Patients and methods

A case-finding study was undertaken at the Low Vision Unit of the Department of Ophthalmology, University Hospital, Nijmegen, to which visually handicapped patients are referred to receive reading aids from an optometrist. Of 511 consecutive patients older than 18 years, 505 gave their informed consent to participate in the study.

Data were collected on demographic characteristics, ophthalmic diagnoses, and visual acuity. All patients underwent a semistructured interview on complex visual hallucinations with one of four trained interviewers. In cases of possible or probable complex visual hallucinations, the patient's informed consent to a further investigation was asked. This investigation comprised an interview by a psychiatrist (RJT) at the patient's home. The psychiatrist checked whether the definition of hallucinations in the *Diagnostic and statistical manual of mental disorders* was met: "A sensory perception without external stimulation of the relevant sensory organ." A general psychiatric examination was done with the Dutch version of the Geriatric Mental State Schedule. The psychiatrist then decided whether the following criteria for the CBS were met:

- at least one complex visual hallucination within the past 4 weeks;
- a period between the first and the last hallucination exceeding 4 weeks;
- full or partial retention of insight into the unreal nature of the hallucinations;
- absence of hallucinations in other sensory modalities;
- absence of delusions.

Using a checklist, we interviewed the patients with special attention to psychopathological characteristics, personal meaning of the hallucinations, factors encouraging or stopping the hallucinations, and the emotional impact of the hallucinations on the patient.

Results

63 of the 505 visually handicapped patients had experienced complex visual hallucinations in the 4-week period before screening; one patient did not meet CBS criteria because of lack of insight and coexistence of acoustic hallucinations; two patients refused further examinations.

18 men and 42 women with CBS remained. Their ages ranged from 46 to 98 years with a mean age of 75.4 (SD 8.0) years. Mean visual acuity in the best eye was 0.23 (SD 0.18). The most frequent causes of visual impairment were age-related macular degeneration (31 patients), diabetic retinopathy (11 patients), glaucoma (four patients), and corneal disease (three patients). 11 patients had less common ophthalmic diagnoses. Psychiatric examination of the patients revealed no disorders which could be considered to be the cause of their hallucinations.

The mean age at onset of CBS was 72 years (SD 5). The duration of the syndrome at the time of screening ranged from 1 month to 30 years: 29 patients had experienced hallucinations for less than 1 year, 21 between 1 to 5 years and ten for more than 5 years.

Psychopathological characteristics

The frequency of hallucinatory episodes varied from several times daily to only twice a year. In the course of time, frequency had decreased in ten patients, had increased in two, and had remained unchanged in 48. Hallucinatory episodes had lasted from a few seconds to many hours. The patients described the content of their hallucinations as people, animals, plants, a large variety of inanimate objects, and sometimes complete scenes. Often, the content of hallucinations was mundane (an unfamiliar person, a bottle, a hat), but it could be funny (two miniature policemen guiding a midget villain to a tiny prison van), ghostly (translucent figures floating in the hallway), bizarre (a dragon, people wearing one big flower on their heads), as well as beautiful (a shining angel, wonderful bunches of flowers). Most patients described a large variety of hallucinations, differing in each hallucinatory episode. Sometimes the sensation of specific objects returned, but stereotyped hallucinations (identical in every respect) were uncommon. Hallucinations contained both familiar and unfamiliar images. The hallucinations occurred both in black and white or colour. They could be clearer, equally clear, or less clear in comparison to reality. They could show intrinsic movement, a movement of the total image, or be motionless. Sometimes the hallucinations moved along with the eyes. Most patients hallucinated only with their eyes open. Some perceived hallucinated objects as floating in the air or projected on a wall or ceiling. Others reported that the objects fitted well into the surroundings (eg, an unreal person sitting in a real chair). Patients hallucinating while their eyes were closed perceived hallucinations in the dark subjective space in front of the eyes. The numbers of patients who reported these characteristics are listed in table 1.

49 patients (82%) stated they were always immediately aware of the unreal nature of their hallucinations. 11 (18%) had sometimes been deceived for a short period, but this had happened only when hallucinated objects...
Favourable circumstances studied in all patients | Acts stopping hallucinations studied in all patients
---|---
Specific times of day | Influence of eyelids
Evening | Keeping eyes closed 38
Night | Keeping eyes opened 15
Middle of day | Approaching hallucinated object 20
Early morning | 10

Light intensity | Other acts stopping hallucinations
Poor lighting | Looking/away 15
Bright daylight | Putting on a light 10
Bright day | Blinking 8
Being Inactive | Moving eyes swiftly 5
Sitting in a car | Fixed hallucination with eyes 5
Using temazepam | Concentrating on something else 5
Nervousness/stress | Hitting hallucination 2
Fatigue | Shouting 2

Personal meaning of the hallucinations
46 (77%) patients could not detect any personal relevance of the hallucinations. Though hallucinated objects were familiar to them, they were emotionally of no apparent importance. One woman compared her hallucinations with her dreams: “In my dreams I experience things which affect me, which are related to my life. These hallucinations, however, have nothing to do with me.”

