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Visual Hallucinations and Illusions as Missed Diagnostic Clues in Autoimmune Disease: A Patient Perspective

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Abstract

Non-psychotic visual hallucinations and illusions (referred to here as NVHIs), such as visual snow, can be indicators of serious underlying pathologies, including Systemic Autoimmune Rheumatic Diseases. In this *Patient Perspective* article, I recount some of the impacts of NVHIs, and their attribution/misattribution, on my autoimmune diagnostic journeys. I then draw on these experiences, and the literature, to suggest improvements to policies and practice. It is hoped that these types of changes could contribute to NVHI-related diagnostic opportunities being less often missed.

Keywords

autoimmune, SARDs, Sjögren's Disease, hallucinations, visual snow, diagnosis, diagnostic overshadowing, patient experiences

Introduction

Delays in diagnosing and treating Systemic Autoimmune Rheumatic Diseases (SARDs) are common and contribute to long-term damage.[1] Causes of delay include the misattribution of neurological symptoms of undiagnosed SARDs to psychiatric disorders or to presumed patient characteristics, such as attributing lupus fatigue to "teenage laziness."[1] Among the least researched SARD neurological symptoms are non-psychotic visual hallucinations and illusions. Visual hallucinations are defined in the medical literature as perceptions while awake in the absence of an external stimulus, and illusions as distorted perceptions of external stimuli. Non-psychotic visual hallucinations and illusions (NVHIs) are ones with insight. NVHIs is a term I coined to retrospectively describe some of the symptoms included in my medical records (rather than it being a formal diagnosis I was given). It is also suggested here that NVHIs could prove a useful clinical construct (with proposed categories in Supplemental material, Table A). "Simple"/"unformed" NVHIs (the main focus of this article) include for instance light flashes/photopsia and visual snow, and can be highly intrusive but otherwise relatively benign. They can also, however, be indicators of serious underlying pathologies,[2] some of which (as reported in Supplemental material, Table B) are causally associated with SARDs, including encephalopathies, CNS vasculitis, malignancies, retinopathy, and stroke. For example, the risk of stroke in systemic lupus erythematosus (SLE) is between double and triple that in the general population,[3] and stroke can cause visual snow.[4] In addition, Sloan et al, found that 31% of SARD patients (compared to 9% of healthy controls) reported having experienced non-correctable with glasses "visual changes….e.g. visual snow, after images…" more than three times in their lives.[5] Despite their association with SARDs, however, I have been unable to find case reports of what I have called simple NVHIs making a significant contribution to SARD diagnoses. This may indicate that simple NVHIs represent an important and addressable source of missed diagnostic opportunities/clues.

It is not, however, being argued here that the missed opportunity in my case was a failure to recognize my NVHIs as SARD/SARD-related symptoms, as it remains unclear whether mine are. Rheumatologists seen are divided on the question, and 9 years after the symptoms began I am still waiting to see neuro-ophthalmology for a specialist opinion. The personal experience informed contention is instead that for simple NVHIs to fulfill their potential as diagnostic clues in SARDs and other conditions, it may be

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necessary for patients to feel comfortable to report them, and for clinicians to recognize them as possible symptoms of non-benign pathologies, to be determined in the context of the patient's other signs and symptoms. Findings from the few SARD studies[5,6] with a focus on what I have called simple NVHIs appear consistent with some of my experiences (recounted below in the main text and in Table 1 - "*Diagnostic journey time-line*"). Of particular note, Arunasalam et al, concluded that "understanding … [simple and complex] hallucinations as potential direct effects of SLE could improve attribution, treatment, … while reducing stigma…".[6] In addition, the SARD diagnostic journey literature identifies a number of general problems (such as with referrals)[1,5,7] which applied in my case in relation to simple NVHIs.

