

Barriers to accessing healthcare in patients with olfactory and gustatory disorders

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Introduction

Background and rationale

Smell is the forgotten sense; even when facing a problem with their sense of smell, patients often struggle to get recognition, let alone diagnosis or treatment from healthcare professionals. Olfactory disorders are as common as profound hearing loss and blindness affecting an estimated 5% of the population¹. Common causes of olfactory disorders include chronic rhinosinusitis, post-viral olfactory loss and post-traumatic olfactory loss² as well as it being present in the majority of cases of Parkinson's disease and common in Alzheimer's disease. We are now also witnessing the rise of sudden onset anosmia as a marker of Covid-19 coronavirus infection³⁻⁹. It remains to be seen how many new cases of lasting olfactory loss will arise from those afflicted by the pandemic.

Recent population studies have now identified anosmia as an independent risk factor for shortened longevity, even after controlling for dementia and cardiovascular disease¹⁰⁻¹³. It is not clear why this is so but may suggest that the olfactory system acts as a barometer of environmental impact on the central nervous system as a whole. As this phenomenon has been observed in several countries it clearly demonstrates that olfactory disorders deserve to receive greater attention than they currently do.

Taste is often thought to be lost by those affected by olfactory disorders due to the misperception of retronasal olfaction as a "taste" sensation. In reality only a small percentage of people reporting a problem with their sense of smell or taste experience a true gustatory disorder, but due to this common misperception alongside the need to be representative of all patients with chemosensory disorders, it is always important to encapsulate both senses within any work of this kind.

Fifth Sense, the UK charity for people affected by smell and taste disorders, was founded in 2012 when authors DB and CP met and agreed on the need for patient advocacy to tackle the unmet needs of patients affected by olfactory disorders. Since then, with the help of a growing membership, we have been able to characterise the significant impact of olfactory disorders on those affected^{14,15} and we have also become aware of the frustrations many members in their dealings with the medical profession and getting their sensory loss taken seriously¹⁵⁻¹⁷. In 2019, Fifth Sense was awarded a National Lottery Grant for £238,815 to enable it to develop and grow its work, including the establishment of a network of patient support hubs.

Objectives

Following on from the above, this study aimed to characterise the details of the difficulties faced by patients with olfactory disorders in accessing healthcare as a patient and public co-production¹⁸. This will help us jointly address these issues through the work of the National Lottery Grant in 2020-2023.

Methods

Study design

The study was designed as a cross-sectional survey of the experience of people affected by olfactory disorders in accessing medical care. A survey questionnaire was developed using a focus group meeting of the public, patients and clinicians. The survey was then set live online and ran for 16 weeks. It was promoted via social media internationally. As the survey was anonymous, there was no ethical approval sought. As a small charity, Fifth Sense does not have a research ethics committee, nor is it required to by our regulatory body but the board of trustees gave our full approval for the views of our beneficiaries to be captured in this way.

Setting

The survey was open to anyone globally with access to the world wide web and declaring themselves an affected individual and was promoted through social media channels including the Fifth Sense website, and its Facebook and Twitter accounts. The survey was launched via the website with the following introduction:

Fifth Sense is launching a survey to capture patients' experiences of navigating the healthcare system. We know that so many of you face real challenges in getting support, advice or treatment from your doctors, although there are success stories too. The survey has been designed to capture data that will highlight both these challenges and successes as part of our ongoing efforts to improve awareness amongst the medical profession and improve patient experience.

We believe that this is the first piece of research to focus specifically on this issue and we're very proud to be part of a multidisciplinary project team. Supported by a grant from Newcastle Medical School, Fifth Sense have partnered with Mr Sean Carrie and Stephen Ball from Newcastle Freeman Hospital and Newcastle University and Olfactory Mapmaker Kate McLean and her colleague Rachel Hancock. An event in Newcastle in November 2018 brought together Fifth Sense and Voice North members to share experiences and help with the design of the survey. Kate and Rachel made drawings that captured the issues discussed and asked guests to complete 'smell wheels' to visually represent their own smell experiences.

The results of the survey will be used to:

- *Inform Fifth Sense's ongoing efforts to raise awareness of smell and taste disorders amongst the medical profession and the need for widespread education/training for healthcare professionals*
- *Help us develop information aimed at both patients and healthcare professionals to help ensure that patients have the best possible experience when seeking medical advice*
- *Help future efforts to improve the patient journey through the healthcare system for people with a smell/taste disorder*
- *Provide data to support applications future research studies and projects*
- *Kate and Rachel are designing a poster to accompany the results which will visually represent some of the challenges faced by patients*
- *The results will be published in an appropriate medical journal and on the Fifth Sense website*

The survey is completely anonymous and should take no longer than 10-15 minutes to complete. It is based on the UK healthcare system but it should still be relevant if you are based in another country. We would like contributions from people outside the UK as this data may help to show that this is a global issue. We'd

also like to hear from parents of a child with a smell/taste disorder who have sought medical advice as it's important that your voices are heard too.

