C. Schreiber, C. Ewing	Questionnaire	1. Presence of formed or unformed visual hallucinations 2. Absence of primary or secondary delusions 3. Retention of insight that the hallucinations are unreal 4. Absence of hallucinations in other sensory modalities	1. Type of hallucination (formed, unformed, or combined) 2. Characteristics of the hallucinations (color, objects seen, etc.) 3. Frequency and duration of hallucinations 4. Insight into the hallucinations. 5. Emotional impact of the hallucinations 6. Association with vision loss severity. 7. Presence of cognitive impairment.	Patient history was elicited by the researchers and patients were excluded based on exclusion criteria. Specifically, patients could not have a psychiatric condition that accounted for the hallucinations. MMSE was used to screen out participants with cognitive impairment. Patients with a score below 22 were excluded.

The prevalence and clinical characteristics of Charles Bonnet Syndrome in Danish patients with neovascular age related macular degeneration[42]	2012	A. Singh, T. L. Sørensen	Semi-structured interview	1. Complex and recurrent visual hallucinations (not just simple hallucinations like floaters) 2. No history of psychiatric or neurological disease, substance abuse, or medications known to cause hallucinations	1. Characteristics of the hallucinations (type, duration, frequency) 2. Presence of auditory hallucinations 3. Emotional impact and insight into the hallucinations	They explicitly excluded patients with a history of psychiatric or neurological diseases, such as schizophrenia, dementia, Parkinson's disease, or substance abuse. They also excluded patients taking medications known to cause visual hallucinations. They used the Mini-Mental State Examination (MMSE) to crudely estimate the cognitive status of the patients. They only included patients who reported complex, formed visual hallucinations characteristic of CBS, and excluded those who only reported elementary hallucinations like floaters or flashes of light.
The prevalence and clinical characteristics of Charles Bonnet syndrome in Chinese patients[43]	2012	Y. Hou, Y. Zhang	Questionnaire	1. Presence of complex, formed visual hallucinations 2. Normal insight and mental state examination 3. Absence of delusions or hallucinations in other sensory modalities 4. Exclusion of patients with psychiatric/neurological diseases, substance abuse, or medications known to cause visual hallucinations	1. Frequency of hallucinations 2. Timing of hallucinations (time of day) 3. Duration of hallucinations 4. Content of hallucinations 5. Insight into the unreal nature of the hallucinations 6. Emotional reaction to the hallucinations 7. Whether the hallucinations had been discussed with others and their reactions	Researchers elicited patient history to determine if patients had a psychiatric or neurological disorder, or taking medications known to cause hallucinations through unstructured interviews and clinical judgement.
Negative outcome Charles Bonnet Syndrome[46]	2014	T. M. Cox, D. H. Ffytche	Questionnaire	1. Experiencing visual hallucinations of certain types (patterns, faces, objects, figures, animals) 2. Having been diagnosed with CBS or judging themselves to have CBS 3. Experiencing hallucinations of varying duration and frequency	1. Phenomenology of the hallucinations (eg duration, frequency) 2. Duration and prognosis of CBS 3. Impact on daily living and wellbeing 4. Emotional response to the hallucinations 5. Reporting of symptoms	Not mentioned.
Low awareness of the Charles Bonnet syndrome in patients attending a retinal clinic[44]	2014	A. Singh, Y. Subhi, T. L. Sørensen	Semi-structured interview	Presence of complex visual hallucinations (not photopsias or shadows) with intact insight.	1. Presence of visual hallucinations 2. Simple vs Complex hallucinations	Review of patient history

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Table 4 (Continued).

Study Name	Year	Authors	CBS Screening Tools	Diagnostic Criteria	Domains Assessed	Psychiatric/ Neurologic Diagnoses Exclusion
Prevalence and clinical characteristics of Charles Bonnet syndrome in Madrid, Spain[45]	2014	E. Santos-Bueso, F. Sáenz-Francés, M. Serrador-García, J. Porta-Etessam, J. M. Martínez-De-La-Casa, J. García-Feijoo, J. García-Sánchez	Semi-structured interview	Presence of visual hallucinations with no other diagnosis that could explain the visual hallucinations.	1. Complex (objects or faces) vs Simple (geometric shapes) hallucinations 2. Evolution period 3. Frequency of hallucinations 4. Duration of hallucinations	Formal assessment by neurologist and psychiatrist
Charles Bonnet syndrome: characteristics of its visual hallucinations and differential diagnosis[94]	2014	T. C. Vale, L. C. Fernandes, P. Caramelli	Semi-structured interview	Significant visual impairment with visual hallucinations and insight about the visual hallucinations.	1. Duration 2. Localization 3. Risk factors 4. Position of eyes when hallucinations occur 5. Benignity 6. Time of day 7. Associated features (eg neurologic symptoms)	Full neurologic examination was conducted by a neurologist including brief cognitive assessment with MMSE and category fluency-animals, functional evaluation, with Pfeffer's functional activities questionnaire, a standardized neuropsychiatric inventory assessment, and part III Unified Parkinson's Disease Rating Scale. MRI of the brain was also done on all patients
Charles Bonnet Syndrome in Advanced Retinitis Pigmentosa[48]	2015	F. O'Hare, S. A. Bentley, Z. Wu, R. H. Guymer, C. D. Luu, L. N. Ayton	Semi-structured interview	Presence of visual hallucinations and a positive affirmation to the question: "Somepeople with certain types of vision loss have difficulty seeing certainthings and may even see things that are not really there. They maysee things such as colorful patterns, animals, buildings, people orplants, and trees. Have you ever seen anything similar to this?"	1. Presence of visual hallucinations 2. Type of visual hallucinations (simple vs complex) 3. Onset of hallucinations 4. Frequency of hallucinations 5. Duration of hallucinations 6. Triggers for hallucinations 7. Suppressors of hallucinations 8. Emotional stress associated with hallucinations 9. Number of people the participant had talked about the hallucinations	Clinical history was elicited through unstructured interview to determine if patients had psychiatric or neurological conditions or were taking medications known to cause hallucinations. No standard diagnostic tool was used, however the CBS questionnaire characterized the visual hallucinations and screened for potential confounding diagnoses.

