Visualising Charles Bonnet Syndrome: Digital Co-Creation of Pseudohallucinations

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Abstract: Charles Bonnet Syndrome (CBS) is when a person experiences pseudohallucinations that fill in visual information from any type of sight loss. CBS arises from an epiphenomenal process, with the physical actions of sight resulting in the mental formations of images. These pseudohallucinations—referred to as visions by the CBS community—manifest in a wide range of forms, from complex scenes to simple geometric shapes. To share these unique visual experiences, a remote cocreation website was created where CBS participants communicated their lived experiences. This created a reflexive process, and we worked to produce true representations of these interesting and little-known phenomena. Digital reconstruction of the visions is utilised as it echoes the vivid, experiential movie-like nature of what is being perceived. This paper critically analyses co-creation as a method for making digital assets. The implications of the participants' vision impairments and the application of ethical safeguards are examined in this context. Important to note, this research is of a medical syndrome for a non-medical, practice-based design. CBS research to date is primarily conducted by the ophthalmic, neurological, and psychiatric fields and approached with the primary concerns of these specialties. This research contributes a distinct approach incorporating practice-based digital design, autoethnography, and phenomenology. Autoethnography and phenomenology combine as a foundation, with the first bringing understanding and insights, balanced by the second philosophical, bigger picture, and established approach. With further refining, it is anticipated that the research may be applied to other conditions. Conditions where articulating internal experiences proves challenging and the use of digital methods could aid communication. Both the research and CBS communities will benefit from the insights regarding the relationship between cognitive perceptions and the vision process. This research combines the digital visualising of visions with interest in the link between metaphor, embodied cognition, and image. The argument for a link between CBS visions and metaphor may appear evident due to the crosscategory mapping of images that is necessary for comprehension. They both are—CBS visions and metaphors—the experience of picturing images, often with lateral connections and imaginative associations.

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