

An unmet need: Patients with smell and taste disorders

Running title: Smell and taste disorders; a qualitative review

Abstract

Objectives

There are large numbers of patients with olfactory disturbance in the UK and shortfalls in assessment and support amongst mainstream practice in both primary and secondary care leading to significant quality of life impairment and potential missed diagnoses. The aim of this study was to determine the key themes which can be identified from the accounts of anosmia sufferers and to identify important areas to target for future research or service development.

Design

Qualitative analysis of written patient accounts from patients corresponding with a tertiary smell and taste clinic in the UK. This qualitative study utilised unstructured written patient accounts from consenting patients experiencing olfactory disturbances received by the Smell and Taste clinic. Framework analysis was performed using Nvivo 10 software.

Setting

Tertiary Smell and Taste Clinic

Participants

Consenting patients who contacted the Smell and Taste Clinic with accounts of their experiences.

Main Outcome Measures

Themes generated by qualitative analysis with Nvivo software.

Results

Accounts submitted by 71 participants were included in the analysis; age range 31-80 years, 45 females, 26 males. Themes identified include negative emotional impact, feelings of isolation,

impaired relationships and daily functioning, impact on physical health and the difficulty and financial burden of seeking help.

Conclusions

Olfactory disturbances have a wide-ranging impact on the lives of sufferers, compounded by a lack of knowledge of the disorder amongst clinicians. There is a role for further support and education both for sufferers and clinicians, as well as a need to improve our understanding of olfactory disturbance.

Key words

Olfaction, anosmia, hyposmia, phantosmia, quality of life, rhinology, depression

Level of evidence: 2c – outcomes research

Background

Olfactory disorders are reported to affect significant numbers of the population with prevalence estimated between 1-49%; people with anosmia account for approximately 5% of the population¹⁻⁵. There are a multitude of causes ranging from local nasal problems to central neural aetiologies with sinonasal disease and post-viral olfactory loss being the two most common⁶. Olfactory disturbance can be present due to use of certain medications and can also be a symptom of psychiatric disease, and growing evidence connects olfactory problems to serious neurodegenerative disease and even death⁷⁻¹¹. Olfactory disorders increase in incidence with age, even in an otherwise healthy population, in a similar manner to impaired hearing or sight, but whereas hearing and vision are readily investigated or tested and frequently improved or corrected today^{2,12,13}; similar management is not undertaken for olfactory problems. This inattention may be due to a lack of appreciation of the impact of loss of olfaction, ignorance regarding management strategies or frustration at a lack of good treatment options¹⁴.

Increasing evidence shows that sufferers of these disorders have a major impairment of their quality of life. Establishment of a registered charity in the UK, Fifth Sense, has helped to quantify some of these issues in patients, with a survey of 496 patient members in the UK conducted in 2014¹⁵. In specific response to their olfactory impairment they reported high rates of depression (49%), anxiety (47%), impairment of eating experience (95%), isolation (64%) and relationship difficulties (59%); these findings have been replicated in other studies^{7,16}. Most patients suffer a loss of flavour perception which can adversely affect their appetite, but this can be made even worse if distortions in their sense of smell (such as parosmia) co-exist^{17,18}. Adoption of poor dietary habits with negative impacts on their nutritional status and global health, as they will tend to eat a less varied diet¹⁸⁻²⁰.

Considering all of these negative connotations, patients who are afflicted by these disorders should rightly expect their problem to be taken seriously by medical professionals. This includes the discussions with patients at their consultations and with their onward management. An

increase in collective patient awareness about olfactory and gustatory problems in the wider populous has been demonstrated by growing membership of the patient support charity, Fifth Sense²¹, as well as an increase in referrals to dedicated smell and taste clinics such as the tertiary referral unit at the James Paget University Hospital (JPUH), the first dedicated Smell and Taste Clinic established in the UK. After opening in 2010, the Smell and Taste Clinic received a large amount of written correspondence from a body of patients in the UK requesting help; this increased rapidly following media articles to promote engagement events for Fifth Sense. Many correspondents wrote in great detail about their disorder and the way it had impacted on their lives as well as expressing frustrations about their difficulties in getting their health disorder taken seriously. In order to formally address the issues raised the research team proposed to carry out a *qualitative* analysis of these communications to add depth to the quantitative findings of the 2014 survey¹⁵.