Charles Bonnet syndrome in older adults with age-related macular degeneration: Its relationship to depression and mild cognitive impairment[49]	2015	H. Boxerman, W. Wittich, O. Overbury	Semi-structured interview	No formal diagnostic criteria were used, however patients had to have visual hallucinations without sensory hallucinations, insight about the hallucinations, and not potentially contributing psychiatric or neurological conditions.	1. Whether the participant had experienced any unusual visual experiences or hallucinations 2. The type of hallucinations, including the specific images seen. 3. Whether the hallucinations were static or dynamic 4. The emotional impact of the hallucinations on the participant. 5. Whether the participant had disclosed the hallucinations to others.	Patient history was elicited through unstructured interviews. Study excluded participants with a diagnosis of Alzheimer's disease, clinical depression, or other psychiatric illnesses, as well as those taking certain medications which may cause hallucinations.
The Prevalence and Characteristics of Charles Bonnet Syndrome in Turkish Patients with Retinal Disease[51]	2016	S. Nalcaci, O. Ilim, Z. Oztas, C. Akkin, A. Acarer, F. Afrashi, J. Mentes	Questionnaire	1. Exclusion of patients with hallucinations like floaters or light flashes, neurological/psychiatric disorders, drug use, or severe metabolic problems 2. Cognitive assessment using the MMSE for the blind, with exclusion of patients scoring less than 183. Classification of hallucinations as either noncomplex (simple shapes) or complex (well-formed images)	1. Duration and frequency of hallucinations 2. Emotional impact/distress caused by hallucinations 3. Patients' insight into the unreality of the hallucinations 4. Whether patients had disclosed the hallucinations to others 5. Whether patients had sought medical support for the hallucinations 6. Whether patients lived alone	Excluded patients with known neurological or psychiatric diseases, as well as those using antipsychotic or potentially hallucinogenic drugs. Neurological examination was conducted by a neurologist and the used of the MSSE was used to screen for cognitive impairment. Patients with a score below 18 were excluded.
Prevalence of visual hallucinations in a national low vision client population[52]	2016	K. D. Gordon	Screening question	No formal diagnostic criteria	Whether participants had experienced visual hallucinations, with examples provided of different types (patterns/ shapes, images of people/ animals)	Not mentioned.

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Table 4 (Continued).

Study Name	Year	Authors	CBS Screening Tools	Diagnostic Criteria	Domains Assessed	Psychiatric/ Neurologic Diagnoses Exclusion
Charles Bonnet's syndrome: not only a condition of the elderly[53]	2016	H. M. Elflein, M. Rudy, K. Lorenz, K. A. Ponto, A. Scheurich, S. Pitz	Semi-structured interview	1. Presence of complex visual hallucinations 2. Ruling out of psychiatric causes or medication-related causes for the hallucinations 3. Conducting a detailed interview to gather more information about the characteristics of the hallucinations	1. Presence of visual hallucinations: whether the subject had ever experienced seeing objects, persons, animals, or something else not reflecting reality 2. Detailed characteristics of the visual hallucinations: for those who reported experiencing them, the interviews obtained descriptions and details about the hallucinations	Researchers used a combination of standardized diagnostic tools such as the DemTect test, MMSE-Blind, and DIA-X interview to screen for and exclude any patients with dementia, psychiatric illnesses, or other conditions that could account for visual hallucinations.
The Charles Bonnet Syndrome in Patients With Neovascular Age-Related Macular Degeneration: Association With Proton Pump Inhibitors[54]	2017	J. E. Leandro; J. Beato; A. C. Pedrosa; J. Pinheiro-Costa; M. Alberto Falcão; F. Falcão-Reis; Â. M. Carneiro	Questionnaire	1. Patients fully understood the question and were not reluctant to answer 2. The hallucinations were not entoptic phenomena like photopsias or floaters 3. The hallucinations were well-organized, defined, and clear 4. The hallucinations were exclusively visual and recurrent, not just isolated events 5. Patients retained full insight into the unreality of the hallucinations 6. Patients had no history of dementia or major psychiatric disorders 7. Patients had no history of drug or alcohol abuse	1. Whether the patient fully understood the question and was not reluctant to answer 2. Whether the hallucinations were not entoptic phenomena 3. The contents and characteristics of the hallucinations 4. Whether the patient had insight into the unreality of the hallucinations	Not mentioned.
Cognitive impairment and Charles Bonnet syndrome: a prospective study[56]	2018	G. Russell, R. Harper, H. Allen, R. Baldwin, A. Burns	4 item screening section of the NEVHI and semi-structured interview	1. Formed, complex, persistent visual hallucinations 2. Occurring with insight (or partial insight) 3. No delusions or hallucinations in other modalities	Insight into the hallucinations, assessed using the "awareness" items from the North East Visual Hallucination Interview (NEVHI)	Full history, mental status exam, and neurological exam. Standardized cognitive assessment with ACE-R. Standardized psychiatric assessment with BPRS

