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RESEARCH ARTICLE

Visual Snow Syndrome is unstable: A longitudinal investigation of VSS symptoms in a Naïve population

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Abstract

Objective: This study aimed to investigate the nature of subclinical Visual Snow Syndrome (VSS). We sought to develop a means of recruiting naïve participants with subclinical VSS symptoms to participate in research; and to understand whether subclinical VSS symptoms are stable across time. VSS is a recently characterised neurological condition, whose primary symptom is visual snow (dynamic noise in the visual field). There is evidence that VSS may be common in the general population and that it is unnoticed by many who experience it. To fully characterise VSS, it is important to understand whether (and how) subclinical VSS progresses to a clinical form. **Methods**: Here, we present two related studies: Study 1 develops and validates the Melbourne Visual Snow Questionnaire (MVSQ), a tool for screening the general population for VSS symptoms; and Study 2 investigates the stability of subclinical VSS. We developed the MVSQ based on the results of other recent work investigating undiagnosed cases of VSS, and a validated questionnaire designed to identify people with tinnitus for research participation. We then tested the MVSQ in a population with clinical VSS, including assessing face validity (i.e., the extent to which people with clinical VSS believed the questionnaire accurately captured their symptoms). In Study 2, we deployed the MVSQ in a naïve sample of 155 participants, who completed the MVSQ twice, 6 weeks apart. **Results**: The results of Study 1 indicated that the MVSQ was a viable method of recruiting people who experience VSS symptoms for research participation. It was deemed to have appropriate face validity and to pose little burden to those who completed it. In Study 2, VSS symptoms changed substantially across a 6-week period. Cohen's weighted kappa for diagnosis was 0.56, 95% CI [0.43, 0.69]. However, the impact of perceptual experiences was low and did not change over time, rank ICC = 0.71, 95% CI [0.59, 0.82]. **Interpretation**: The MVSQ is appropriate for assessing perceptual experiences in the general population. Determining the exact time scale across which symptoms fluctuate is important for understanding both clinical and subclinical cases of VSS.

Introduction

Visual snow (VS) is a perceptual phenomenon characterised by persistent, flickering noise throughout the visual field. It is the primary perceptual phenomenon of Visual Snow Syndrome (VSS),[1] in which it is experienced continuously for at least 3 months. People with VSS also experience at least two other visual phenomena from a list including palinopsia (trailing of moving objects), a range of enhanced entoptic phenomena, photophobia, and nyctalopia (poor night vision).[2] Some research has additionally indicated that VSS includes a range of non-visual symptoms, including paraesthesia and a variety of mental health symptoms.[3]

Characterising subclinical VSS experiences

VSS was first characterised in 2014,[1] and has seen much research interest in recent years. However, until 2020, the condition had only been studied in clinical populations.

Consequently, our understanding of VSS is largely based on severe presentations with substantial quality-of-life impacts. In some cases, people with lifelong VSS who are barely impacted but pursued diagnosis after recognising their perceptual experience differed from the 'norm' have also been included in research.[4] These studies provided the first indication that VSS is not always a debilitating condition.[3]

More recent research has provided evidence that VSS might represent one end of a spectrum of normal variation in perceptual experience, and that the perceptual phenomena associated with VSS may not themselves be inherently debilitating.[5,6] For example, in 2020, Kondziella and colleagues conducted the first epidemiological study attempting to estimate the population prevalence of VSS.[7] In this study, a sample of 1,015 British adults were screened for VSS, with the population prevalence of the condition estimated at 2.2%. The study was advertised as relating to 'medical conditions' (and not VSS or a visual condition specifically), and permitted participants to disclose any known diagnosis which might explain their symptoms. None disclosed any knowledge of VSS. Although the study did not measure symptom impact, it can be inferred that participants likely experienced limited impact from their symptoms as few seemed to have pursued medical diagnoses.

