

Visual hallucinations more common than previously thought

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(Medical Xpress)—Vivid hallucinations experienced by people with sight loss last far longer and have more serious consequences than previously thought, according to new research from King's College London and the Macular Society.

The study is the largest survey of the phenomenon, known as Charles Bonnet Syndrome, and documented the experiences of 492 <u>visually impaired people</u> who had experienced visual <u>hallucinations</u>. The findings, published in the *British Journal of Ophthalmology*, show there is a serious <u>discrepancy</u> between medical opinion and the realities of the condition.

Charles Bonnet Syndrome is widely considered by the <u>medical</u> <u>profession</u> to be benign and short-lived. However, the new research



shows that 80% of respondents had hallucinations for five years or more and 32% found them predominantly unpleasant, distressing and negative.

The study described this group of people as having "negative outcome Charles Bonnet Syndrome". The group was more likely to have frequent, fear inducing, longer duration hallucinations, which affected daily activities. They were more likely to attribute hallucinations to serious mental illness and were less likely to have been warned about the possibility of hallucinations before they started.

Of respondents, 38% regarded their hallucinations as startling, terrifying or frightening when they first occurred and 46% said hallucinations had an effect on their ability to complete daily tasks. 36% of people who discussed the issue with a medical professional said the professional was "unsure or did not know" about the diagnosis.

Dr Dominic ffytche, who led the research at the Institute of Psychiatry at King's, says: "Charles Bonnet Syndrome has been traditionally thought of as benign. Indeed, it has been questioned whether it should even be considered a medical condition given it does not cause problems and goes away by itself. The results of our survey paint a very different picture.

"With no specific treatments for Charles Bonnet Syndrome, the survey highlights the importance of raising awareness to reduce the distress it causes, particularly before symptoms start. All people with Charles Bonnet Syndrome are relieved or reassured to find out about the cause of their hallucinations and our evidence shows the knowledge may help reduce negative outcome."

People with macular disease are particularly prone to Charles Bonnet hallucinations. They are thought to be a reaction of the brain to the loss of visual stimulation. More than half of people with severe sight loss



experience them but many do not tell others for fear they will be thought to have a serious mental illness.

Age-related macular (AMD) degeneration affects the central vision and is the most common cause of sight loss in the UK. Nearly 600,000 people have late-stage AMD today and more people will become affected as our population ages. Around half will have hallucinations at some stage.

Tony Rucinski, Chief Executive, the Macular Society, said: "It is essential that people affected by <u>sight loss</u> are given information about Charles Bonnet Syndrome at diagnosis or as soon after as possible.

"Losing your sight is bad enough without the fear that you have something like dementia as well. We need medical professionals to recognise the seriousness of Charles Bonnet Syndrome and ensure that people don't suffer unnecessarily. More research is also needed to investigate Charles Bonnet Syndrome and possible ways of reducing its impact."

Dr ffytche is also leading a large NIHR funded research programme on visual hallucinations to develop a much-needed evidence base to inform NHS practice in managing and treating the symptoms.

More information: Thomas M Cox & Dominic H ffytche "Negative Outcome Charles Bonnet Syndrome" published in the *British Journal of Ophthalmology* DOI: 10.1136/bjophthalmol-2014-304920

Provided by King's College London

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