DOI: 10.1308/003588414X13814021678358

SMELL AND TASTE DISORDERS IN THE UK: FIRST EXPERIENCES WITH A SPECIALISED SMELL AND TASTE OUTPATIENT CLINIC

Carl Philpott Anthony Long Senior Lecturer and Honorary Consultant ENT Consultant & Rhinologist[1,2]
[1]The Smell and Taste Clinic, James Paget University Hospital, Great Yarmouth
[2]Norwich Medical School, University of East Anglia, Norwich

Olfactory dysfunction is common, affecting 1–5% of those under the age of 60[1] and at least 20% of those aged more than 60 years.[2] In many UK centres, the approach to it is variable and routine olfactory testing is not performed, as noted by a recent survey of British ENT surgeons.[3] This is in contrast to Europe and the USA, where many specialist smell and taste centres already exist.

Ann R Coll Surg Engl (Suppl)
2014; **96:** 156–159

Key causes of olfactory dysfunction include sinonasal disease, upper respiratory tract infection, post-viral olfactory loss (PVOL) or post-traumatic olfactory loss (PTOL), but its onset can sometimes mark neurodegenerative diseases, such as Parkinsonism, or point to underlying systemic disease, such as hypothyroidism. True gustatory dysfunction is rare. Although many patients complain of a 'loss of taste', this is actually due to their loss of retronasal olfaction, where 80% of the flavour of food is derived from its aroma.

What does olfactory loss mean to the sufferer?

> *'When I lost my sense of smell it was like being struck blind. Life lost a good deal of its savour... My whole world was radically poorer.'*
>
> – Excerpt from *The Man Who Mistook His Wife For a Hat* by O Sacks, as featured in *Aroma.*

An absent or poor sense of smell can cause wide-ranging problems for patients, including reduction in quality or enjoyment of life, leading to depression, feelings of social isolation, breakdown of relationships, threat of personal injury and potential loss of livelihood. Most patients with olfactory loss will complain about a loss of taste. Although true gustatory function is rarely impaired, sufferers will have a loss of flavour perception, which can adversely affect their appetite and this can be made even worse if distortions (such as parosmia) co-exist.

Patients may well adopt poor dietary habits as a consequence, which may then have other impacts on their global health, as they will tend to eat a less varied diet. There are currently no estimates of the total burden or cost of anosmia to the UK as a whole, or the proportion of patients currently treated. In studies from other countries, three quarters of patients are reported to have experienced hazards due to their disorder, with half suffering depression.[4-6] As well as decreased appreciation of food and suppression of appetite, other negative effects are seen on physical health, financial security, profession, partnership, friendship, emotional stability and leisure.[7]

History of the smell and taste clinic

In October 2010, a monthly clinic was established at the James Paget Hospital with a view to focusing referrals from the local catchment area into a specialist clinic where olfactory and/or gustatory testing could be performed. However, with increasing awareness of the clinic regionally and nationally, the clinic's referral base grew and more than 75% of referrals now come from outside the immediate catchment area. This was accentuated when the anosmia patient support group, Fifth Sense, was founded and organised publicity for a fundraising event in Norwich, drawing heightened media attention.

The clinic now runs at least twice a month, with a limit of six new and six follow-up patients over a three-hour period, allowing time for adequate consultation for each patient. Patients complete an Olfactory Disorders Proforma and Sino-Nasal Outcome Test-22 (SNOT-22) questionnaire on arrival. Prior to consultation, a

dedicated nurse performs a Sniffin' Sticks® olfactory test (Heinrich Burghart GMBH, Germany). This test uses pen-like odour-dispensing devices to assess olfactory threshold, discrimination and identification (TDI), each scored to give an overall TDI score (specific to Sniffin' Sticks), which ranks patients as anosmic, hyposmic or normosmic. The test has been validated for our local UK population,[8] with TDI scores comparable to normative data published on large European samples.[9,10] Each replacement set costs £320 after an initial purchase of £700 and will last for 6 months (threshold) or 12 months (discrimination/identification) – this can be for any number of patients within this timeframe.