Visual acuity and contrast sensitivity are two important factors affecting vision-related quality of life in advanced age-related macular degeneration[57]	2018	M. Roh, A. Selivanova, H. J. Shin, J. W. Miller, M. L. Jackson	Semi-structured interview	Presence of visual hallucinations consistent with Charles Bonnet syndrome	Presence of visual hallucinations consistent with Charles Bonnet syndrome	Not mentioned
Looking at Charles Bonnet Syndrome: Prevalence and Experiences of Patients Attending a Vision Rehabilitation Clinic[58]	2018	L. M. Ord, A. Henderson, R. M. Christiansen	Semi-structured interview	Presence of simple or complex visual hallucinations manifested after a marked loss of visual acuity in the absence of cognitive impairment.	1. Patient description of experience 2. Duration of images 3. Frequency of images 4. Emotional response to images	Patients with a history of cognitive impairment or psychiatric disease were excluded. Patients on certain medications known to cause visual hallucinations were also excluded.
Screening for Charles Bonnet syndrome: Should the definition be reconsidered?[62]	2019	P. Satgunam, R. Sumalini, G. Chittapu, G. Pamarthi, B. Holden	Questionnaire	1. Presence of visual hallucinations 2. Intact cognition (no dementia or other cognitive impairment) 3. Lack of other sensory inputs (eg no auditory or olfactory hallucinations) 4. Awareness that the hallucinations are not real	1. Whether the participant has experienced seeing imaginary Figures 2. Description of the hallucinations, including whether they involved people, animals, or other objects 3. Insight about the hallucinations, ie whether the participant was aware that the hallucinations were not real 4. Duration and frequency of the hallucinations	Rowland Universal Dementia Assessment Scale (RUDAS) was used to screen for and exclude patients with cognitive impairment or dementia. Patients included in the CBS survey if they had a score of 23 or higher.

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Table 4 (Continued).

Study Name	Year	Authors	CBS Screening Tools	Diagnostic Criteria	Domains Assessed	Psychiatric/ Neurologic Diagnoses Exclusion
Clinical Characteristics of The Charles Bonnet Syndrome In Patients with Neovascular-Age Related Macular Degeneration: The Importance of Early Detection[71]	2020	J. E. Leandro, J. Beato, A. C. Pedrosa, J. Pinheiro-Costa, M. Falcão, F. Falcão-Reis, Â. M. Carneiro	Questionnaire	1. Patients fully understood the question and were not reluctant to answering 2. The hallucinations were not entoptic phenomena like photopsias or floaters 3. The contents of the hallucinations were well organized, defined and clear 4. The hallucinations were exclusively visual and recurrent, not just isolated events 5. Patients had full insight that the hallucinations were not real 6. Patients had no history of dementia or major psychiatric disorders like schizophrenia or psychotic depression 7. Patients had no history of drug or alcohol abuse	1. Phenomenology of the hallucinations (eg type, color, motion, location) 2. Duration and frequency of the hallucinations 3. Impact on daily activities and well-being 4. Patients' knowledge and reporting of the symptoms	Researchers elicited patient history to determine if patient had neurologic or psychiatric conditions that could potentially explain the visual hallucinations.
Charles Bonnet Syndrome Prevalence in a Younger Ophthalmology Outpatient Population[73]	2021	A. Karagöl	Questionnaire	1. Presence of visual hallucinations with insight (ie the patient recognizes the hallucinations as not real) 2. No known psychiatric or neurological disorders 3. Diagnosed with an eye disease (eg myopia, astigmatism)	1. Temporal characteristics (duration, frequency) 2. Emotional impact (comfortable, uncomfortable, neutral) 3. Localization (in front, in periphery, in blind areas) 4. Physical characteristics (clarity, completeness, colors, patterns, etc). 5. Triggers (eyes closed, blinking, head movement)	Researchers excluded participants with psychiatric or neurological diagnoses through a structured psychiatric interview conducted by a psychiatrist. They also excluded participants with a history psychiatric disorder, use of psychiatric medications, and the presence of hallucinations in other modalities or cognitive impairment.
Charles Bonnet syndrome in patients with Stargardt disease: prevalence and risk factors[75]	2021	P. A. Dhooge, R. J. Teunisse, B. Liefers, S. Lambertus, N. M. Bax, C. B. Hoyng, J. R. M. Cruysberg, B. J. Klevering, O. Ids	Semi-structured interview	1. At least one complex visual hallucination within the past 4 weeks 2. A period between the first and last hallucination exceeding 4 weeks 3. Full or partial retention of insight into the unreal nature of the hallucinations 4. Absence of hallucinations in other sensory modalities 5. Absence of delusions	1. Presence of complex visual hallucinations within the past 4 weeks 2. Duration of hallucinations (period between first and last exceeding 4 weeks) 3. Insight into the unreal nature of the hallucinations (full or partial) 4. Absence of hallucinations in other sensory modalities 5. Absence of delusions	Excluded patients who used hallucinogenic drugs or had psychiatric symptoms. Diagnosis of CBS was made by a psychiatric familiar with the syndrome based on a structured interview and the presence of certain criteria.

Benefit of psychiatric evaluation on anxiety in patients with Charles Bonnet syndrome[76]	2021	B. Doeller, M. Kratochwil, L. Sifari, N. Hirnschall, O. Findl	North East Visual Hallucination Interview (NEVHI)	1. No mental pathologies, normal cognition, and inability to control the visual hallucinations 2. Recognition that the visual hallucinations are not real 3. Significantly reduced visual acuity due to bilateral ocular pathology 4. Exclusion of patients with certain medical conditions that could cause visual hallucinations 5. Visual hallucinations that are complex, repetitive, and disappear when the eyes are closed	1. Description and drawings of the visual hallucinations (VHs) 2. Characteristics of the visual hallucinations, such as whether they disappear when the eyes are closed, are repetitive, and their complexity (eg objects, patterns, faces, animals)	Standardized diagnostic tools including the TICS-m, NEVHI, and SWLS, as well as clinical criteria related to the nature of the visual hallucinations, to screen for and exclude patients with psychiatric or neurological conditions. Specifically, they excluded patients with dementia, psychosis, neurological diseases, temporal lobe epilepsy, moderate to severe Alzheimer's disease, chronic alcohol or drug use, and poor cognitive function.
Charles Bonnet Syndrome in Patients with Open-Angle Glaucoma Prevalence and Correlation to Visual Field Loss[77]	2022	D. Peters, M. Stellan, L. Trine, S. Amardeep	Semi-structured interview	1. Presence of complex visual hallucinations 2. Patient awareness that the hallucinations are unreal 3. Absence of other conditions known to cause hallucinations, such as dementia or other neurological conditions	1. Nature and frequency of the hallucinations 2. Emotional impact/ disturbance of the hallucinations 3. Whether the patient had shared their experiences with others 4. Insight - whether the patient was aware the hallucinations were not real	Excluding patients with a record of dementia or other neurological conditions that could lead to hallucinations. Conducting interviews with patients to ask about known neurological diagnoses, head trauma, and current medical treatment. Defining CBS based on the presence of complex visual hallucinations and excluding patients with only simple visual experiences like floaters or photopsias.
The Incidence and Characteristics of Charles Bonnet Syndrome in a Large Cohort of Leber's Hereditary Optic Neuropathy (LHON) Patients[78]	2022	H. Nguyen, M. Kreimei, E. Mollanji, L. Poincenot, R. Karanjia	QR-SCB tailored for LHON	1. Presence of complex visual hallucinations 2. Patient awareness that the hallucinations are unreal 3. Absence of other conditions known to cause hallucinations, such as dementia or other neurological conditions	1. Nature and frequency of the hallucinations 2. Emotional impact/ disturbance of the hallucinations 3. Whether the patient had shared their experiences with others 4. Insight - whether the patient was aware the hallucinations were not real	Not mentioned