Personal Perspective

Having been in good physical health all my adult life, in 2015 I began accumulating rheumatological-type symptoms (Table 1, rows 2–3). In 2016, NVHIs were added, including (to-date permanent) visual snow, after-images, light flashes, spider's web-like squiggly lines and a large gray "blob," swirling "clouds" and "self-lighting" of the eye when shut, and night blindness (row 4). After a 12 month wait, I saw NHS (National Health Service) ophthalmology who advised seeing neuro-ophthalmology. As I was told this was not available in Wales, I asked for an NHS referral to England, which the local health board refused (rows 9, 11–12). In 2019, I moved health board areas within Wales and in 2022 rheumatology in my local hospital referred me to an English NHS trust with neuro-ophthalmology (rows 13, 17). The trust later said that it never received this 2022 referral, rheumatology said it never received the trust's rejection of its second attempted referral in 2023, and the trust said it never received rheumatology's 2025 third attempted referral (rows 20, 21, 24–27). Thus, 9 years after my NVHIs began, I am still "waiting" to see neuro-ophthalmology. In the meantime, I was diagnosed with anti-phospholipid syndrome (APS) (a systemic autoimmune condition) (row 8), the SARD Sjögren Disease (row 14), and a range of idiopathic diagnoses (eg, cerebral small vessel disease) (row 7). The NVHIs have continued to progress with, for instance, white surfaces now having a pink hue; and I was knocked unconscious in 2022 in an accident arising from the NVHIs (row 18). It remains unclear whether my NVHIs are SARD symptoms or symptoms of an undiagnosed condition, and I have so far received no treatment for them. On the positive side, in 2019 I joined Cambridge University's ongoing SARD studies as a "patient researcher".

It is not possible from the contradictory NHS England and Wales accounts to determine why administratively I have still not seen neuro-ophthalmology, while not having seen them may help explain the uncertainty that surrounds the etiology of my NVHIs. Nonetheless, the NVHIs and how clinicians responded to them do seem to have impacted my autoimmune diagnostic journeys. It may have speeded-up the APS diagnosis as the rheumatologist in 2017 took account of the visual symptoms—along with eg, "obvious ischaemic changes"—in suspecting APS. This suspicion in turn led to autoimmune blood tests which contributed to the Sjögren Disease diagnosis. However, as NVHIs can not be objectively verified (at least without a functional MRI), and clinician knowledge of them is limited, they were vulnerable to initially being dismissed in primary care as imagination/exaggeration or anxiety. This in turn seemed to contribute to the GP also attributing more physical symptoms (such as swollen hands) to anxiety. Despite these uncertainties as to the NVHI's net diagnostic impact, my diagnostic journey, combined with the literature, arguably casts some light on why the diagnostic opportunities NVHIs offer may be missed. In addressing these issues, I focus on five critical elements of the diagnostic process.

History taking and differential diagnoses: More detailed history taking may have reduced the misattribution of the NVHIs. I cannot, for example, recall a clinician asking about the symptoms that arose at the same time as the NVHIs (such as fever and acute cognitive confusion), and which may have pointed towards possible NVHI etiologies. When I did give a history unprompted it generally felt like it went unheeded. For instance, a clinic letter reported "floaters" (a generally benign phenomena) which I had not mentioned but did not mention any of the neuro-ophthalmological symptoms that I had reported. On the other hand, consistent with Arunasalam et al's findings about SLE patient reluctance to report hallucinations,[6] I did not report my hypnogogic [ie, experienced between sleep and wakefulness] hallucinations for fear that doing so would further fuel GP attribution of my symptoms to anxiety. In addition, with the exception of rheumatology, there appeared to be little differential diagnosis. A neurology clinic letter, for instance, recorded "visual disturbance" under "diagnosis" and did not recommend investigations into what might be causing this. Indeed, there appeared to be a general lack of "diagnostic ambition," with more institutional incentive to see patients and reduce waiting lists than to diagnose them.

Referrals: Problems with history taking and differential diagnosis led to problems with referrals. For instance, the clinic letter which only reported "floaters" (referred to above) appears to have contributed to the GP deciding that a neuro-ophthalmology referral was unnecessary. Recent research found that GPs not recognizing SARD symptoms, refusing to refer, and/or inappropriate referrals (eg, to psychiatry not rheumatology) could be among the principal reasons for delayed SARD diagnoses.[1] As illustrated with my attempts to get a neuro-ophthalmology referral, there are particular problems in Wales. These are on account of a shortage of some specialists, noted in other studies[7]; and the NHS Wales out of area/"prior approval" policy which entails an apparently chaotic and inequitable process in which clinicians must apply to their local health board for permission to make a cross-border referral, and which the British Medical Association has criticized.[8] In my case, the health