Objectives

The primary objective of this study was to determine the key themes around patient pathways which can be identified from the accounts of anosmia sufferers, the secondary objectives are to determine whether there are any key areas to target for future research or service development and to establish what are the educational needs for doctors to be better equipped to deal with these problems.

Study design

Qualitative analysis of written reports sent in by patients. A qualitative methodology allows an opportunity to gain an understanding of underlying reasons, opinions, and motivations for data produced in quantitative research. Samples sizes are not calculated as recruitment is normally stopped when there is saturation of themes elicited from the analysis. In this circumstance there was an abundance of material with which to perform the qualitative analysis.

Ethical considerations

The study was given ethical approval by the West of Scotland Research Ethics Committee 4.

Participants and setting

Patients were approached for consent if they had previously contacted the Smell and Taste clinic at the Paget Hospital by e-mail or letter or if they attended the clinic during the study period between 01/06/2013 and 01/12/2014. The following criteria were used for participants:

Inclusion criteria:

- Any patient who had suffered a (self-reported) quantitative loss of smell (hyposmia or anosmia), irrespective of aetiology
- Any patient who had suffered a (self-reported) distortion in their sense of smell (parosmia/phantosmia), irrespective of aetiology

Exclusion criteria:

- Any patient aged 18 or over

Data collection and variables

Participants were sent an information sheet and consent form, either via e-mail, post or in person in the clinic, in order to obtain their written informed consent to participate in the study. Support for the study was given through Fifth Sense newsletters, mailshots and the charity's website (www.fifthsense.org.uk). The accounts of those who agreed to participate, were then anonymised, removing all identifiable links to the patient (e.g. name, date of birth) and any identifiable references to any hospitals or doctors with whom the patients have had prior contact. Where existing accounts given were brief, a hint sheet was provided to guide them to submit a more detailed account (appendix 1). As not all participants attended the clinic, olfactory testing was not included as part of the study.

Data analysis

A framework approach to analysis was undertaken, using NVivo qualitative software to manage data analysis. Framework analysis is a five-stage process that ultimately allows for sensitive analysis of the relationship between concepts and typologies across and within individuals, thus showing variation in experiences across participants but also drawing out common themes.

Qualitative data was stored on password-protected computers at the University of East Anglia, with individual participants identified only by unique anonymous study identifiers, and all personal contact details destroyed. Accounts were analysed by TB with a sample checked by SE in line with qualitative methodology.

Results

A total of 71 participants submitted accounts that were used in the analysis with an age range of 31 to 80 years, including 45 females and 26 males. The analysed data collected revealed a large number of themes relating to the experiences of anosmia sufferers. Key issues raised by participants include those of reduced physical wellbeing, emotional distress and impairment of social function. Whilst many topics interlink, we have divided the issues into four broad themes.

1. Physical concerns

a) Diet and Appetite

Given the integral relationship between olfaction and gustation, it is unsurprising that a large number of participants reported that anosmia had a negative impact upon their enjoyment of food. As a consequence of the reduced pleasure of eating, some participants reported a reduction in their appetite with subsequent weight loss. Others reported a general decline in the quality of their diet with the reduced perception of flavours leading to an increased intake of foods with low nutritional value (particularly those high in fat, salt and sugar).

“As all food tastes bland there is no incentive to prepare a variety of different meals which has resulted in weight gain as I have resorted to eating too many cakes and sweet things”

b) Hazard Perception

It is well established that the olfactory system is an important component of hazard perception (17). Key examples include expired food products, smoke and gas, with a large number of participants specifically raising these as issues that were a cause for concern. In some accounts, altered olfaction was deemed solely responsible for serious ‘near-misses’, some of which had the potential to result in significant harm. Attention must be paid to the patients’ professions.

c) Personal Hygiene

The proper maintenance of personal hygiene carried an emotional burden, causing anxiety, worry and embarrassment.

“Personally I have found it very difficult when around people. I am very strict about personal hygiene but still find it embarrassing when anyone mentions smells around me, after all how do I know it’s not coming from me?!”

2. Emotional concerns

A diverse range of negative emotions were reported by sufferers’, including but not limited to anger, anxiety, frustration, bereavement, boredom, depression, desperation, embarrassment, guilt, isolation, loss of confidence, loss of identity, regret and sadness.