Three (5%) patients were uncertain whether or not some of their hallucinations had a personal meaning: an elderly, childless gentleman was intrigued by recurrent hallucinations of a little girl and boy. He wondered whether these hallucinations reflected his unfulfilled wish to become a father.

Ten (17%) patients experienced hallucinations involving emotionally important as well as unimportant objects. For instance, one patient perceived a great number of people, most of whom were unfamiliar, but occasionally a deceased relative appeared among them.

Only one (2%) patient had hallucinations with an exclusively personal, emotionally relevant content: these always involved her late husband. Since his death, 3 years earlier, she experienced these hallucinations several times weekly.

Factors influencing hallucinations
No patient was able to consciously evoke hallucinations or exert influence on their content. Many, however, had noted circumstances which seemed to favour the occurrence of hallucinations and/or had found methods to stop hallucinating. Details are shown in table 2.

Emotional impact of the hallucinations
The emotional response to the hallucinations was mainly negative in 19 (32%) patients: anxiety in 14 and irritation in five. 11 (18%) patients showed mixed emotions and in 22 (37%) the emotional response was neutral. Eight (13%) had felt joy or amusement during their experiences. General feelings of well-being were not disturbed by the hallucinations in 43 (72%) patients. 17 (28%) suffered from their hallucinations and hoped that they would disappear; only six felt enough distress to consider taking medication to suppress their hallucinations.

44 (73%) patients had not mentioned their extraordinary experiences to doctors: 15 feared their doctor would not take them seriously or would think they were insane; 20 thought this was not the kind of complaint for which one consults a doctor; nine gave no explanation. Only one of the 16 who had consulted a doctor (mostly a general practitioner or ophthalmologist) was informed about the proper diagnosis. Seven had experienced the doctor’s reaction as negative. A patient who consulted a psychiatrist because of family problems was informed about the proper diagnosis. This treatment had not suppressed hallucinations but had only made her feel awkward. The general practitioner of another patient had responded with; “you’d better not talk about such silly things!”

Discussion
The clinical characteristics of CBS show rich variety. We found no characteristics which were common to all patients in addition to the inclusion criteria we used. However, in this population, the criterion “full or partial insight” could be sharpened to “full insight”. Some patients had occasionally needed correction by others, but this was because the ordinary appearance of their hallucinations, fitting well in the surroundings, made it very difficult or even impossible to discriminate real from unreal.

There is a continuing discussion in the literature as to whether CBS-type hallucinations are newly created products of fantasy or reproductions of earlier true perceptions. The fact, that the majority of our patient’s hallucinations contained objects that they did not remember having seen in reality seems to support the first theory. However, sometimes familiar objects were recognised, though one could argue that these familiar objects are also new creations, which are modelled after earlier true perceptions. In favour of the second theory it could be suggested that the patients had once seen the unfamiliar objects in reality, but had forgotten them because they were of no particular interest. We cannot bring this discussion to a conclusion.

Some authors have suggested that the content of the hallucinations in CBS is influenced by wishes or preoccupations of the patients. This theory seemed probable in only a minority of the patients in our study. The infrequent occurrence of emotionally important objects in the large variety of hallucinations may just be coincidental.

The circumstances favouring hallucinations provide some support for the suggestion that sensory deprivation and a low level of arousal are triggers for CBS-type hallucinations. Circumstances such as “early...
morning”, “evening” and “night”, “being inactive”, “home environment”, “fatigue”, and “using temazepam” might be associated with a low level of arousal. “Poor lighting”, “being alone”, and “laser therapy for the eyes” may point to sensory deprivation. Possibly typical acts that stop hallucinations reflect an increase in the level of arousal and/or sensory stimulation.

CBS had little impact on the general feelings of well-being in the majority of patients. Nevertheless, all of them were glad to be informed that it was a known phenomenon, which had a name and was not considered to be a mental disorder. This study shows that many patients do not consult a doctor about CBS. We also found that patients tended to conceal their extraordinary experiences from others: “Why have you not told me about this?”, the amazed wife of one man asked as he confessed to the interviewer that he had perceived faces for 3 years. “I didn’t want to upset you”, he replied.

The experiences of those patients who sought professional advice also indicate that many doctors are not familiar with CBS. Patients would benefit if doctors recognized CBS and gave them proper information, including reassurance that they are not mentally ill. For most patients this response will be sufficient. Support should be offered to those who cannot cope with their hallucinations. No treatment of proven effectiveness is yet available.

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