Current clinic data

Since October 2012, over 400 patients have visited the clinic. The average age was 57 (range 15 to 88 years). The female-to-male ratio was 1.5:1 (=105, =70). The most common aetiologies were chronic rhinosinusitis (CRS) with or without polyps (40%), idiopathic cases (30%) and PVOL (17%). Nineteen per cent had concurrent pathologies (more than one potential factor causing olfactory dysfunction) and three per cent had congenital anosmia (Figure 1). Average scores for quantitative olfactory disorders varied according to diagnostic groups, thus patients with PVOL typically had a higher TDI score (me=18.48) compared with patients with idiopathic loss (me=13.82). There were gustatory disorders in 14 patients, with causes including idiopathic, post-tonsillectomy and zinc-deficiency.

A common pathway for patients coming to the clinic has been used (Table 1). Qualitative disorders (eg distortions such as parosmia/phantosmia) usually occur in the presence of quantitative disorders, but not exclusively and are managed according to patient need (Table 2). Derived from the Olfactory Disorders Proforma, 20% of patients reported qualitative disturbances but only a minority felt this was more troublesome than their quantitative loss.

Difficulties faced by the clinic

Owing to the pressures on nursing staff, the main difficulty is the provision of olfactory/gustatory testing. Unlike patients who come to clinic with hearing or visual disturbances, where there is a recognised tariff for the relevant test and staffing provided to facilitate this, there is no equivalent for smell or taste tests and this is not recognised by the National Institute for Health and Care Excellence (NICE) as the gold standard. Therefore follow-up tests have only been available for 10% of cases and so there is a need to collect further data on outcomes. Furthermore, there is always a financial concern regarding the clinic being maintained, owing to the costs of providing staff and test kits for this service and the lower capacity of such clinics. Submissions to NICE and NHS specialist commissioning are in progress but in the current financial climate, this service may not get the attention it needs to continue.

FIGURE 1

BAR CHART OF DIAGNOSES OF PATIENTS ATTENDING THE SMELL AND TASTE CLINIC

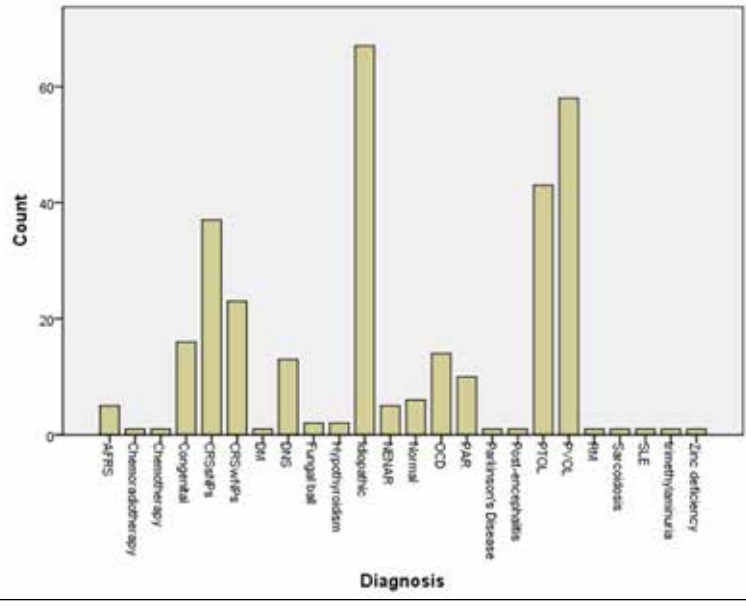
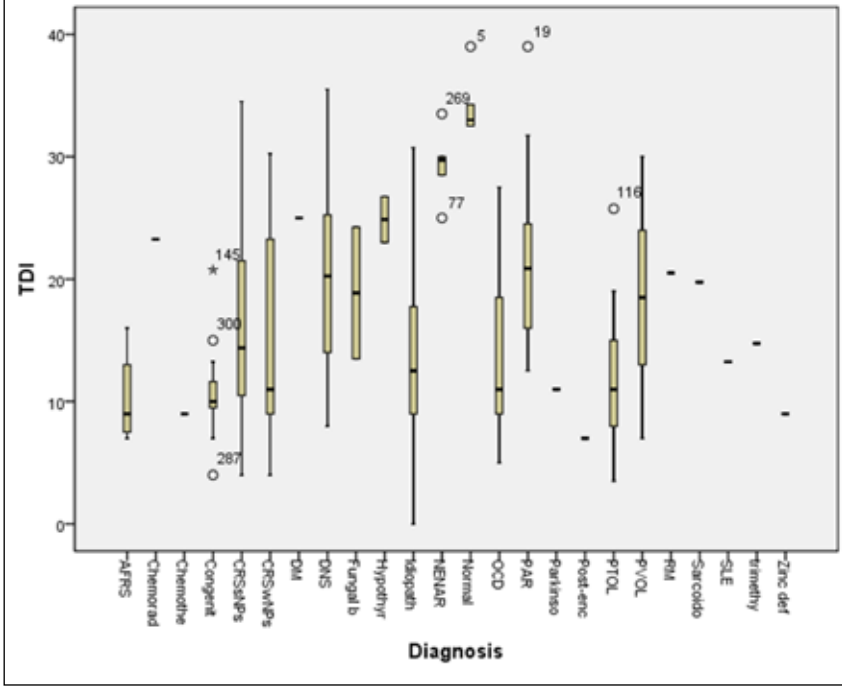