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Table 4 (Continued).

Study Name	Year	Authors	CBS Screening Tools	Diagnostic Criteria	Domains Assessed	Psychiatric/ Neurologic Diagnoses Exclusion
Investigation of structural brain changes in Charles Bonnet Syndrome[80]	2022	M. J. Firbank, K. D. Morgan, D. Collerton, G. J. Elder, J. Parikh, K. Olsen, J. Schumacher, D. Ffytche, J. P. Taylor	Adapted version of the North East Visual Hallucinations Interview (NEVHI), and an adapted version of the Neuropsychiatric Inventory (NPI) hallucinations subscale where participants directly related the severity (0–3) and frequency (0–4) of their visual hallucinations.	1. Presence of visual hallucinations, including both simple (eg flashes of light, geometric patterns) and complex (eg hallucinations of people, animals, scenes) hallucinations 2. Visual impairment due to eye disease or damage to visual pathways or cortex.	1. Specific types of visual hallucinations experienced 2. Frequency and duration of the hallucinations 3. Emotional impact and distress caused by the hallucinations 4. Severity and frequency of the hallucinations using standardized scales 5. Overall hallucination intensity calculated from severity and frequency	Excluded participants with history of major psychiatric or neurologic disease.
Shedding Light on Charles Bonnet Syndrome: An In-Depth Analysis in South Gujarat[81]	2023	S. S. Saiyad, H. R. Suthar, M. K. Bhabhor, A. R. Vara, H. R. Suthar	Semi-structured interview	1. Intact cognitive function with no other apparent cause for hallucinations 2. Presence of visual hallucinations, as assessed through detailed interviews examining characteristics such as frequency, timing, duration, eye involvement, emotional impact, content, and insight into the unreal nature of the hallucinations.	1. Frequency of hallucinations 2. Time of day when hallucinations occurred 3. Duration of hallucinations 4. Eye affected (left, right, or both) 5. Influence of eyelids on hallucinations 6. Emotional impact of hallucinations 7. Content of hallucinations 8. Insight into the unreal nature of the hallucinations	Not mentioned
Charles Bonnet syndrome in age-related macular degeneration prevalence and clinical features in a Portuguese population[82]	2023	M. Portela, P. Arede, M. Picoto, F. Vaz	Questionnaire	1. Complex, formed, and recurrent visual hallucinations 2. Preserved insight into the unreal nature of the hallucinations 3. Absence of hallucinations in other sensory modalities 4. Exclusion of simple hallucinations like floaters and flashing lights	1. Characteristics of the visual hallucinations (content, location, color, movement, duration, frequency, onset, time of day) 2. Emotional impact (anxiety, distress) 3. Whether the participant had discussed the hallucinations with anyone and with whom	Clinical judgement and exclusion based on the presence of certain symptoms including hallucinations in other sensory modalities besides vision, lack of insight, or simple hallucinations like floaters or flashes of light rather than complex visual hallucinations characteristic of CBS. Patients with a history of psychiatric or neurologic disease were excluded.

