
The Impact of Olfactory Disorders in the United Kingdom

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Abstract

Olfactory disorders are believed to affect 5% of the general population and have been shown to bear significant psychosocial consequences to sufferers. Although more common than blindness and profound deafness in the United Kingdom, the impact of these disorders has not been assessed to date and the plight of British patients has yet to be quantified. In 2012, a patient support organization, Fifth Sense, was founded to provide information and support to sufferers of chemosensory disorders. Following a recent members conference, a survey of the membership was conducted anonymously using a series of questions based on an existing olfactory disorders questionnaire. From 496 respondents, this has demonstrated high rates of depression (43%) and anxiety (45%), impairment of eating experience (92%), isolation (57%), and relationship difficulties (54%). Women appear to have significantly more issues than men in terms of social and domestic dysfunction relating to olfactory loss ($P = 0.01$). Qualitative disorders also affected more than 1 in 5 members with parosmia reported in 19% and phantosmia in 24%. This paper discusses the details of the British story of anosmia and other related disorders as depicted by those most affected.

Key words: anosmia, hyposmia, parosmia, phantosmia, quality of life

Introduction

Hearing and visual loss are prominent sensory losses in the United Kingdom, both with their own Royal institutions. More than 800 000 people in the United Kingdom are severely or profoundly deaf and about 2 million people in the United Kingdom are living with sight loss. The prevalence of olfactory disorders in many national groups has been depicted in other studies with estimates varying between 1 and 20% (Wysocki and Gilbert 1989; Brämerson et al. 2004; Landis et al. 2004; Vennemann et al. 2008), with the larger figures representing older patient groups (Murphy et al. 2002). It is however believed from surveys done in other countries that 5% of the population is affected by anosmia, accounting for about 3 million people, with an additional 15% affected by hyposmia (Mullol et al. 2012), with some patients perhaps unaware of their reduced sensory capacity. Causes for olfactory loss are varied but the main diagnostic groups include sinonasal disease (such as chronic rhinosinusitis and allergic rhinitis) (62%) and post-viral olfactory loss (PVOL) (11%) (Damm et al. 2004). In specialist smell and taste centers, other key groups of patients that are seen include post-traumatic olfactory loss and idiopathic cases, both of which account for about 20%, respectively, of the

total volume of patients in those clinics. In the United Kingdom, a previous survey of consultant members of ENT United Kingdom showed that the management of olfactory disorders in the United Kingdom was variable and few respondents (12%) routinely performed any formal assessment of olfactory function (McNeill et al. 2007). Therefore, these patients have received limited evaluation and support in mainstream Ear Nose and Throat practice in the United Kingdom despite these patients being known to suffer significant psychosocial consequences from the loss of this sensory modality (Hummel and Nordin 2005). This mostly stems from the lack of therapeutic options available to clinicians, that is, there is no clear clinical pathway as many doctors believe the condition is untreatable.

In chronic rhinosinusitis, which has been estimated to affect 11% of Europeans (Hastan et al. 2011), a reduced sense of smell is one of the diagnostic symptoms and yet in practice, reduction of this symptom appears to be deemed a lesser goal than other symptoms (Erskine et al. 2012). While sinonasal disease is considered a conductive and potentially reversible cause, there is currently no accepted effective and routine medical treatment for sensorineural causes, although

patients are sometimes offered a trial of oral corticosteroids. Some cases, such as PVOL, will resolve spontaneously with time in approximately 30% within 3–5 years; but otherwise these patients are left with a permanent sensory deficit. This sensory deficit is therefore borne by the sufferer without the absence of external signs, (e.g., stick, hearing aid), that are present with other sensory deficits. This study aims to characterize the consequences of olfactory disorders in the United Kingdom to help raise awareness of the plight of many sufferers.