Table 1. Diagnostic Journey Time-Line.[a]

	Dates	Occurrences	Details
1.	Childhood	*Meningitis*	*C/S:* Meningitis followed by sudden onset OCD (Obsessive Compulsive Disorder).
2.	Adulthood to 2014	*Good health apart from OCD*	*Hc:* Very limited use of healthcare.
3.	2015	*Rheumatological-type symptoms began*	*Hc:* Brain MRI found widespread white matter hyperintensities. "Differential … includes ischaemia or demyelination" (Radiology report).
4.	2016 (Aug.)	*N-O symptoms began*	*C/S:* N-O symptoms included visual snow, after-images, light flashes, "splodges" of color, squiggly black lines and a large gray "blob" in my field of vision, and swirling cloud like shapes and "self-lighting" of the eye when shut, and night blindness.
5.	2016 (Aug.)	*A&E visit*	*Hc:* Visited A&E as the GP said an NHS ophthalmology referral would take 6 months. Only A&E investigation was a standard visual acuity test.
6.	2016–2017 (Feb.)	*Additional symptoms*	*C/S:* Swollen fingers and feet, livedo reticularis, fever, acute confusion, hair falling out, fatigue etc *Hc:* GP suggested that anxiety could explain most of these and the N-O symptoms.
7	2017 (Spring)	*Idiopathic diagnoses*	*Hc:* Diagnoses made without appearing to consider underlying conditions which might explain/link some or all of the symptoms. Diagnoses included osteoporosis, TMJ, PETD, pulsatile tinnitus, alopecia, and cerebral small vessel disease. Brain MRI showed possible "cerebellar infarct" but this was apparently not noticed until the scan was reviewed in 2023.
8.	2017 (July)	*Antiphospholipid Syndrome (APS) diagnosed*	*Hc:* Privately seen rheumatology consultant began anti-platelet medication for suspected APS. *Coms:* Rheumatologists have been/are divided on this diagnosis.
9.	2017 (Autumn)	*Ophthalmology appt.*	*Hc:* NHS ophthalmologist felt the visual problems were mostly neurological. As there was no neuro-ophthalmology in Wales, I asked the GP to refer me to neuro-ophthalmology in England.
10.	2017 (Winter)	*Depression and anxiety*	*C/S:* Developed depression for the first time in my life. *Hc:* In 2026, I am still waiting for NHS Wales CBT (Cognitive Behaviour Therapy) requested in 2017.
11.	2018 (July)	*GP requested N-O referral*	*Hc:* After a complaint, the GP agreed to apply to the health board for an "out of area" referral to neuro-ophthalmology in England.
12.	2018 (Oct.)	*Health board rejected N-O referral request*	*Hc:* Health board rejection letter to GP stated: "Your letter states that the patient … believes he has various rare elusive underlying medical conditions … you have correctly advised the patient that you are unable to refer him out of area when investigations can be undertaken locally." *Coms:* There was no neuro-ophthalmology in Wales.
13.	2019 (Jan.)	*Moved health boards within Wales*	*Hc:* I again asked to be referred to N-O, was again referred to ophthalmology, who (as with the previous ophthalmology appt) said I needed to see N-O.
14.	2022 (Jan.)	*Sjögren Disease diagnosed*	*Hc:* Wales-Rheum diagnosed Sjögren Disease as I met the criteria *(eg, "*highly positive" for RO52 autoantibodies).
15.	2022 (May)	*Neurology appt.*	*Hc:* Neurologist diagnosed Visual Snow Syndrome (VSS). As I did not seem to meet the criteria for VSS - eg, some of the co-arising N-O symptoms were not possible VSS symptoms—I wrote asking for a second opinion but did not receive a response.
16.	2022 (June)	*Severe hypertension discovered*	*Hc:* No clinician (nor I) had thought to test my BP from the time I started getting ill in 2015 until June 2022 when I registered with a new GP. The new GP found it was beyond the point at which A&E attendance is highly recommended. This was in the absence of any usual risk factors (eg, I had a normal BMI).
17.	2022 (July)	*First Wales-Rheum N-O referral attempt*	Wales-Rheum says it made an NHS referral to a named neuro-ophthalmologist in England in July 2022. The English Trust (EngNO) has stated—in response to my 2025 complaint [Row:25]—that it never received this referral.
18.	2022 (Sept.)	*Knocked unconscious*	I was knocked unconscious as result of an accident arising from N-O visual problems.
19.	2022 (Dec.)	*Mix-up with ophthalmology appt.*	*Hc:* Referred to a Wales ophthalmologist with an interest in Connective Tissue Diseases. At the appt I was told he was not there but I was able to speak briefly (between his appointments) to Wales's only neuro-ophthalmologist (appointed since I had been asking for an N-O appointment).
20.	2023 (May)	*Second Wales-Rheum N-O referral attempt*	Wales-Rheum made a fresh NHS referral to EngNO.
21.	2023 (July)	*EngNO rejected the referral*	*Hc:* EngNO has stated (in response to my 2025 complaint [Row:25]): "Your referral letter was sent back on 23 July [2023] to your consultant … with the following: 'Dr [name redacted] is not taking named referrals …. If you wish for this patient