Prevalence of Charles Bonnet Syndrome (CBS) in patients with vitreoretinal and inherited retinal disease[84]	2024	M. Naik, Y. Bakr, A. Y. Ong, B. Ip, S. M. Downes, P. C. Issa, S. Aslam, J. K. Jolly	QR-SCB	Not mentioned in paper	1. Characteristics of hallucinations (type, vividness, perceived reality) 2. Coping strategies 3. Context of appearance of hallucinations (timing in relation to vision problems) 4. Psychological impact (emotional response to hallucinations)	Not mentioned.
Epidemiology and phenomenology of the Charles Bonnet syndrome in low-vision patients[86]	2024	S. E G Christoph, K. T. Boden, A. Pütz, K. Januschowski, R. Siegel, B. Seitz, P. Szurman, A. Schulz, K. Heimann	Questionnaire	1. Presence of visual hallucinations, regardless of complexity 2. Hallucinations not explained by other ocular or neurological conditions 3. Exclusion of cognitive impairment, psychiatric disorders, or substance use	1. Phenomenology and characteristics of the hallucinations 2. Insight into the unreality of the hallucinations 3. Content/type of hallucinations 4. Circumstances of hallucination occurrence (time of day, lighting conditions, location) 5. Ability to manipulate or resolve the hallucinations 6. Psychosocial impact and communication about the hallucinations	Careful medical history and interview to screen for and exclude psychiatric and neurologic conditions that could cause visual hallucinations, as well as the use of psychoactive substances.
Visual cortical activity in Charles Bonnet syndrome: testing the deafferentation hypothesis[90]	2025	K. D. Morgan, D. Collerton, M. J. Firbank, J. Schumacher, D. H. Ffytche, J. P. Taylor	Neuropsychiatric inventory hallucination subscale (NPI hall) and an adapted version of North-East Visual Hallucination Interview (NEVHI)	1. Presence of visual hallucinations, including both simple and complex hallucinations 2. Presence of eye disease sufficient to cause visual impairment 3. Absence of hallucinations in other modalities, delusions, impaired insight, or concurrent psychiatric or neurodegenerative illness	1. Frequency and severity of visual hallucinations (using the NPI hallucination subscale) 2. Phenomenology, frequency, duration, and emotional impact/distress of the visual hallucinations (using the NEVHI)	MMSE-Blind to screen for cognitive impairment and dementia. Excluded patients with a history of moderate-to-severe cerebrovascular disease or epilepsy.
Charles Bonnet syndrome in patients with geographic atrophy secondary to age-related macular degeneration: a cross-sectional study[91]	2025	N. S. Eriksen, N. Mousavi, Y. Subhi, T. L. Sørensen, M. K. Nielsen	Semi-structured interview	1. Experiencing complex visual hallucinations 2. Awareness that the hallucinations are unreal 3. Reporting the experience of visual hallucinations when directly asked	1. Time of day the hallucinations occurred 2. Frequency of the hallucinations 3. Duration of the hallucinations 4. Content of the hallucinations 5. Whether the hallucinations caused distress 6. Whether the patient had told anyone about the hallucinations	Not mentioned

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Mental State Examination (MMSE), Mini-Mental State Examination, Blind Version (MMSE-Blind), or other tools to rule out cognitive or psychiatric comorbidities that could explain the hallucinations. Approximately 10% (6/61) of studies employed formal specialist evaluations to aid in the diagnosis and rule out potential confounding diagnoses, through structured examination. Two of the studies (3%, 2/61) used unclear methods that were not touched upon in appreciable detail.

Validated screening tools were underutilized, which was a prominent trend identified. In total, validated CBS-specific screening tools were used in approximately 11% of studies (7/61). Excluding all studies prior to the introduction of validated CBS-specific screening tools mentioned, ie studies published after 2009, only 20% (7/35) of studies used validated instruments. Most studies relied on structured or semi-structured interviews that were created by study authors.

These findings suggest adoption of a systematic approach to CBS screening and diagnostics would be beneficial. The lack of universally accepted screening and diagnostic methods likely increases the risk of underdiagnosis of CBS patients. Additionally, the use of non-standardized methods in research has the risk of significantly impacting validity.

Barriers to Diagnosis: Systemic, Clinical, and Psychosocial Obstacles to Recognizing Charles Bonnet Syndrome

During our review, it was noted that CBS is underdiagnosed and underreported among many patients experiencing symptoms. This can be explained by a lack of awareness of CBS among healthcare providers and patients, patient reluctance to report symptoms, misdiagnosis or underreporting, contextual factors, insufficient screening tools, and misperceptions about the clinical significance of CBS. Multiple patient, provider, and system-level barriers contribute to this diagnostic gap.

Familiarity of CBS among healthcare professionals remains low, a contributing factor being lack of thorough education about the condition in medical training.[60] In a random sampling of Family Practice physicians across Canada, over 50% (N = 4856) were completely unaware of the condition.[60] This demonstrates a significant lack of awareness among physicians, thus leading to underdiagnosis of CBS.

There is a reluctance of patients to disclose symptoms of visual hallucinations due to fear of stigma or misinterpretation. A qualitative study of experiences of children living with CBS showed that there was significant disruption to their daily lives, with some hallucinations being described as “creepy creatures” which led to fear of being seen as mentally ill.[72] It was also noted in a study of CBS in patients with retinitis pigmentosa that many individuals reported symptoms only after being asked specifically about hallucinations; they did not self-report even though emotional distress was associated.[48] In a cross-sectional survey of 1077 patients from a tertiary ophthalmology clinic in Singapore, 4 met criteria for CBS, but only 1 of the 4 patients discussed symptoms with their doctor.[25] It has also been noted in a survey of one Portuguese population that many patients with CBS lived alone and did not disclose their hallucinations to anyone, leading to further emotional distress,[82] and indicates that the number of cases of CBS is likely underreported. There is concern over psychiatric labeling and stigma that occasionally prevents patients from seeking the necessary care and revealing their symptoms to physicians.

CBS symptoms are often misclassified, as there are a multitude of psychiatric and neurological conditions that present similarly. One prospective study also notes a possible higher risk of dementia in patients with CBS,[56] emphasizing that there may be clinical overlap with cognitive or psychiatric conditions that make it difficult to identify if CBS is occuring. A study among Asian patients at a tertiary ophthalmic center showed a CBS prevalence rate of 0.4%, with only one of the four CBS patients discussing their symptoms with the doctor and subsequently being incorrectly diagnosed with another condition.[25] Misdiagnosis is another contributing factor to a reduced quality of life in these individuals, as the condition being unrecognized continues to go unmanaged.

Another diagnostic barrier is the lack of adequate, regular screening for CBS in ophthalmic offices. As discussed in a study that found that one-third of patients with retinitis pigmentosa experienced hallucinations characteristic of CBS, many did not report their symptoms.[48] Not only are screenings not incorporated into the typical workup of low vision patients but many of the standard assessments historically performed failed to elicit hallucination history, highlighting the

need for structured tools to survey for CBS existence.[32] The high prevalence of CBS in individuals with low-vision indicates the need for routine screening with effective tools incorporated into the clinical workflow.