Materials and methods

Members of the patient support organization, Fifth Sense (now a fledgling charity), were invited via e-mail by Mr Boak and asked to complete an online anonymous survey regarding the quality of life impact of their disorders; membership is spread around the United Kingdom. No identifiable data was requested but the demographics of sex and age were recorded. The survey did not request any details about the cause of this disorder and the specific questions were derived from the olfactory disorders questionnaire produced by Frasnelli and Hummel (2005). The questions were adapted by the second author to be familiar to British patients and discernible. Domains included emotional, eating/nutrition, and psychiatric morbidity. The survey (see Appendix 1) had 4 components:

1. 24 quality of life statements/questions to be ranked with one of the following options: Agree, Agree partly, Disagree partly, Disagree, I think this question has no value, I don't understand the question.
2. 7 questions requiring a yes or no answer to specifics about depression and anxiety.
3. 4 questions on impact rated on a scale of 0–10 where 0 = no impact and 10 = large daily impact.
4. Free text entries relating to the above 4 questions or to anything not covered by the rest of the survey.

As the survey was performed out with the clinical domain using the membership of the support organization Fifth Sense, no ethical approval was sought; however, Mr Boak made explicit his intention for anonymized data to be used in the public domain. Differing rates of variables such as depression were compared between men and women using a chi-squared test. Differences in ratings using the 0–10 scale were compared between sexes using *t*-tests.

Results

From a membership of over 1000 sufferers with olfactory disorders, 496 completed the online survey during a 9-month period. The age range of respondents was 8–95 with a mean of 55 (parents responded on behalf of the 8-year olds). The sex distribution was 178 men to 318 women meaning that two

thirds of respondents were female. In the first section of the survey where members were asked rank the 24 statements/questions, key subjects that elicited the response of “agreed” or “agreed partly” in more than 50% included (Figure 1):

- Reduced appreciation of food and drink (92%)
- Exposure to certain dangers (e.g., gas, rotten food) (85%)
- Emotional difficulties including anger, frustration, stress, and isolation (56–76%)
- “I go to restaurants less often than I used to” (55%)
- “My relationship with my partner/family/friends is affected by my difficulties with smelling” (54%)

In the second part of the survey where members were asked to provide a yes or no answer, the rate of depression was 43% with those suffering either depression and/or anxiety comprising 45% of respondents (see Table 1); compared with a rate of depression in the adult population of 8–12%, this represents a significant burden (Singleton et al. 2003). Prescription of medications or use of NHS counseling services had occurred in 25% of respondents in relation to anxiety and depression resulting from their olfactory disorder. Furthermore, there are significantly higher rates of depression and anxiety in female respondents (47% [*n* = 151] compared with 34% [*n* = 60] of men, *P* = 0.003). Twenty percent of members had tried various alternative medicine therapies including acupuncture, hypnotherapy, cranial osteopathy, and reflexology.

In the third part of the survey, members appeared to have noticed the greatest impact upon social and domestic life (Table 2), but with women again significantly more affected than men (social *P* = 0.028, domestic *P* < 0.001), even taking into consideration the higher number of female respondents. When these impact ratings were correlated against increasing age, significant trends can be seen with all 4 factors (*P* < 0.001) such that younger sufferers are more likely to be adversely affected by these issues.

Looking in more detail at the specific impact of the qualitative disorders, parosmia and phantosmia, shows some significant differences compared with those who do not experience these symptoms. In both categories of qualitative disorders, there is a significant difference from those without qualitative disturbances for flavor perception eating unhealthily, eating less, despair, being less sociable, and stress (*P* ≤ 0.05). Phantosmia sufferers reported significantly higher rates of depression related to their olfactory disorder (*P* = 0.008) than in those without (53 vs. 40%); parosmia sufferers did not show any significantly different rates of depression but instead a higher rate of anxiety (*P* = 0.007). Other notable findings are that younger aged sufferers (<50 years) show significantly higher rates of weight gain (*P* = 0.011), isolation (*P* = 0.002), depression (*P* = 0.008), and being scared of dangers (*P* = 0.038); older sufferers showed higher rates of resignation to their sensory loss (*P* = 0.03).