(continued)

Table 1. (continued)

	Dates	Occurrences	Details
			to be reviewed at [EngNO], the referral will be assigned to another consultant'." *Coms:* No one told me the referral had been sent back and Wales-Rheum say they have no record of it being sent back.
22.	2023 (Winter)	*EngNO text told me I'm "on a waiting list"*	*Hc:* The text said I was on the waiting list and will be contacted "in due course." But I never heard back. *Coms:* It is not clear why EngNO would have sent this text if my referral had been rejected in July 2023 [Row:21].
23.	2024	*Overwhelming tinnitus became my focus*	*C/S:* Tinnitus had gone from none in 2014 to 3 distinct noises in 2015 to well over 10 in 2024, some of which is pulsatile and audible to the ENT with auscultation. *Hc:* ENT did not take a history, link the tinnitus with other symptoms or suggest an etiology other than "age-related." As I had not aged centuries in eight years this explanation seemed inadequate.
24.	2025 (May)	*Third Wales-Rheum N-O referral attempt*	*Hc:* Wales-Rheum made a new referral to a different named consultant at EngNO (as EngNO suggested it should) [Row:21].
25.	2025 (June)	*I complained to EngNO*	*Hc*: The complaint asked what had happened with the various referrals. I also made a Data Protection Act (DPA) request to EngNo for my medical records. Under the DPA this should have been provided within 21 working days but 8 months later I am still waiting.
26.	2025 (Oct.)	*EngNO responded to the complaint*	*Hc*: EngNO stated that they had not received the first Wales-Rheum referral and that their response (referral rejected) to the second Wales-Rheum had been sent to Wales-Rheum.
27.	2025 (Nov.)	*I chased-up third Wales-Rheum N-O referral*	EngNO indicated that they did not receive the third referral from Wales-Rheum (from May 2025). [Row:24]).
28.	2025 (Dec.)	*Resigned to no help with N-O symptoms*	*C/S:* N-O symptoms have slowly worsened since 2016. *Hc:* It is unclear whether I am any closer to seeing neuro-ophthalmology.
29.	2026 (Jan.)	*Postscript*	I received a text from EngNO (similar to the text received in 2023 [Row:22]) stating: "we will be in contact to schedule your appointment within an appropriate medical timeframe." I am not "holding my breath."

[a]*Key:* C/S = Conditions and symptoms. Hc = healthcare. Coms = Author comments. N-O = neuro-ophthalmology or neuro-ophthalmological. EngNO = English NHS Trust with neuro-ophthalmology. Wales-Rheum = Author's local rheumatology department. Aptts = appointments. NHS = National Health Service. A&E = Accident and Emergency.

board application seemed half-hearted/ironic in that I pushed the GP to make it but he worded it in such a way as might indicate that it should be rejected. In particular, it states: "He has a plethora of symptoms for which he has been investigated very very thoroughly … but still feels he has a connective tissue disease"; and goes on to stress OCD as a factor. Four years later I was diagnosed with Sjögren's, a connective tissue disease.