In the intervening time, three further papers have used population screening techniques to identify subclinical cases of VSS (i.e., cases of VSS which are unrecognised by the person who experiences them and have thus not warranted clinical attention). Results indicate that around 40% of the general population experience VS itself some of the time, and up to 5% of people may have a latent or subclinical form of VSS.[6,8,9] These studies show that subclinical VSS and VS may be more common than previously thought, and confirm that some people who meet the VSS diagnostic criteria do not experience negative impacts from their perceptual experiences.

To fully characterise the experience of VSS, it is important to understand the experience of subclinical VSS before a person becomes aware of it. Awareness of the 'unusual' nature people's symptoms or perceptual experiences may alter their subjective experience.[4,10,11] However, there are currently no validated tools for screening the general population for symptoms associated with VSS.

Is VSS stable over time?

Our understanding of the longitudinal nature of VSS is mostly based on clinical experience and anecdotal evidence, neither of which necessarily provides an accurate representation of the dynamics of VSS across time. There has been little longitudinal research into the condition: in 2022, Puledda and colleagues published the results of a study involving a 30-day diary of people's VS, showing that this symptom is changeable depending on circumstances such as alcohol intake and external light conditions.[13] In the same year, Graber and colleagues showed that the experience of VSS evolves over time.[14] At two timepoints across an 8-year period there was a non-significant shift in the presence of perceptual phenomena other than VS, which remained continuous for all participants. Most participants experienced more perceptual phenomena at follow-up than baseline. However, the frequency and intensity of perceptual experiences were not measured. Importantly, the impact of perceptual experiences on day-to-day life changed substantially. Participants seemingly 'adapted' to their VS whereas other phenomena had a greater impact on their lives. However, it remains unclear whether these changes occur gradually or whether they reflect temporary fluctuations in the experience of VSS.

Given our limited understanding of the long-term impacts of VSS and the extent to which perceptual experiences are stable, more research is required to characterise the condition over time. An improved understanding of the evolution of VSS will allow clinicians to provide better advice to those whose VSS causes distress and may provide insight into the pathophysiology of VSS.

Given the difficulty in recruiting patients with diagnosed VSS whose experiences have so far not been influenced by either their engagement with the medical profession or with online support groups, it is important to first characterise these changes in naïve populations. This approach may help identify biomarkers and preventative treatments associated with subclinical changes that may be obscured by social influences. The ability to recruit naïve participants who share perceptual experiences with those diagnosed with VSS will also provide future researchers with a far larger pool of participants from which to recruit.

Aims

We present two studies addressing separate aims: first, we develop and validate a questionnaire-based tool to screen naïve populations for subclinical VSS and associated symptoms; and second, we investigate whether VSS symptoms change over 6 weeks in a naïve population.

These studies were approved by the University of Melbourne Human Research Ethics Committee and were conducted in accordance with the Declarations of Helsinki. All participants provided informed consent via an online form prior to participation. In both studies, analyses were conducted using R 4.0.3.[15] Scale scoring and Cohen's kappa calculations were conducted using the psych package, and ICCs were calculated using the rankICC package.[16,17]

Study 1: Developing and Validating a Screening Questionnaire for Visual Snow Syndrome

Methods

Development of the Melbourne Visual Snow Questionnaire

In developing the Melbourne Visual Snow Questionnaire (MVSQ), we aimed to produce an instrument which allows researchers to identify people with perceptual experiences which are relevant to VSS, and which are most likely subclinical, but who have not been diagnosed with VSS. The MVSQ does not require specific knowledge of any symptoms of VSS and does not prime the way people report their perceptual experiences, or provide cause to investigate these experiences further. As much as possible, this should maintain the 'naïve' status of participants. Importantly, the MVSQ is not designed to be a diagnostic tool: it should be used for research purposes only.

The initial framework for the MVSQ was based on Kondziella et al.'s screening questionnaire.[7] Our previous research indicates that this tool may be influenced by prior symptom knowledge, as the only significant difference between naïve participants with subclinical VSS and people with VSS diagnoses was in the number of symptoms experienced.[9] Inspired by the European School for Interdisciplinary Tinnitus Research Screening Questionnaire (ESIT-Q), we adapted the language of Kondziella et al.'s questionnaire to ensure that it was both consistent with the literature and accessible to naïve participants.[18] At no point does the questionnaire use the name of any perceptual phenomenon (except floaters, which we considered to be sufficiently understood).