CBS is often viewed as a benign condition, which leads to diagnostic complacency. A diagnosis of CBS can have a significant social and emotional impact on a patient, and dismissing it as benign can prevent proper support and early management.[46] One survey of 4000 ophthalmic patients identified 492 individuals with CBS, and of those it was reported that CBS persists for 5 years or more in 75% of the sample, causing distress and reducing quality of life reported by 32% of the patients (N = 492).[46]

Individuals with or at risk for CBS undergo multiple barriers to a proper diagnosis, including variance in physician understanding, patient reluctance and fear of reporting due to stigma of symptoms, overlap of symptoms with other conditions, and lack of regularly used screening tools – all of which can lead to a decreased quality of life for patients. It is important to recognize these obstacles in order to understand the importance of identifying a standardized pathway for patients to be properly screened for CBS and promptly provide appropriate management and support.

Implementing a Stepwise Screening and Management Pathway for Charles Bonnet Syndrome

Based on the information gathered, we have devised a clinical pathway that can easily be adapted to ophthalmology clinics to screen for CBS in a practical and effective manner. The first portion of the screening pathway requires the identification of at risk groups. This pathway could potentially be universally applied to low vision clinics where the prevalence rate of CBS is expected to be as high as 18.8%,[52] and selectively applied in general ophthalmology clinics where the positive predictive value is likely to be lower given the lower number of cases.

Identifying High-Risk Patients in Ophthalmology Clinics

CBS predominantly affects individuals that have bilateral visual impairment but can also occur in those with unilateral field loss. Therefore, patients in clinics with unilateral field loss should be screened for CBS as there have been cases reported. In multiple studies, the male-to-female ratio has been very close to 1:1.[87] Given the roughly equal distribution between genders, gender alone should be a significant criteria for determining which patients to screen for CBS. Pathologies that increase the risk include patients with bilateral visual impairment due to AMD, glaucoma, DR, stroke, and congenital retinal disorders. AMD is the most frequent ocular pathology associated with CBS, with several studies reporting a prevalence of CBS in AMD patients ranging from 10% to 30%.[2,12,13,18,26] In low vision patients aged over 40, prevalence stands at around 19.7%, with increased risk in patients with visual acuity below 20/60.[68] Glaucoma patients, particularly those with open-angle glaucoma and visual field deficits have shown a prevalence ranging from 7.1% to 20.1%.[21,77] In general, CBS is more commonly associated with older adults, but there have been cohorts having an average age of 39.4 years.[95] Overall, populations most at risk include patients with bilateral visual field loss from AMD (wet and dry), glaucoma, DR, cortical lesions, and congenital retinal diseases. Therefore, patients with complete unilateral visual loss or underlying visual field loss with an ongoing pathology such as AMD have an increased risk of developing CBS and therefore should be considered for screening.

Once populations are identified, patients with these characteristics can be further assessed for CBS symptoms. Based on current evidence, the initial screening question for CBS can be effectively incorporated into clinical intake forms. One consideration to keep in mind is the reluctance of patients to report CBS diagnosis given the possibility of being labelled as mentally ill, therefore it is imperative to structure the question in such a way to encourage disclosure of visual hallucinations by ensuring the patient it is a normal phenomenon in patients with low vision. One specific screening question used commonly is the question posed by Holroyd et al.[12] This question is both sensitive and provides a patient-centered approach in screening for CBS: When people have trouble with their eyes, it frequently affects their vision. It may make it difficult to see things that are there, but sometimes people see things that are really not there or see things that other people do not see. Has this ever happened to you?

Including this question on intake paperwork can allow for an unobtrusive identification of patients who may be experiencing CBS symptoms without the associated label of a psychiatric or neurological diagnosis. Additionally, it is

important for ophthalmologists and other medical professionals to educate patients as a potential outcome of low vision given the potential lack of awareness among certain patient populations, ie glaucoma patients, regarding CBS.[69]

Patients that respond positively to this question can then undergo a more rigorous, structured assessment using one of the available CBS-specific screening tools. The two major validated tools that currently exist include the NEVHI and the QR-SCB which have been discussed previously. Given the ease of administration, we believe that the QR-SCB may be a more clinically useful option for routine ophthalmologic assessments, though the NEVHI may provide a more comprehensive assessment in cases where the symptoms or diagnosis are unclear due to the inclusion of open-ended questions that take into account patient descriptions of hallucinatory activity. This tool may provide more detailed information into the patient's visual hallucinations, which is time intensive, however may yield more valuable diagnostic information in certain cases. These should both be used in specific cases based on clinical judgement.

In addition to the QR-SCB, the use of a validated measure of cognition can also be employed. The most commonly used screening tool includes the MMSE or the MMSE-Blind. In patients with significant visual impairment, the MMSE-Blind may be a better assessment as low vision could potentially be a confounder with the standard MMSE.[96] If there is further uncertainty about the patient's cognition of psychiatric history, it may be appropriate to seek a referral from a psychiatrist or neuro-ophthalmologist to rule out any potentially confounding diagnoses through a full neuropsychiatric assessment. Additionally, special consideration should be paid to patients on certain medications, namely dopaminergic, anticholinergic, certain antibiotics, benzodiazepines or sedative-hypnotics, opioids, steroids, or recreational drugs, which can potentially lead to visual hallucinations and can complicate the diagnosis of CBS. Clinicians should use clinical judgement to ascertain whether the patient's stated symptoms are secondary to another cause or secondary to their visual loss, and expert opinion is warranted if there is further uncertainty.

Following the confirmation of CBS, education about the condition is essential for patients. Education should be centered around the benign nature of the syndrome and clinicians should emphasize that this is a well-recognized and common sequelae of visual impairment and not indicative of psychiatric disease. Additionally, it is important for clinicians to assess the degree of functional impairment in patients with CBS symptoms. If there is significant disturbance of daily activities, significant distress, or emotional consequences, patients should be referred for appropriate visual rehabilitation or psychological support.

We believe this structured, stepwise approach to CBS screening, beginning with a simple intake question, followed by the use of a validated screening tool, patient education, assessment of functional impairment, and the use of available visual support services, will significantly improve outcomes for patients, greatly reduce misdiagnosis, and help integrate CBS care seamlessly into routine ophthalmological clinical practice. A visual representation of this clinical pathway is depicted in Figure 2.

