Post-Viral Olfactory Loss: A Survey of One Hundred and Twenty Patient Experiences

# Key Points

1. The age range of patients responding to the survey was 28-85 with a mean of 58 ±12 years with the duration of their disorder less than 5 years in 63% of cases.
2. Patients experience variable treatment, if at all, for post-viral olfactory loss
3. If treatment is given oral and/or intranasal steroids are typically given.
4. Several patients reported receiving imaging despite this not being clinically useful when there is a clear history and normal examination.
5. Over two thirds of patients experience parosmia and up to 5 years of the onset of the problem were still actively seeking a solution.

# Introduction

Loss of smell is a common complaint in adults and yet has been underestimated. Anosmia, complete loss of smell, is thought to affect at least 1-5% of the population1. Based on European estimates, anosmia is more prevalent than profound hearing loss or blindness in the UK. Causes for olfactory loss are varied but the main diagnostic groups include sinonasal disease (62%) and post-viral olfactory loss (PVOL) (11%)2. Olfactory dysfunction has now emerged as a key symptom in the coronavirus pandemic and it is possible we may see a cohort of patients with lasting problems following the peak of the Covid-19 impact3. Historically, there is wide variation in clinical practice reported by clinicians to patients on prognosis or treatment4. Guidelines for the overall management of olfactory disorders now exist in the Position Paper on Olfactory Dysfunction5 but the impact of those guidelines may yet need to penetrate routine clinical practice.

Previously published data has shown the high impact on quality of life experienced by olfactory disorder patients, including depression, anxiety, impairment of eating experience, feelings of isolation and relationship difficulties6. Most patients suffer a loss of flavour perception which can adversely affect their appetite, but this can be made even worse when parosmia is also present. Given the number of potential treatment options for PVOL that have been proposed but yet to undergo formal evaluation through a randomised clinical trial7, there is a pressing need to deliver more RCTs in this area. A recent German study has highlighted Vitamin A as a potential therapeutic agent for further evaluation8. In anticipation of setting up a clinical trial to evaluate the role of vitamin A intranasally for PVOL, a survey was set up at the Norwich Clinical Trials Unit in conjunction with Fifth Sense to establish the current experience of PVOL sufferers and any treatments they currently receive for their symptoms in routine practice.

# Materials and Methods

A survey designed by the authors (clinician and patients with olfactory loss) was uploaded on to the RedCap server at the Norwich Clinical Trials Unit and a secure link was then circulated to members of Fifth Sense via e-mail as part of the Public and Patient Involvement in the proposed trial application. The questions were designed to set the scene for the experience of PVOL sufferers in the UK and beyond. The survey was live for 2 months at the beginning of 2019.

## Survey Questions:

Only the questions that did not refer specifically to involvement in a clinical trial are listed here.

1. Do you have a reduced sense of smell because of a bad cold/infection you suffered? If no, you can stop the survey here.
2. Did you suffer the cold/infection … less than 5 years ago? more than 5 years ago?
3. Have you suffered from smell distortions (parosmia) or smell hallucinations (phantosmia)?
4. Have you received any treatment to date?
5. What treatment did you receive?
6. Do you have any of the following problems?
   * Chronic rhinosinusitis (CRS) with or without nasal polyps?
   * Allergic rhinitis (hayfever)?
   * Severe deviation of the nasal septum?
   * I am using nasal medications at the moment
7. Do you have any comments about smell loss due to a bad cold?
8. If you are willing, please tell us your age

# Results

There were 142 Fifth Sense members who responded to the survey; of these 120 declared they had PVOL.The age range was 28-85 with a mean of 58 ±12. The duration of their disorder was less than 5 years in 63% of cases, with 64% reporting the presence of parosmia. In terms of treatment received, 48% had not received anything from their GP/specialist. Interestingly 26 members stated they also had CRS and 30 allergic rhinitis, with only 7 reporting severe septal deviation. Only 24 members reported they were currently using nasal medications. Prior medication use included oral and intra-nasal corticosteroids (OCS, INCS) as the most commonly given. Additionally, antibiotics were received by some patients despite any evidence to support this. Figure 1 shows the treatments reported by respondents with only 52% of respondents having been prescribed any treatment. Nine patients also reported having undergone an MRI and/or CT scans, neither of which are indicated if the history is clear and endoscopy shows no evidence of chronic rhinosinusitis or other intranasal pathology.