FIGURE 2

BOX AND WHISKER PLOT OF TDI SCORES GROUPED BY DIAGNOSIS



What does the clinic offer that is new?

First and foremost, the clinic is there to allow patients to have a thorough assessment of their sensory disorder. Experience to date is that many patients have come to the clinic feeling isolated about their 'invisible' problem, which they feel has been neglected by medical professionals. Some patients have not progressed beyond primary care, whereas others have been seen in secondary care and perhaps received some investigations, but ultimately many have felt that their olfactory or gustatory loss has either not been fully explained or evaluated or they have not been counselled on the prognosis or consequences. As the subjective impression of olfactory function often correlates poorly with performance on psychophysical testing,[11,12] formal olfactory assessment is therefore crucial alongside a thorough history and examination. Furthermore, this information aids prognosis, as patients with hyposmia are more likely to demonstrate potential for recovery in certain conditions than those with hyposmia (eg PVOL, PTOL).

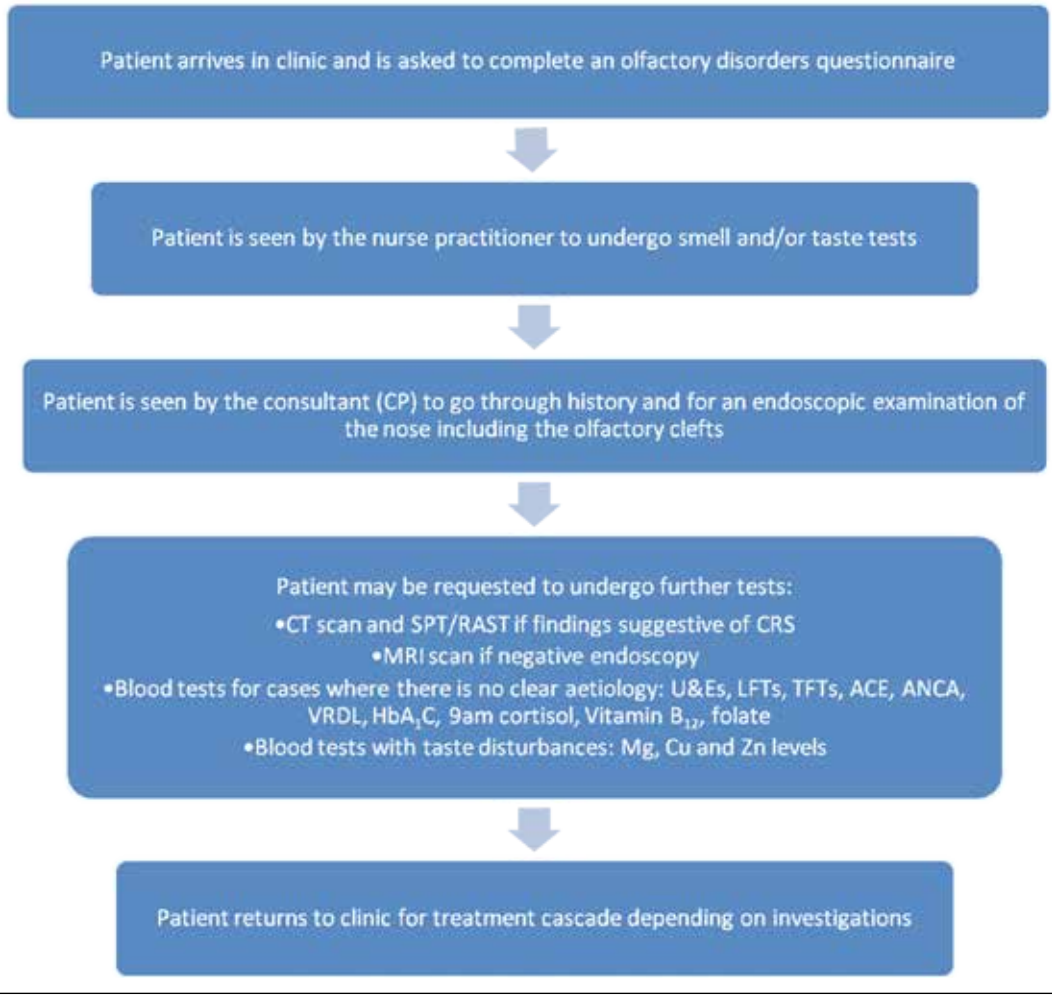
'MANY PATIENTS HAVE COME TO THE CLINIC FEELING ISOLATED ABOUT THEIR "INVISIBLE" PROBLEM'