As the MVSQ is designed for use in naïve populations, we also considered the need to assess the same experience in multiple ways, to ensure response accuracy. To account for the possibility of false positive cases of VS, we included two qualitative questions at the start of our questionnaire. These ask participants to describe what they see when they look at a white wall, and what they see when they close their eyes. Participants who experience VS reliably describe static, snowfall, or pixelation in response to these questions, whereas those without visual snow tend to respond with statements describing the wall or the nature of darkness (e.g. 'I just see the wall', 'a plain environment') or, fantastically (e.g. 'I saw the breeze blowing the grass, the lake shimmering, the leaves rustling'). Additionally, to account for the fact that some people with migraine do not view themselves as necessarily experiencing headaches per se, we added a specific question addressing migraine experiences and diagnoses, in addition to Kondziella et al.'s question.[19]

Some aspects of our questionnaire may be surprising to clinicians. Whereas the International Classification of Headache Disorders (ICHD-3) requires continuous VS for at least 3 months for a diagnosis of VSS to be made, we do not include a question addressing this.[2] People who experience subclinical VS are unlikely to be able to answer questions with this degree of precision. With naïve populations, the continuous experience of VS is sufficient for the participant to be of research interest, especially if a study is interested in basic phenomenology. Additionally, the ICHD-3 states that VSS cannot be diagnosed if some other condition better explains a person's symptoms. Many researchers and clinicians have used this criterion to preclude diagnosis in the case that a patient has used recreational drugs, as Hallucinogen Persisting Perceptual Disorder (HPPD) may be a 'better' diagnosis. Our questionnaire enquires about drug history and asks participants who first experienced phenomena associated with VSS to specify whether their symptoms occurredAltheir drug experience. We are satisfied that symptoms which begin prior to or 'a long time after' drug use are of research interest in the context of VSS, given there are few differences in symptom presentation between people with VSS and people with type 2 HPPD.[20] Future researchers may choose to use this question to be either more liberal or strict with their inclusion criteria, depending on the nature of their research.

Two versions of the MVSQ are presented in the supplementary material: the short form MVSQ contains only questions which are essential to assessing the perceptual experiences of naïve participants, and the long form MVSQ contains additional questions which may be relevant in some research situations.

Validation of the MVSQ

To validate the MVSQ, we recruited a sample of 150 participants with clinical VSS (either by medical or self-diagnosis) from several online support groups including the Visual Snow subreddit, several Facebook groups for people with VSS (including one specifically for people with lifelong VSS), and via Twitter and Instagram using hashtags relevant to VSS and visual snow. Participants were required to be 18 years of age or older, to self-assess as fluent in English, and to check a box confirming that they had VSS.

Participants completed the study online in Qualtrics.[21] In addition to the MVSQ, participants also completed the Visual Snow Handicap Index (VHSI), the only scale-based measure of VSS impact which has been used so far; and the QQ-10, which is designed to test the face validity of questionnaires used in clinical samples.[20,22] Face validity refers to the extent that a test taker believes the test accurately assesses the content it claims to relate to. Participants were also asked to report whether they had a formal diagnosis of VSS, and if so which category of clinician made the diagnosis.

Participants' VSS diagnoses (or self-diagnoses) were not checked against medical records, due in part to the fact that our research interests are in basic phenomenology and subjective experience, where self-assessed experiences remain useful; and in part to ethics compliance constraints and privacy regulations. Additionally, where participants stated that they had received a diagnosis from a medical professional, we did not verify this for ethical reasons. However, some participants were unsure which category of medical practitioner their diagnosing physician was best described by, and instead provided their names. In these cases, we used available online information to correctly allocate the medical professional to a category.