Discussion

Limitations

The aims of this study were to delineate the currently validated screening tools for CBS and to propose a standardized clinical guideline that can be integrated into practice with minimal disruption to efficiency. Our review identified several available screening tools; however, to our knowledge, no specific screening pathway incorporating validated tools has previously been suggested for CBS. This highlights an important gap in the literature. By outlining a pathway that leverages validated tools, our work directly addresses the diagnostic challenges of CBS. The heterogeneity in prevalence estimates and lack of standardized criteria have historically led to underrecognition and misdiagnosis, often as psychiatric disease. Our proposed framework eases diagnosis by providing a structured sequence: first identifying high-risk populations, then incorporating sensitive intake questions, and finally applying validated screening instruments when appropriate. This stepwise method allows ophthalmologists to differentiate CBS from psychiatric or neurologic conditions, facilitates earlier recognition, and enables timely patient education and referral for supportive care. In this way, our review contributes not only to greater consistency in research but also to practical improvements in day-to-day clinical diagnosis.

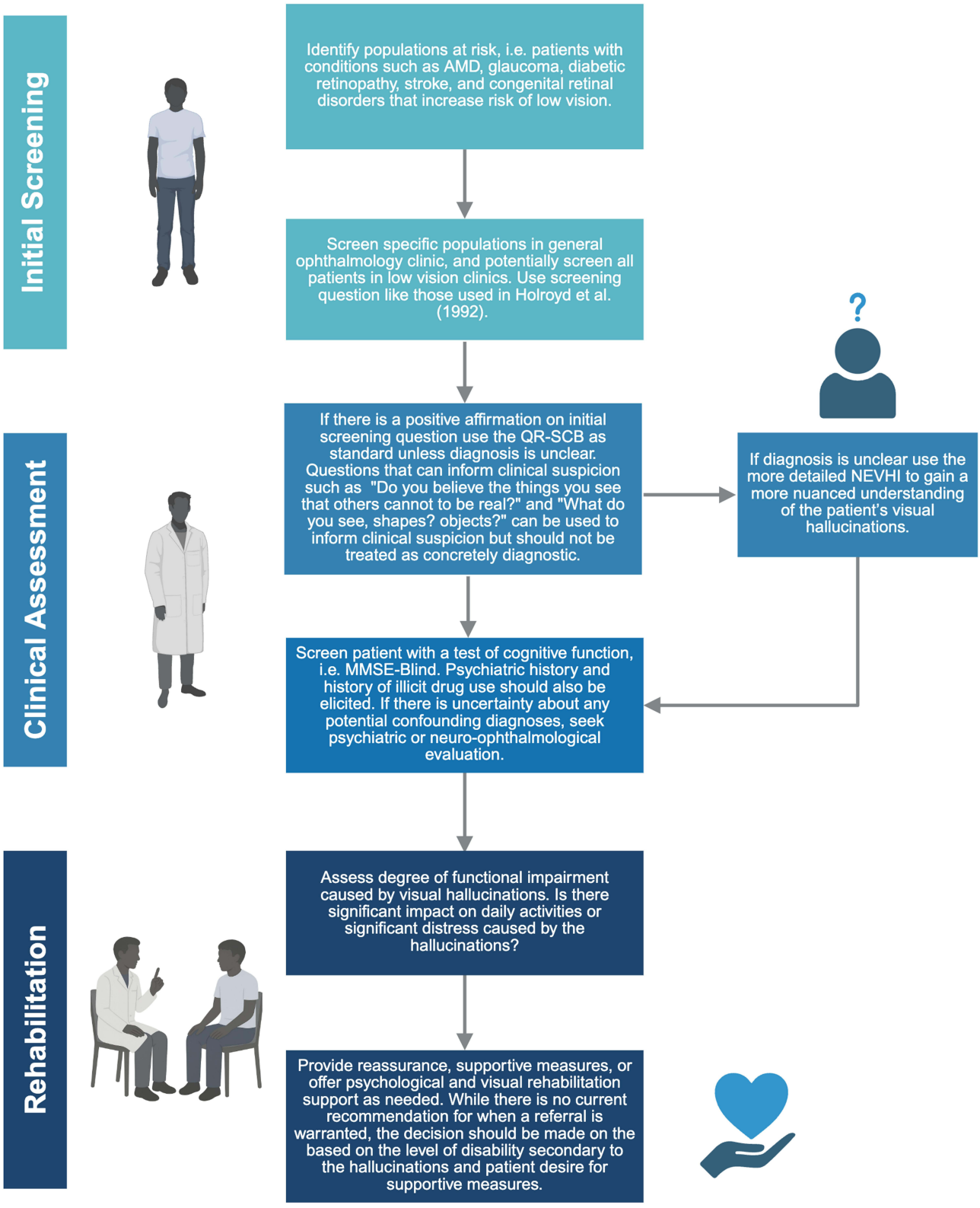

Figure 2 Clinical workflow for screening, assessment, and management of Charles Bonnet Syndrome (CBS). This clinical algorithm presents a structured approach to identifying and managing CBS in ophthalmology clinics. Clinicians screen patients with risk factors such as AMD, glaucoma, or stroke using a direct question (eg, "Have you seen things others cannot see?"). If positive, they apply a validated tool like the QR-SCB. They then assess cognition and psychiatric history to rule out alternative causes. If needed, they use the NEVHI for further characterization. Management includes education, reassurance, and referral for visual or psychosocial rehabilitation when appropriate.

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While our proposed framework offers a pragmatic approach to CBS recognition, several important limitations must be acknowledged.