Participants

Eligibility criteria

All members of the public self-reporting a loss or disturbance of olfaction and/or gustation were entitled to participate in the survey.

Sources and methods of selection of participants

Survey participants were able to access the survey themselves free of charge via the web-based platform SurveyMonkey. Participants were self-selecting and could participate from any country internationally.

Data sources/management and variables

The survey asked for basic demographics including age and sex. Participants were asked to declare the underlying cause for their smell loss. Further questions explored participants use of medical services, costs borne in doing so and any resistance encountered. See appendix 1 for details.

Bias

We aimed to reduce bias in responses by making the survey widely available but inevitably, those who are not online or have access to the aforementioned social media would not have seen this opportunity. Although the survey was initiated in the UK and Fifth Sense membership is predominantly UK based, the international availability aimed to derive a broader healthcare view across other healthcare systems.

Study size and Statistical Methods

As this was an exploratory study, no sample size was set. Due to the nature of the study, descriptive statistics only have been utilised in reporting the survey data.

Results

Participants

A total of 673 participants recorded information on the survey during the study period. Not all 673 participants responded to every question, so percentages below are expressed with the total number of responses as the denominator. For reference there are currently 3000 people registered as members of Fifth Sense.

Descriptive data

Of the 673 participants, 510 were female and 160 were male. The age of participants ranged from 10 to 88, with a mean age of 56 and a mode age of 63. The geographic distribution of participants can be seen in figure 1 with 469 (70%) reporting their location as being in the UK. The aetiology reported for participants can be seen in table 1 with 28% reporting chronic rhinosinusitis, allergic rhinitis or Aspirin/Non-Steroidal

Exacerbated Respiratory Disease (A/NERD) and 25% reporting post-viral olfactory loss (PVOL). The range of duration of reported olfactory disorders was 1 month to 67 years with a mean of 13 years and a mode of 2 years.

Main results

Recognition of the olfactory disorder as a significant problem

Getting recognition from doctors that their condition is a significant problem for them was challenging for some participants, with 64% reporting that their GP positively recognised their disorder and 76% reporting recognition by an Otorhinolaryngologist ; for those who had seen a neurologist, only 47% reported that they felt their disorder had been recognised and for those seeking a private specialist opinion, 66%.

Prescription of treatment

In primary care, 195 respondents (40%) reported receiving a prescription related to their olfactory disorder. In secondary care respondents reported receiving a prescription from 54% of Otorhinolaryngologists and 10% of Neurologists respectively. For those who sought private consultations, 46% reported receiving a prescription. Repeated treatments were reported from 31% of GPs and 37% of Otorhinolaryngologists. In terms of effectiveness of the treatment, 8% of GP prescriptions, 23% of ENT prescriptions, 2% of Neurology prescriptions and 20% of private prescriptions were deemed by the patients to have helped improve their sensory deficit.

Useful information and advice

In primary care only 7% felt that they received useful information and advice, with a rise to 33% for ENT and 13% in Neurology in secondary care and in the private sector only 28%.

Healthcare consultations

The range of reported GP consultations for respondents was 0 to 150 with a mean of 5.8 and a mode of 1. In Otorhinolaryngology the range was 0 to 75 with a mean of 4.6 and a mode of 1. For Neurology this was much lower with a range of 0 to 54 and a mean of 0.9 and similarly in private healthcare the range was 0 to 50 with a mean of 1.7. Seventy-one percent of respondents reported being able to get a referral to Otorhinolaryngology and of these 34% were given a choice of location but only 20% a choice of specialist. Information from the Fifth Sense website informed 29% to guide their choice of referral centre with 54% having to request the referral themselves and 59% stating they felt their case was recognised as needing a referral. Only 4% of respondents reported having their case declined by their local Clinical Commissioning Group but 40% felt that Fifth Sense information had helped the process of getting medical advice.

Travel and cost of healthcare appointments

Respondents were asked to estimate how far they had travelled in miles to seek information or treatment for their disorder and reported a range of 0 to 15250 miles with a mean of 200 miles. The personal cost of doing so showed a range of £0-41,100 (highest figure in USA) with a mean of £421.

Improvement and treatment impact

Only 138 respondents reported an improvement of their disorder with 89 (17%) saying they felt as if this was as the result of medical advice and/or treatment and 59 (11%) who felt that it was in response to smell training.