Participants were screened to assess for responses which indicateda lack of comprehension or bad-faith participation. Attention checks comprised two questions, requiring different kinds of responses (radio buttons and text input). These occurred separately at different points in the questionnaire. The text input asked participants to copy a sentence but with the words in the reverse order (for example if the prompt was *fun are trucks red*, the response would be 'red trucks are fun'). The radio button question asked participants to select the response which would be last, if responses were organised in alphabetical order. All free-text responses were also screened for nonsense responding, or bad faith responding. We looked for examples where participants had clearly not answered the question, or when they had pasted in copied text, such as text used elsewhere in the questionnaire or text from the study description and relevant ethics documents with which they were provided.

We operated on a 'three strikes' principle, whereby participants were allowed two errors on the above-described checks prior to being screened out. This is because we assume that even good-faith respondents might make mistakes, misunderstand a question, or respond too quickly from time to time. In total, 93.33% (n = 140) of participants were included for analysis.

We calculated the percentage of participants correctly categorised as having VSS using the MVSQ against both medical and self-diagnoses. In cases where the MVSQ assessed that a participant did not have VSS, we compared their data against the diagnostic criteria for VSS in the ICHD. Scale scores for subscales of the QQ-10 were also calculated. The value subscale indicates the extent to which participants feel the MVSQ accurately represents their experiences with VSS, and the burden subscale assesses the extent to which they felt burdened by the MVSQ.

Results

Of 140 participants included for analysis, 90 were female, 41 were male, eight were non-binary, and one preferred not to say. Participants' mean age was 33.52 years (*SD* = 10.2). Table 1 presents demographic data and details of symptoms experienced.

Seventy-seven participants (55%) were self-diagnosed with VSS. Of the 63 participants (45%) with formal medical diagnoses, 26 were diagnosed by neuro-ophthalmologists, 27 were diagnosed by neurologists, four were diagnosed by ophthalmologists, five were diagnosed by opticians or optometrists, and one was diagnosed by a clinical psychologist. The language in the questionnaire allowed participants to select for 'optometrist or optician' to account for the fact that trained medical professionals who routinely conduct eye tests and are often the first

Table 1. Summary of sample characteristics.

	N = 140
Demographic data	
Age (mean, SD)	33.52, 10.2
Gender count (male, female, non-binary, prefer not to say)	41, 90, 8, 1
Probable migraine (no aura)	30 (21.42%)
Probable migraine (aura)	76 (54.29%)
Drug history	73 (52.14%)
Tinnitus (at least some of the time)	124 (88.57%)
Diagnosed by a medical professional	63 (45%)
Diagnostic category	
VSS (lifelong/acquired)	58 (41.42%), 61 (43.57%)
Possible HPPD	12 (8.57%)
Visual snow	9 (6.53%)
No visual snow	–
Visual phenomena	
Palinopsia	100 (71.43%)
Excessive floaters	112 (80%)
Blue Field Entoptic Phenomenon	113 (80.71%)
Self-light of the eyes	100 (71.43%)
Other entoptic phenomena	100 (71.43%)
Self-report photophobia	121 (86.43%)
Nyctalopia	115 (82.14%)
Visual Snow Severity measures (mean, SD)	
Total symptoms	5.57, 1.2
VSHI score	51.11, 24.8
Face validity (mean, SD)	
QQ-10 value	20.19, 3.07
QQ-10 burden	1.86, 2.15

Unless otherwise specified, data are counts (%).

point of contact for problems related to vision are referred to using different terminology in different countries. This study was not limited to people in a specific geographic location.

Validation against medical diagnoses

The MVSQ categorised 119 participants (85%) as experiencing VSS. Twelve participants (8.5%) developed their symptoms 'soon after' using recreational drugs, and thus HPPD could not be ruled out. Nine participants (6.43%) were categorised as having the symptom VS but failed to meet the full criteria for VSS. Table 2 shows MVSQ categorisation against diagnosis type.