The most significant limitation of our research, as previously mentioned, is considerable heterogeneity in diagnostic criteria used throughout the literature. As highlighted by Hamedani and Pelak,[8] there is no universally agreed-upon criteria that exists regarding key diagnostic features of CBS. Specifically touched upon by Hamedani and Palek, there is no consensus regarding the degree of vision loss, the nature of hallucinations (simple vs complex), the necessity of preserved cognitive function nor are there standardized methods for excluding neuropsychiatric disorders. Some studies have accepted minimal visual loss as sufficient for a diagnosis, while other studies have required severe vision loss. In a similar vein, the degree of insight required for patients varies greatly across the literature. This level of heterogeneity is a complicating factor for systematic case identification and the appropriate selection of screening thresholds in clinical practice. Studies using more strict criteria are likely to underreport the prevalence of CBS, while studies that use less strict criteria are likely to overreport the prevalence of CBS. Without the creation of standardized criteria, there is a large risk of overdiagnosis and underdiagnosis in clinical practice depending on the criteria used.

Additional limitations that exist in the present study include the underdevelopment of the validated CBS-specific screening tools. Unfortunately, the NEVHI and the QR-SCB were not systematically validated across large, diverse patient populations, and thus their diagnostic utility, sensitivity, and specificity in routine ophthalmologic settings is not completely delineated.

It should also be noted that previous studies have also shown that cultural differences play a role in the underreporting of hallucinations, likely due to social stigma, which is an important consideration when dealing with CBS patients of diverse cultural or ethnic backgrounds.[97,98]

Addressing these limitations will require continued study of CBS to generate a broader consensus regarding the threshold for diagnosis and careful validation and refinement of screening tools. Through addressing these limitations, we can improve our certainty of CBS diagnosis and help patients get much-needed education and support in a systematic and timely manner.

Future Directions

Future endeavors to improve recognition and management of CBS will need to focus on critical weaknesses in the existing clinical approach. There is a definite need for the development of large-scale, rigorously validated CBS screening instruments that can be practically applied in ophthalmology clinics. While current tools exist, such as the NEVHI and the QR-SCB, these tools lack large-scale validation and have aspects that make them less clinically useful in the setting of an ophthalmology clinic. They offer a good foundation for future researchers to devise more abbreviated screening tools that can be systematically validated in a large population to ensure the sensitivity, specificity, and the feasibility.

Another important weakness to address is the lack of universally applicable diagnostic criteria for CBS. As mentioned previously, there is a great deal of heterogeneity throughout the literature regarding the diagnostic criteria used to confirm CBS. Specifically, there is variability regarding the degree of vision loss required, the phenomenology of the hallucinations, necessity of insight into the hallucinations, and our ability to diagnose this condition in patients who have comorbid and confounding neurologic or psychiatric disease. Future efforts should be made by researchers to establish a singular diagnostic definition of CBS for use in research and clinical practice.

There is also a need for longitudinal studies, which can characterize the natural history of CBS and give clinicians a better understanding of the factors underlying persistent symptoms, resolution, or psychiatric comorbidities that are exacerbated by CBS. This would be a great benefit for risk stratification and implementation of management strategies.

Finally, the development of structured clinical pathways that include a standardized approach to psychological support and visual rehabilitation would be an appropriate extension of our current research and may help to improve the lives of those living with distressing visual hallucinations due to vision loss.

We believe that further research into these areas can potentially transform CBS from something underdiagnosed and misunderstood aspect of visual care into a routinely recognized and expertly managed aspect of visual care.

Conclusion

CBS remains a frequently overlooked diagnosis among patients with significant visual impairment. Despite being benign, it can profoundly affect quality of life. Underreporting by patients, limited clinician familiarity, and the lack of standardized diagnostic criteria have all contributed to persistent underdiagnosis. As the burden of vision loss increases with an aging population, systematic and practical screening approaches that can be integrated into routine care are increasingly necessary.

This review highlights the importance of structured screening for CBS and proposes a pragmatic diagnostic framework that can be incorporated into routine ophthalmologic practice. By streamlining the identification of at-risk patients, encouraging disclosure through sensitive screening questions, and recommending validated tools for confirmation, this framework directly eases the diagnostic process. Such an approach facilitates earlier and more accurate recognition, reduces misdiagnosis as psychiatric illness, minimizes unnecessary referrals, and ensures patients receive appropriate education and rehabilitative resources. Future efforts should focus on validating this framework across diverse clinical settings, refining tools for diagnostic accuracy, and developing consensus diagnostic criteria to establish CBS as a routinely considered component of comprehensive vision care.

Artificial Intelligence

Besides traditional searches like PubMed, we used Elicit.com (accessed on 25 March 2025) and Consensus.app (accessed on 12 June 2025) to target specific areas for the best available evidence. We developed this manuscript using GPT-4o (OpenAI), which helped generate initial outlines, which we extensively revised to fit our planned structure. We used GPT-4o to explore structural drafts and subheading phrasing, which we subsequently revised and grounded in empirical data. We rewrote these drafts to articulate our ideas fully and include the necessary citations. We used GPT-4o throughout the writing process to review and enhance grammar and sentence structure periodically. In alignment with recommended guidelines for the ethical use of AI in research and publishing,[99] we affirm full accountability for the accuracy, originality, and scientific validity of the content in this manuscript. While AI tools supported evidence synthesis, we independently conducted all key evaluations, interpretations, and revisions to ensure the work adheres to current scientific knowledge and meets rigorous academic standards.

Abbreviations

AMD, age-related macular degeneration; CBS, Charles Bonnet syndrome; DR, diabetic retinopathy; MMSE, Mini-Mental State Examination; MMSE-Blind, Mini-Mental State Examination, Blind Version; NEVHI, North-East Visual Hallucination Interview; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PICO, Patient/Population/Problem, Intervention, Comparison, and Outcome; QR-SCB, Questionnaire de Repérage du Syndrome de Charles Bonnet; VEGF, vascular endothelial growth factor.

Disclosure

The authors report no conflicts of interest in this work.

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