Coordination and the proactive patient. Arguably, the most consequential problem was that no clinician saw it as their role to drive forward and coordinate the diagnostic process. As "gatekeepers" to secondary care, GPs seem best placed to perform this role but this may not in general occur.[1,7] In my case, this meant that the diagnostic journey kept running into the ground. In particular, when MS was ruled out (as the lesions were "more ischaemic than demyelinating"), the GP wrote that there had now been "sufficient investigations." Compounding these problems was a general lack of coordination between specialisms. As a result, I felt that it was left to me to coordinate and keep restarting my own diagnostic process, such as seeing a rheumatologist privately to find out what might be causing the "ischaemic" lesions. Patients being proactive—eg, suggesting referrals—often leads to the correct diagnosis in SLE.[1] Reliance on patients, however, seems highly inequitable in that those most in need of a rapid SARD diagnosis (such as someone with vascular dementia) may be least able to orchestrate one. In addition, patients in general may not have the knowledge to know what tests/referrals would be most useful nor (as illustrated in this article) the power to ensure that tests/referrals are undertaken/made.

Practical Recommendations

1. *For academics:* Increase research on NVHI prevalence. The absence of NVHIs from clinical guidance may contribute to them not being recognized as possible indicators of non-benign conditions. However, the inclusion of NVHIs in SARD guidance requires more data on how prevalent different NVHIs are in different SARDs.
2. *For the Welsh government:* Scrap the current NHS Wales out of area/"prior approval" policy. The policy asserts that it ensures equity of access but seems to most disadvantage those on low incomes who cannot afford a private appointment in England.
3. *For Clinicians:* Approach diagnosis "as a team endevour,"[9] and learn more about NVHI etiologies. Being told by an ophthalmology nurse that "everyone has visual snow, but some focus on it" could have left

me feeling like a fraud if I hadn't known how rare visual snow is. In addition, believe patient neurological symptom reports. Those reporting multiple symptoms may have a systemic disease, not health anxiety.

4. *One eye open test:* Initially, my squiggles etc were attributed to collagen "floaters," and the blue light flashes to Posterior Vitreous Detachment. It seems possible that these apparent misattributions could have been avoided with one simple question: "Are the patterns/appearances the same with the right eye open and the left shut and the left open and right shut?" That mine are suggests their origin lies with the brain/visual pathway and not the vitreous of the eye.

This article is a I hope honest but inevitably biased personal account, and I make no claims as to the generalizability of the findings. Nonetheless, it may resonate in parts with other people's experiences and perhaps suggest lines of inquiry for future studies, including ones involving representative samples of patients and clinicians.

Conclusions

Simple NVHIs (such as visual snow, illusory palinopsia, and light flashes) if interpreted along with symptoms that arose at the same time can be indicators of serious underlying pathologies. However, my diagnostic journey experiences suggest that limited clinician knowledge of NVHIs and their associations, and issues with history taking and referrals, may contribute to these diagnostic opportunities being missed. In addition, while health service plans[10] tend to focus on care/treatment for diagnosed patients, the SARD literature,[1,7] consistent with my experiences, indicates that a timely correct diagnosis is a neglected but equally critical component of quality care.

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Any Other Identifying Information

Information redacted for review:

Under "Personal perspective": "On the positive side, in 2019 I joined [redacted for review] University's ongoing SARD studies as a 'patient researcher'. "

This should read: "On the positive side, in 2019 I joined Cambridge University's ongoing SARD studies as a 'patient researcher'."

Author Contributions

The shown author is the only author. The four people included under acknowledgements gave invaluable feedback.

Data Availability Statement

Data for this self-study consists of the author's medical records. These are not available to be shared, as it would risk revealing clinician and institution identities, and unnecessarily compromise patient (ie, the author's) privacy. However, the author is happy to try and answer any specific questions relating to the data.

Declaration of Conflicting Interest

The author declares no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval and Consent

The study (which this self-study was a part of) was approved by Swansea University's Research Ethics Committee (approval no. SUMS RESC 2022-0008) on March 1, 2023. Participants gave both written informed consent and then verbal informed consent before being interviewed. The author of this article was the study investigator and so his informed consent was implicit in him writing this article and was not otherwise required.

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