Of those categorised as experiencing VS in the absence of the full syndrome, one participant experienced VS with no other relevant visual symptoms, two were unsure whether their VS was continuous, and six experienced VS only occasionally. According to the ICHD-3, a VSS diagnosis requires continuous VS in addition to two other specified visual symptoms.[2]

Of those categorised as possibly having HPPD, six were self-diagnosed and six were medically diagnosed. It is possible that those who had a medical diagnosis either did not disclose their history of recreational drug use to their diagnosing physician or that the physician's judgement was that their drug use was unlikely to have precipitated their symptoms. We did not collect data pertaining to the specific drugs people had used due to ethical constraints.

Face validity

The results of the QQ-10 indicate that the MVSQ has appropriate face validity. The mean value score was 20.19 (*SD* = 3.07) out of 30. Higher scores indicate that participants believe the MVSQ accurately represents their experience of VSS (Fig. 1). The mean burden score was 1.86 (*SD* = 2.05) out of a possible score of 10, where higher scores indicate that the MVSQ was more burdensome to complete (Fig. 2).

The QQ-10 also gave participants the opportunity to provide qualitative responses to questions about aspects of the MVSQ. A representative sample of qualitative responses is available in the Supporting Information.

Table 2. Categorisation by the Melbourne Visual Snow Questionnaire compared to medical diagnoses.

MVSQ categorisation (*n* = 140)	Medical diagnoses (*n* = 63)	Self-diagnoses (*n* = 77)
Visual Snow Syndrome	51	68
Possible HPPD	6	6
Visual snow	6	3

HPPD, Hallucinogen Persisting Perceptual Disorder.

Study 2: Investigating whether VSS Symptoms Are Stable in a Naïve Population

Methods

Participants

We recruited a sample of 300 students enrolled in undergraduate psychology classes at the University of Melbourne. Participants received course credit for participation and were required to be ≥17 years old. The study was advertised to a cohort of over 1800 undergraduates via an online portal. Participants were self-selected to participate in this study based on the title 'Population Screening for Perceptual Experiences' and a 3-sentence description of the study. This may have resulted in some self-selection bias, with participants who were interested in their perceptual experiences being more likely to take part.

Participants were asked to complete the study twice, 6 weeks apart. We selected this timeframe as a wide range of questionnaires in our field show stable results across 2 to 4 weeks: we, therefore, determined that a longer timeframe may be required to identify fluctuations in perceptual experience. Data were stored anonymously, and individuals' data at each timepoint were linked by a code in the research participation platform used to advertise the study. At each timepoint, participants who failed two or more attention checks, or provided two or more nonsense answers, were excluded in accordance with the criteria described in study one.

At both timepoints, the questionnaires ended with the opportunity to provide further information related to the data collected, including whether participants knew of any medical condition which might explain their perceptual experiences. In other instances where we have used this specific question at the end of a questionnaire, we have received information relating to known HPPD diagnoses. This time, none of our participants disclosed any known medical diagnoses, indicating that there was no prior knowledge of VSS in this sample.

Upon completing the questionnaire, participants were directed to contact the researchers if they had any questions or concerns about the perceptual phenomena described in the questionnaire. We did not receive any such enquiries from participants.

Measures

Participants completed the same online questionnaire via Qualtrics on both occasions.[21] All participants completed