Defining the relationship between these emotions and the experience of anosmia is complicated and seems to involve a multitude of factors including the loss of enjoyment of key activities, the status of an/hyp-osmia as an ‘invisible disease’ with difficulty in expressing the impact of

symptoms and little sympathy or understanding from outsiders, reduced participation in social activity, poorly established treatment pathways and little hope of recovery.

“I feel I live in a world behind glass, because I cannot smell and taste anything and feel depressed and sad much like being bereaved”.

3. Social impact

a) Preparation of food

A theme widely reported by participants was a loss of interest in cooking, or an impairment of their cookery skills. Some reported that they were now embarrassed to serve their dishes to family members and friends, and this subsequently had an impact upon their social life.

“I have retreated from the company of family and friends, no longer wanting to accept invitations which include food and drink.”

b) Celebrations

Some participants reported that they were unable to take pleasure in occasions that would usually be a cause for celebration. For sufferers of an/hyp-osmia, the inability to link smells with happy memories may render these events underwhelming experiences.

“Having no smell means that I miss out on all the memories that smell can evoke, bonfire night, Christmas smells, the smell of a certain perfume or food. I have some clothes that belonged to my nana who has died and I miss being able to smell her on them.”

c) Childcare

Various parental tasks were reported as being made more difficult by an/hyposmia; parents of young children were unable to detect soiled nappies. Being unable to perform such essential tasks led some parents to feel they were failing in their role.

d) Financial/work

Some participants reported that their olfactory disorder had a financial impact. For example, the expense of seeking alternative treatments and the value of lost earnings. Many participants reported that their work was directly affected by the symptoms of anosmia.

e) Spiritual

Perhaps unsurprisingly, the impact of olfactory disturbance extended beyond physical and social activities. One participant reported their lack of smell as impeding upon their ability to carry out activities of a spiritual nature. This is a particularly clear demonstration of just how far-reaching the impact of anosmia can be.

f) Memories

We carry smells with us as memories throughout our lives. Smells link us to people, places, and emotional experiences. Without a sense of smell, memories and links with the past can be lost.

“The thought of not smelling my children again was/is too distressing to accept.”

4. Interpersonal impact

a) Relationship with partners, friends and family

Many participants described profound effect on their relationships with other people as a results of their olfactory disturbance. These range from not enjoying eating together to more intimate relationships,

particularly sex. Participants described strain on relationships caused by a lack of understanding of the problem.

“I am sure there was an impact on sex and being close to my husband when he did not smell as he normally did. Although our marriage was already in difficulty, I believe anosmia helped end it.”

Those with children found bonding with very young children and babies difficult.

“I had a baby boy born at the age of 45 and I could not smell him and therefore felt I could not bond with him like I had with my other four sons.”

b) Health care professionals

“My GP felt I should get used to it, it just happens.”

Participants often described negative or unhelpful interactions with healthcare professionals both in the community and also specialist ENT surgeons, with difficulties in accessing specialist care. Participants were concerned by a lack of empathy.

“More understanding and support would have been very welcome! If I had lost my sight or hearing, I suspect I would have received a lot more attention.

I saw a Neurologist who said I could see and hear and would have to be stoic.”’

Those who had managed to get help and were supported were very pleased. Even if nothing could be done about anosmia, participants were very grateful for advice and understanding.

Discussion

Key findings

This study has shown that olfactory impairment exposes an individual to potential physical environmental dangers, and impacts negatively on a vast range of activities and experiences, causing significant harm. Our participants' accounts have shown the extent and depth of the impact this has on daily life. In reality, this is not surprising given the extra dimension olfaction gives to the enjoyment of food, exploration of our environment and evocation of memories; olfaction is both a life-saving and life-enhancing sense.

In terms of physical health, potential harms discussed included loss of interest in food and difficulty identifying expired food products and the inability to detect smoke or gas. Emotional negatives were described with great depth of feeling, including embarrassment, sadness, depression, worry and bereavement. Every aspect of life was disrupted from everyday concerns such as personal hygiene to loss of intimacy and the break-down of personal relationships. The financial burden described included the cost of private referral and alternative treatments. The effects were profound for some, especially if their profession or safety depends upon it, and many clinicians often feel unable to do much to assess or treat the problem.