Quality of Life including mental health

All but 14 respondents reported an impact on their quality of life with 60% reporting either anxiety and or depression as a consequence of their sensory loss. Specific treatments reported included 102 taking GP-prescribed antidepressants/sedatives/anxiolytics, 42 taking over the counter remedies, 73 receiving counseling and other alternative therapies used included acupuncture, marijuana use and meditation.

Overall patient perspective

An open comments section was included to supplement the quantitative data that provided some important insights from our participants perspectives.

- *It is not really taken seriously. The attitude is almost " Well, at least you are not deaf or blind". The effect on my daily life is not recognised.*
- *I am low in mood. I hate eating and don't feel hungry. It affects my job and makes me feel unsafe from fire and gas leakages.*
- *I feel that even ENT specialists do not see this problem which truly affects your quality of life as even a problem.*
- *Feel like it's minimized by people and professionals who think it must be nice not to smell kids' dirty nappies or that you're only missing out on smelling flowers and cookies in the oven. It is a real issue - gas hob, smoke, taste diminishes, lack of shared experience with family, and memories compromised.*
- *Following treatment, I am able to smell again much of the time. It is so wonderful to be able to smell the ocean, to smell coffee brewing, to smell bacon or onions cooking. I can smell my husband's skin, or the soap he last used. I can smell the soap I use in the shower, which never ceases to amaze me. I can smell whether fruit is ripe or not. This is all incredibly wonderful, it adds such a richness to your life. Not to mention: I can smell gas, if the burner on the stove didn't turn on correctly, or paint, if a hallway is newly painted. I can smell if milk has gone sour. If I can smell these things I can protect myself from them better.*

Discussion

Key results

Our study serves to illustrate a number of significant issues faced by patients with chemosensory disorders. Firstly, a lack of recognition in the wider medical profession but still with 1 in 4 ENT specialists failing to convince their patients that they appreciated the impact of their olfactory disorder; this was even more noticeable in over half of neurologists encountered. In fact, it is evident that the experience of this patient group with neurologists was largely disappointing. Secondly, knowledge of appropriate treatments is lacking thus leading to no treatment or to repeated ineffective treatments being applied. This was further exacerbated by participants expressing little satisfaction with the usefulness of the advice given. Thirdly, accessing a specialist consultation was a challenge with 1 in 4 reporting difficulty in getting a referral. Due to the paucity of specialists dedicated to chemosensory disorders, respondents reported significant journeys and costs associated with that. Finally, mental health aspects of being affected by chemosensory disorders have been clearly highlighted and 15% reported taking prescribed medication for this, therefore also emphasising an additional healthcare burden.

Limitations

The survey will not have been seen by those who are not online or do not have access to the aforementioned social media. This is likely to have disproportionately affect the older generations. Due to the origin of the survey in the UK and with Fifth Sense being a UK based charity, over two thirds of the respondents reflect

their experience with the National Health Service setting in the UK. It is also possible that an unknown number of patients may have had a good response to treatment, but these cases will not be apparent if they are not Fifth Sense members or have chosen not to respond to the survey because they were happy with the outcome of their treatment. It may also be that the treatments applied were reasonable, but nonetheless proved ineffective in resolving or improving the olfactory disorder. The charity membership and survey respondents will also tend to be more likely to be those who have persistent symptoms and thus are more difficult to treat.

Interpretation

The demographics and aetiology of study participants was in keeping with the typical female predominance seen in other studies and with sinonasal disease and post-viral olfactory loss as leading causes¹⁹⁻²². The study also underlines the mental health impact of previous studies in those with olfactory disorders^{14,15,19}. However, this study makes a clear reflection on the paucity of services provided to this patient group and shows that the relatively poor engagement by the medical profession has changed little in nearly two decades²³. Our data would suggest this is clearly an issue in the UK healthcare setting, but international responses also suggest this is potentially a global issue with little emphasis placed on either the importance of these senses in everyday life or the consequences of losing them.

Generalisability

There is an unmet need for patients with olfactory disorders in accessing healthcare including engagement from the medical profession and signposting to appropriate information and treatment options. It remains to be seen as to whether the current wave of Covid-19 related smell loss as a result of the global pandemic will give rise to an increase in patients presenting with post-viral olfactory loss but with an estimated rate of anosmia globally of 5% and hyposmia up to 20%, these disorders are common and engagement from the medical profession is not matching this. This underlines the *raison d'être* of Fifth Sense which amongst its strategic aims is the need to improve education of the role of these senses in everyday life as well as providing support for those affected by these disorders. To move this forward, Fifth Sense plans to work with the medical profession to not only provide patient support, but also to work with the wider body of stakeholders that need to be engaged in improving the current situation faced by these patients in accessing suitable care, including appropriate psychological support.