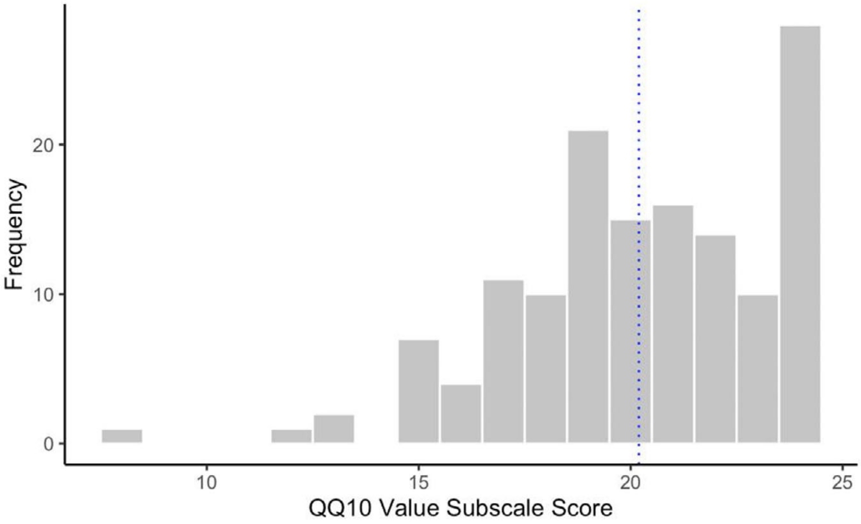

Figure 1. Scores on the Value Subscale of the QQ-10. Blue dotted line indicates the mean score.

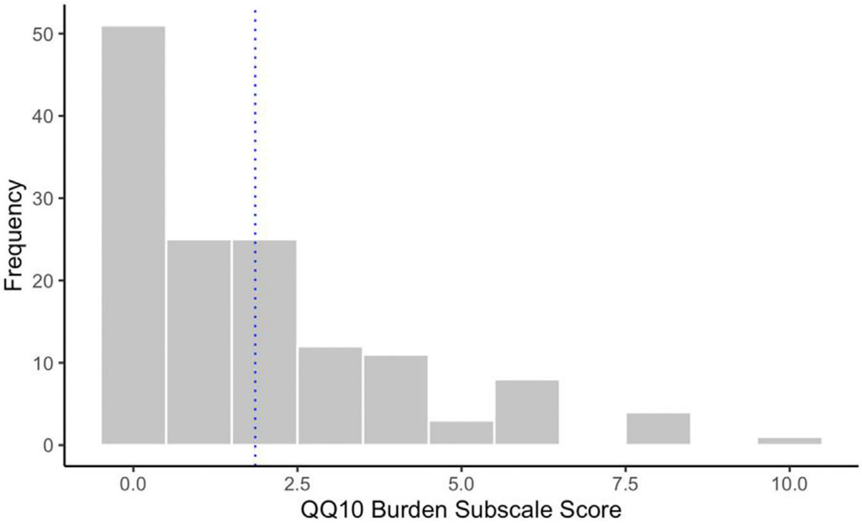

Figure 2. Scores on the Burden Subscale of the QQ-10. Blue dotted line indicates the mean score.

the long-form MVSQ, and those who had experienced VS also completed the Visual Snow Handicap Inventory (VSHI).[20] Responses at baseline did not impact the version of the questionnaire received at follow-up. As data collection for this study formed part of a larger project, participants also completed additional scale-based measures which are not reported here.

Participant retention

There were 279 valid responses at baseline and 160 valid responses at follow-up. The attrition rate was 43%. Of the 160 participants at follow-up, 155 could be linked to a valid response at baseline. As such, 155 participants were included for analysis.

Statistical analyses

As we were interested in understanding the stability of participant responses over time, we used statistical techniques relevant to test–retest reliability. We calculated Cohen's kappa for categorical data and the rank intraclass correlation (rank ICC) for continuous data.[23–25]

Results

Of 155 participants included for analysis, 122 were female, 32 were male, and one was non-binary. Participants' mean age was 18.86 years (*SD* = 1.74). Table 3 presents a comparison of demographic and symptom data at baseline and follow-up.

Test–retest reliability

Analyses relating to group-level perceptual experience stability over time were conducted for the MVSQ's key outcome variables: VSS category, VS presence or absence, total numbers of phenomena experienced, and VSHI score. These are described in more detail below. For thoroughness, Cohen's kappa values for specific symptoms are presented in Table 3. With the exception of blue-field entoptic phenomenon and other entoptic phenomena, there is at least moderate agreement between timepoints for all symptoms.

Table 4 shows the confusion matrix for VSS category. Cohen's weighted kappa was 0.56, 95% CI [0.43, 0.69], indicating moderate agreement between timepoints.[23] Table 5 shows the confusion matrix for VS presence. Cohen's kappa was 0.35, 95% CI [0.2, 0.51], indicating weak agreement between timepoints. Among naïve participants, experiences associated with VSS fluctuate considerably over a 6-week period.