Endoscopic nasal examination is always performed to assess contributing pathology such as mucosal congestion, mucopus, polyps, neoplasms, anatomical anomalies and cerebrospinal fluid leaks. Images are captured using a voice-activated image capture device (D-scope). In cases where nasal endoscopy is negative and there are no obvious causative factors in the history, blood tests may elucidate underlying medical causes such as hypothyroidism, diabetes mellitus, autoimmune disorders, anaemia and syphilis and MRI scans will assess any intracranial pathology. For patients with troublesome dysgeusia, copper, magnesium and zinc levels are checked. Any previous imaging is reviewed carefully to look for any subtleties that may have been overlooked.

Treatments offered will vary on an individual basis but any patients with chronic rhinosinusitis will be managed according to the guidelines from European Position Paper and those more recently provided by ENT UK

TABLE 1

INITIAL MANAGEMENT PATHWAY FOR PATIENTS ATTENDING THE SPECIALIST OLFACTORY AND GUSTATORY DISORDERS CLINIC

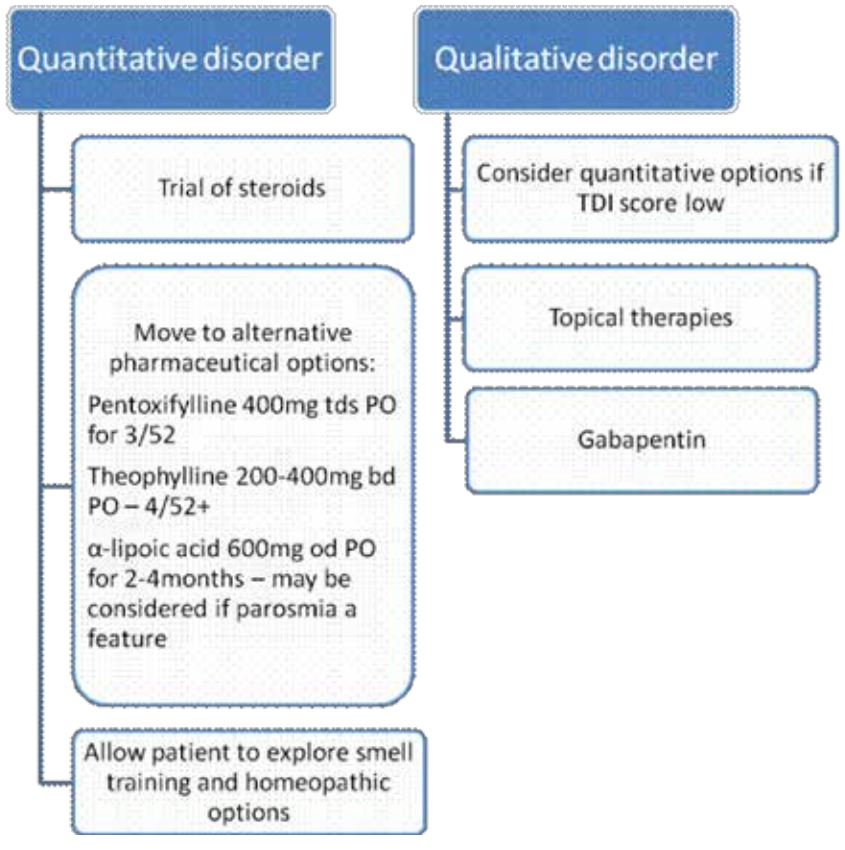


on rhinosinusitis and nasal polyps.[13] In this respect, any patients who require surgical intervention have the option to undergo image-guided sinus surgery using the Medtronic Fusion system to map preoperative CT images during the procedure. For patients without a conductive cause, treatment options are much more limited, owing to paucity of randomised controlled trials that underpin them. If patients have been given a trial of oral corticosteroids then other pharmaceutical options are explored with patients on the understanding that they are unlicensed for this indication. Another focus of the clinic is therefore to lead on research into the benefits of new potential treatments and a double-blinded randomised controlled trial on the benefit of sodium citrate spray in sensorineural olfactory loss is currently underway. Smell training, wherein patients actively sniff bottles containing clove, lemon, rose and eucalyptus odours twice daily for at least 12 weeks, is encouraged as this has been shown to have some benefit.[14]