Clinical applicability

Along with the knowledge of the extent of impact of such symptoms, reflection on potential causes of olfactory disturbance highlights the need for attention to be paid to such symptoms in a careful and systematic manner. Further guidance on this can be found in the Position Paper on Olfactory Dysfunction²² and on 2 articles on the assessment and management of olfactory loss^{23,24}. 'Specialists' which may include ENT and neurology should ensure that they have a plan for investigation of such patients. The causes of olfactory disturbance contribute to the difficulties in management. On one hand symptoms from chronic sinus disease often begin

insidiously, and can therefore be dismissed as harmless or insignificant by both patients and clinicians²⁵, on the other hand, olfactory disturbance caused by head trauma can increase distress as the persistent nature of the sensory disturbance is a constant reminder of the injury. Some participants were told there was no treatment available and whilst this may sometimes be the case, management options in terms of advice, support and information should be offered, particularly in a secondary or tertiary care setting. The option of directing patients to Fifth Sense for support, whether in the UK or internationally, is now a very definite option for clinicians when seeing these patients (www.fifthsense.org.uk), and gives the doctor-patient relationship a positive slant even when medical or surgical options may not be appropriate e.g. congenital anosmia.

Clearly these accounts illustrate that a wider range of therapeutic options are needed, this requires research to improve our understanding of the basic science of olfaction so that interventions can begin to match those for the other senses. A recent review of treatments for non-conductive olfactory disorders has highlighted the need for more trials of therapeutic options²⁶ and efforts are currently in progress to secure funding for new trials. Managing CRS is already the subject of a large programme of work funded by the National Institute of Health Research including a trial to assess long-term macrolide therapy and endoscopic sinus surgery (www.themacroprogramme.org.uk).

Comparison with existing literature

This study adds to increasing evidence from patients and healthcare professionals that suggest that olfactory disorders are often poorly managed^{14,27}, which in itself appears to exacerbate the negative impact upon sufferers²⁸. Sufferers describe a lack of acknowledgement of disordered olfaction as a significant problem. A frequently highlighted barrier to treatment was the attitude

of healthcare workers – several participants had been met with disinterest or refused referral. These concerns are highlighted in the recent position paper on olfactory dysfunction²⁹. A basic first step healthcare professionals could take would be to listen to sufferers, acknowledge the significant effect on their lives and offer referral to specialist centre to help diagnose possible causes and treat where possible.

Strengths and limitations

This is the first qualitative study of British subjects affected by olfactory disturbance to describe their experiences in their own words. Participants had voluntarily written to the Smell & Taste Clinic seeking advice about their disorder, so clearly those who were available for inclusion felt most affected by their disorder or most motivated to seek treatment. However, the intention is to describe the experience of those with olfactory disturbance in a qualitative manner not to comment on the prevalence of specific symptoms. Involvement of patients in their own healthcare is increasingly recognised as important; these accounts are unique in allowing participants to voice their concerns regarding experience and management of olfactory disturbance. The synthesis of this information from a wide range of individuals highlights the need for better education for healthcare professionals as well as research to improve understanding of human olfaction and develop therapeutic options. In a qualitative framework, this study did not provide the participants an opportunity to be interviewed.

The source of the information used for the analysis is both a strength and a weakness. The key advantage is that it was provided spontaneously without guidance or prompting and therefore is an unreserved and honest account of patient experiences. However, it does represent a biased group of patients seeking healthcare. Nonetheless, they represent a body of patients who feel they have an unresolved healthcare problem. Fifth Sense now has over 3000 members in the UK, demonstrating that this is a sensory loss that matters to those afflicted by it.

Implications for research and/or practice

Olfactory dysfunction has wide-ranging negative impact on sufferers; such a large number and range of negative experiences of olfactory disturbance as described here should motivate clinicians to take such symptoms seriously and inspire researchers to further their understanding of human olfaction and therapeutic options. Unlike glasses or hearing aids, no simple solutions are yet available for olfactory deficits but even if no reversible cause can be identified, clear information and support can now be provided²¹. Certainly there is room for further research into current healthcare pathways for patients with olfactory disorders and clearly a need for further therapeutic trials to improve treatment options.

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Appendix 1:

Personal accounts of anosmia (reminder sheet)

History –

- When you first noticed your anosmia
- Sudden or gradual
- What triggered it

Day to day experiences –

- food/taste
- cooking
- work issues
- socialising

Major incidents – e.g.

- gas not lit
- food burning
- pans boiled dry
- children issues etc

How it affects you psychologically

- personal relationships
- missing smells which would evoke memories
- missing smell which would trigger activities

Seeking help –

- how you were received by the medical team e.g. GP, when seeking help or referral