As our data were positively skewed, we calculated rank ICCs for continuous variables.[16] The rank ICC approximates the ICC and is suitable for use on skewed data, with the same interpretation. The rank ICC for the number of phenomena experienced was 0.67, 95% CI [0.58, 0.76], indicating substantial agreement. Among participants who experienced VS at both timepoints, the rank ICC for VSHI score was 0.71, 95% CI [0.59, 0.82], indicating substantial agreement.

Discussion

We have shown that the MVSQ is a valid tool for assessing VSS-related perceptual experiences of naïve participants. It has good face validity in populations with confirmed VSS and is conservative compared to clinical judgement. We have also used the MVSQ to demonstrate that VSS symptomatology varies substantially across a 6-week period in naïve populations, but that the impacts of perceptual phenomena are reasonably stable in this timeframe.

Table 3. Summary of sample characteristics.

	Baseline (*n* = 155)	Follow-up (*n* = 155)	Cohen's Kappa (symptoms)
Demographic data			
Age (mean, SD)	18.75, 1.76	18.76, 1.74	–
Gender count (male, female, non-binary)	122, 32, 1	As baseline	–
Probable migraine (no aura)	46 (29.68%)	42 (27.1%)	–
Probable migraine (aura)	22 (14.19%)	20 (12.9%)	–
Drug history	20 (12.9%)	23 (14.84%)	–
Tinnitus (at least some of the time)	77 (49.7%)	73 (47.1%)	–
Diagnostic category			
VSS	13 (8.4%)	12 (7.42%)	–
Possible HPPD	0	1 (0.65%)	–
Visual Snow	75 (48.39%)	73 (47.1%)	–
No Visual Snow	67 (43.23%)	69 (44.52%)	–
Visual phenomena			
Palinopsia	40 (25.81%)	42 (27.1%)	0.57
Excessive floaters	45 (29.03%)	39 (25.16%)	0.58
Blue Field Entoptic Phenomenon	78 (50.32%)	69 (44.51%)	0.39
Self-light of the eyes	62 (40%)	60 (38.71%)	0.49
Other entoptic phenomena	15 (9.7%)	24 (15.48%)	0.39
Self-report photophobia	87 (56.13%)	76 (49.03%)	0.58
Nyctalopia	49 (31.61%)	46 (29.68%)	0.56
Visual Snow Severity measures (mean, SD)			
Total symptoms	3.44, 1.82	3.24, 2.41	–
VSHI score (people with VS)	8.45, 9.85	8.83, 10.49	–

Unless otherwise specified, data are counts (%). Cohen's Kappa scores in the range of 0.4–0.6 indicate moderate agreement in longitudinal analyses.[18]

Table 4. Confusion Matrix for Diagnostic Category.

Baseline	Follow-up VSS	Visual snow	No visual snow
VSS	9	4	0
Visual Snow	3	49	23
No Visual Snow	1	20	46

After detailed inspection of the results of the one person classified as having possible HPPD at follow-up, they were moved to the VSS category for purposes of the Kappa calculation. This is because they met the criteria for VSS at baseline and had their first experience of recreational drugs between baseline and follow-up. They developed additional visual symptoms soon after their drug experience, but the visual snow and two initial symptoms remained stable.

Table 5. Confusion matrix for visual snow presence.

Baseline	Follow-up Present	Absent
Present	89	30
Absent	12	24

Study 1

The MVSQ is a valid research tool for studying subclinical perceptual experiences related to VSS, in naïve populations. In the cases where the MVSQ's categorisation differed from a person's clinical or self-diagnosis, this was because the MVSQ is conservative in its categorisations, compared to clinical judgement.