Advice on safety measures, such as labelling to prevent spoilt food consumption, is given. Accentuating eating experiences with condiments, foods and recipes is extremely beneficial. Patients are also allowed to explore homeopathic therapies like ginkgo biloba. Counselling patients on their likely prognosis ensures realistic expectation about outcomes; based on the patient mix to date, approximately 50% have the potential for recovery with treatment or spontaneously. Finally, patients are directed to the patient support group Fifth Sense, which has a website and newsletter. See: www.fifthsense.org.uk.

TABLE 2

MANAGEMENT PATHWAY FOR PATIENTS WITH SENSORINEURAL OLFACTORY DISORDERS



Conclusion

Disorders of olfaction and taste are often ignored and trivialised when in fact they result in extremely poor quality of life. Often these problems are not thoroughly investigated and managed in the general otolaryngology clinic without the necessary expertise, equipment and time. This dedicated service has been appreciated by the patients who have been seen to date but more work is needed to measure outcomes and develop new treatments.

References

1. Landis BN, Konnerth CG, Hummel T. A study on the frequency of olfactory dysfunction. *Laryngoscope* 2004; **114:** 1764–69.
2. Murphy C, Schubert CR, Cruickshanks KJ *et al.* Prevalence of olfactory impairment in older adults. *JAMA* 2002; **288:** 2307–12.
3. McNeill E, Ramakrishnan Y, Carrie S. Diagnosis and management of olfactory disorders: survey of UK-based consultants and literature review. *J Laryngol Otol* 2007; **121:** 713–20.
4. Nordin S, Bramerson A. Complaints of olfactory disorders: epidemiology, assessment and clinical implications. *Curr Opin Allergy Clin Immunol* 2008; **8:** 10–15.
5. Hummel T, Nordin S. Olfactory disorders and their consequences for quality of life. *Acta Oto Laryngologica* 2005; **125:** 116–21.
6. Smeets MA, Veldhuizen MG, Galle S *et al.* Sense of smell disorder and health-related quality of life. *Rehabil Psychol* 2009; **54:** 404–12.
7. Temmel AF, Quint C, Schickinger-Fischer B *et al*. Characteristics of olfactory disorders in relation to major causes of olfactory loss. *Arch Otolaryngol Head Neck Surg* 2002; **128:** 635–41.
8. Neumann C, Tsioulos K, Merkonidis C *et al.* Validation study of the "Sniffin' Sticks" olfactory test in a British population: a preliminary communication. *Clin Otolaryngol* 2012; **37:** 23–27.
9. Hummel T, Kobal G, Gudziol H, Mackay-Sim A. Normative data for the "Sniffin' Sticks" including tests of odor identification, odor discrimination, and olfactory thresholds: an upgrade based on a group of more than 3,000 subjects. *Eur Arch Otorhinolaryngol* 2007; **264:** 237–43.
10. Hummel T, Sekinger B, Wolf SR *et al.* 'Sniffin' sticks': olfactory performance assessed by the combined testing of odor identification, odor discrimination and olfactory threshold. *Chem Senses* 1997; **22:** 39–52.
11. Philpott CM, Rimal D, Tassone P *et al.* A study of olfactory testing in patients with rhinological pathology in the ENT clinic. *Rhinology* 2008; **46:** 34–39.
12. Philpott C, Wolstenholme C, Goodenough P *et al*. A comparison of subjective perception with objective measurement of olfaction. *Otolaryngol Head Neck Surg* 2007; **134:** 488–90.
13. Fokkens WJ, Lund VJ, Mullol J *et al*. European position paper on rhinosinusitis and nasal polyps 2012. Rhinology 2012; 3: 1–298.
14. Hummel T, Rissom K, Hähner A *et al*. Effects of olfactory training in patients with olfactory loss. *Laryngoscope* 2009; **119:** 496–99.