## Quotations from survey participants

Participants were asked to leave comments and many did. Here are a few examples:

*“I found my loss of smell, and therefore taste, to be drastic and so sudden when it happened. Nothing like the small loss you get with a 'normal cold'. In the early days I did go in to panic mode a few times until I reminded myself 'it could be worse'!! My loss has been nearly 18 months now and I have regained many parts of my smell. I wouldn't like to say I smell as others do but some smells/taste have allowed me to enjoy some foods... 'fish' was one of the first smells I partially gained.*

*“I lost my very sensitive sense of smell suddenly after a really bad infection. I went to my GP a few months later but he said bad luck. He did not refer me to an ENT specialist, so I do not know if I have any of the medical conditions mentioned. The only thing I can smell consistently is orange peel. Very occasionally I get a brief 'glimpse' of another smell e.g. fish or carnations. This is why I answered yes re hallucinations, although sometimes the thing I smelt was present, not an hallucination.”*

*“It was a prolonged dose of bad cold then flu in the run up to Christmas 2017 that finally wiped mine out. I could taste something when I started eating my Christmas dinner but by the end of the meal I couldn't taste or smell anything. Since then its improved a little but only a little and something has really left my life. It’s taken the colour from day to day life.”*

*“I have only ever had the flu twice in my life, with the last bout in January 2018 resulting in the complete loss of my sense of taste and smell. I still remember the point at which the loss occurred. It was a serious flu, around the time the Ozzy Flu epidemic was rife in the area I live. The virus left me bed ridden for a few days and it was around the 4/5 day where the virus was at its worst that I remember a complete blockage occurring where I struggled for breath, and after this point I have been unable to taste or smell anything.”*

# Discussion

The survey helps to delineate the paucity of treatment provision for this particular group of patients with olfactory dysfunction. Although PVOL represents a smaller percentage of the causes of olfactory disorders overall compared to chronic rhinosinusitis2, the latter condition benefits from greater attention and PVOL patients typically make up a higher percentage of attendees in a specialist clinic (typically about 25%)9. Managing smell loss has previously been identified as a source of frustration for clinicians in Otorhinolaryngology, in part due to the lack of therapeutic options to deploy4. A number of medical and complimentary medicine options have been studied in case series but precious few have been subjected to the scientific rigour of a randomised controlled trial7. The recent position paper on olfactory dysfunction has outlined the utility of smell training5 but despite increasing uptake of this option through information provided on the Fifth Sense website, significant numbers of patients remain markedly affected. It is perhaps the apparent dearth of therapeutic agents that are deemed effective by clinicians that leads to the picture we see here of half the patients reporting a lack of treatment; certainly 93% of participants expressed a strong willingness to participate in any future trials. Whilst this survey may be biased in its respondents being those who have a persistent olfactory disturbance, they do represent a group of patients who are yearning for new treatment options to be made available.

Post-viral olfactory loss typically occurs following viral injury to the olfactory epithelium that leaves the olfactory sensory neurones lacking in cilia and effectively non-functional10, although the current coronavirus, Covid-19 may wreak its havoc on the olfactory system by different mechanisms3. Treatment of this condition does require some insight into the pathophysiology in order to target potential pathways where therapeutic agents can act. It may be possible that stem cell therapy yields some hope in this area in the future but presently, Vitamin A topically has been promoted as providing the opportunity to stimulate regeneration of the olfactory epithelium. Due to the fact that olfactory system embryogenesis and adult neuronal regeneration involve retinoic acid, a metabolite of vitamin A, this simple and low cost treatment may herald an option for the near future8.

We hope that this survey will provide a platform for more RCTs to be conducted in the area of PVOL, by demonstrating evidence of a need in those persistently affected, but also that it serves as a reminder to clinicians encountering these patients to consider updating their knowledge of managing olfactory disorders, both in PVOL and other causes.

# Figures

### Figure 1: Prior medication use by respondents (number of respondents for each medication)

OCS = oral corticosteroids

INCS = intranasal corticosteroids

# References

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