The results of the QQ-10 suggest that people with confirmed VSS view the MVSQ as an appropriate tool for assessing their perceptual experiences. Our mean value score was similar to that reported in other papers, but the mean burden score was far lower (indicating less burden).[26,27] Overall, participant feedback was largely outside the scope of the MVSQ's aims: for example, participants suggested there should be a focus on which medications have helped relieve symptoms. Some participants also recommended we add additional symptoms such as depersonalisation, derealisation, and the 'vortex', which are not currently in the VSS diagnostic criteria.[3,9] Participants' feedback about areas that were overlooked was similar. Interestingly, some participants wanted the opportunity to describe how their symptoms had changed over time.

Study 2

Our results indicate that perceptual phenomena associated with VSS are not stable in the general population. The test–retest reliability measures we used show that the presence or absence of VS, and the specific additional symptoms experienced, tend to vary substantially across 6 weeks. However, the number of symptoms a person experiences is reasonably stable, suggesting changes in symptoms are not additive. Given the only longitudinal study of VSS (not just VS) in a clinical population studied participants at two timepoints separated by years, this provides the first indication that VSS symptoms fluctuate across shorter timeframes. Further research should be conducted to determine the exact timeframe over which phenomena vary, and whether these variations generalise to people with confirmed diagnoses. Importantly, the VSS diagnostic criteria only specify a timeframe for VS. The timeframes required for other symptoms to be counted would presumably vary between clinicians.

That prospective VSS categories (i.e. whether someone had subclinical VSS) changed over time is somewhat concerning and indicates that there is some measurement error associated with naïve responses. For example, one participant had no VS at baseline but met the diagnostic criteria for VSS at follow-up. This is impossible because VSS requires the continuous experience of VS for at least 3 months. In a naïve population, it is unlikely that participants have ruminated on their perceptual phenomena in the way that a diagnosed population might have, so it is possible that this participant experienced VS at timepoint one, but only came to realise this after completing our study. Importantly, this was not a characteristic of most respondents.

Finally, at the group level, we showed that scores on the VSHI were stable over time, among people whose experience of VS was stable. This suggests that, while the numbers and types of perceptual experiences fluctuate, their impact does not. This should be reassuring as it supports the theory that perceptual phenomena associated with VSS may be somewhat normal in the general population, when experienced occasionally and without negative impacts on quality of life. Our data indicate that the most severe presentation was equivalent to only 'moderate handicap' on the VSHI. Most participants in our sample scored in the 0–5 range, indicating that their perceptual experiences have minimal impact.

A limitation of this study is that it was conducted in a population of undergraduates. While this allowed us to collect a large sample of participants with no prior knowledge of VSS, it does mean that our data relate only to participants with a specific level of education. In future, the MVSQ should be used samples spanning a range of educational achievement, to assess whether education impacts responding. Importantly, previous studies conducted in populations without specific education levels have consistently identified that approximately 40% of people experience visual snow from time to time and that most people will experience at least one symptom of VSS some of the time.[6,8,9] However, the impact of education on responses to this questionnaire should be thoroughly tested.

Conclusion

In summary, the Melbourne Visual Snow Questionnaire (MVSQ) is a valid research tool which will enable future VSS researchers to study populations with subclinical VSS in addition to, or compared to, samples with confirmed, clinical VSS. This will enable a more thorough understanding of the VSS phenotype.

We have also presented evidence that VSS symptomatology varies over time, more substantially than was previously thought. In a naïve population, none of the MVSQ's key outcomes were stable across the 6-week testing period. Given the dearth of longitudinal research into VSS, it is important to understand whether this finding generalises to people with confirmed VSS, and to over which timeframes. Research should also consider investigating factors which correlate with changes in the subjective severity of VSS. This will improve our understanding of both VSS, and the 'normal' experience of perceptual phenomena associated with VSS. It may also further our understanding of the pathophysiology of both visual snow and its syndrome.

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Author Contributions

Dr. Thompson and Dr. Forte designed the study. Dr. Thompson managed data collection, conducted statistical analyses, and drafted the manuscript. Dr. Goodbourn reviewed the manuscript. Dr. Forte edited the manuscript and supervised the project.

Conflict of Interest

The authors report no conflicts of interest.

Data Availability Statement

The data that support these findings are available from the corresponding author on request.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1.