Authorship in conjunction with the ICMJE criteria

Steve Ball – 1, 2, 3

Duncan Boak – 1, 2, 3

Joanne Dixon – 1, 3

Sean Carrie – 1, 2, 3

Carl Philpott – 1, 2, 3, 4

Please see attached author statement forms

Conflict of Interest

There is no declared conflict of interest.

Funding

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Reporting guidelines

This study has been reported in line with the Strobe guidelines

Tables

Table 1: Survey Responses (part 1)

Question	Yes	No	% yes
Have you been seen by a GP?	Have you been seen by a 507	Have you been seen by a 27	Have you been seen by a 95
ENT specialist?	444	68	87
Neurologist?	112	221	34
Private provider?	130	199	40
Have they recognised your smell/taste disorder is a problem to you?	Have they recognised your smell/taste disorder is a problem to you? 319	Have they recognised your smell/taste disorder is a problem to you? 178	Have they recognised your smell/taste disorder is a problem to you? 64
GP	304	104	75
ENT specialist	58	66	47
Neurologist	99	50	66
Private provider	Have you been prescribed any treatment? 195	Have you been prescribed any treatment? 293	Have you been prescribed any treatment? 40
Have you been prescribed any treatment?	238	199	54
GP	11	114	9
ENT specialist	69	78	47
Neurologist	Have they provided you with any useful information or advice about your condition? 35	Have they provided you with any useful information or advice about your condition? 456	Have they provided you with any useful information or advice about your condition? 7
Private provider	149	298	33
Have they provided you with any useful information or advice about your condition?	17	111	13
GP	41	107	28
ENT specialist	Have you been prescribed the same treatment by them on more than one occasion? 149	Have you been prescribed the same treatment by them on more than one occasion? 298	Have you been prescribed the same treatment by them on more than one occasion? 33
Neurologist	17	111	13
Private provider	41	107	28
Have you been prescribed the same treatment by them on more than one occasion?	Have you been prescribed the same treatment by them on more than one occasion? 149	Have you been prescribed the same treatment by them on more than one occasion? 298	Have you been prescribed the same treatment by them on more than one occasion? 33

Question	Yes	No	% yes
GP	123	269	31
ENT specialist	131	223	37
Neurologist	2	85	2
Private provider	34	86	28
Has any treatment prescribed by them improved your sense of smell/taste?	Has any treatment prescribed by them improved your sense of smell/taste?	Has any treatment prescribed by them improved your sense of smell/taste?	Has any treatment prescribed by them improved your sense of smell/taste?
GP	30	349	8
ENT specialist	81	270	22
Neurologist	2	90	2
Private provider	25	99	20

Table 2: Survey Responses (part 2)

Question	Yes	No	% yes
Have you been referred to an ENT Specialist by your GP/Neurologist?	389	158	71
Were you given a choice of location?	148	284	34
Were you given a choice of Specialist?	87	348	20
Did you use information obtained from Fifth Sense?	134	330	29
Did you request a referral?	265	227	54
Were you offered a referral?	251	225	53
Was your case recognised as needing a referral?	274	185	60
Was your case declined by the local Clinical Commissioning Group (CCG) so your GP was unable to help you?	12	294	4
Has information provided by Fifth Sense helped you in your efforts to get medical advice?	223	339	40
Do you consider that your smell/taste disorder has affected your quality of life?	548	14	98

Question	Yes	No	% yes
Have you suffered from anxiety or depression as a result of your smell disorder?	340	221	61
If yes to anxiety or depression, have you?	If yes to anxiety or depression, have you?	If yes to anxiety or depression, have you?	If yes to anxiety or depression, have you?
Taken any medication prescribed by your GP? (e.g. antidepressants, sedatives, anxiolytics)	102	238	30
Taken an over-the-counter medicine?	42	298	12
Taken an alternative medicine remedy?	75	265	22
Received counselling?	73	267	21
Do you think your ability to smell/taste has improved since you first encountered problems with it?	138	376	27
Do you feel that this is as a result of medical advice and/or treatment?	89	353	20
Do you feel that this is the result of a complementary therapy such as smell training?	59	354	14

Table 3: Survey Responses (part 3)

	Mean	Range
How many appointments have you had in total with?	How many appointments have you had in total with?	How many appointments have you had in total with?
GPs	5.6	0-150
ENT specialist	4.6	0-75
Neurologist	0.9	0-54
Private provider	1.6	0-50

Figure Legends

Figure 1: Geographic distribution of survey respondents

Figure 2: Aetiology of respondents

Figure 3: Workshop in progress - Group discussions between participants, Fifth sense members, clinicians, researchers and artists to expand on the themes of the day – ‘mapping the patient journey & its challenges’.

Figure 4: “Customer journey” – workshop activity

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