In the free text components of the professional, social, domestic, and sexual issues, written entries were made by

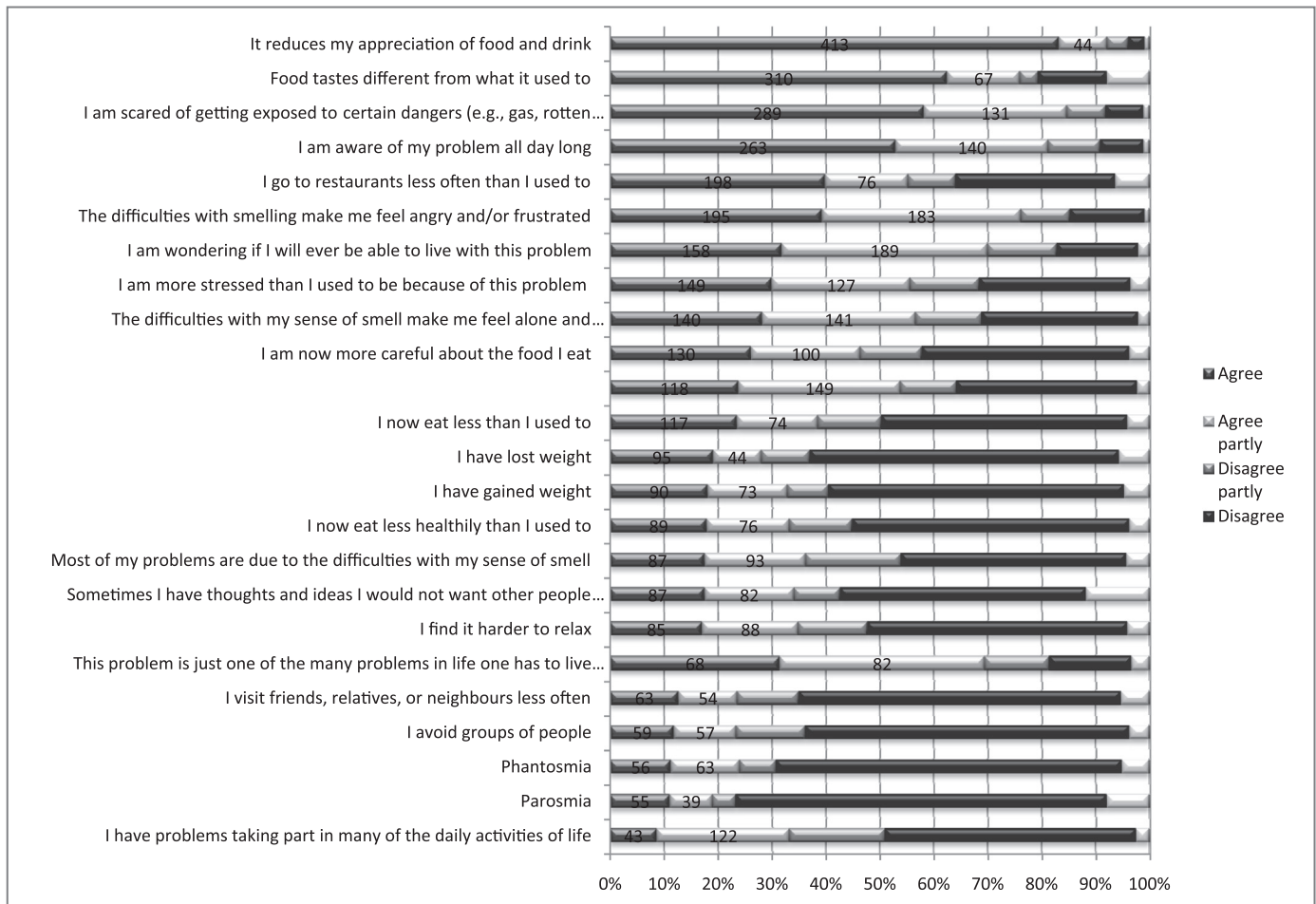


Figure 1 Quality of life questions—percentage of respondents agreeing or disagreeing (no response indicates that the member thought the question was invalid or did not understand it).

Table 1 Members responses for depression and anxiety in relation to their olfactory disorder

Question target	Percentage of respondents answering yes
Depression	42.5
Anxiety	44.5
Depression or anxiety	52.4
Medications prescribed	13.5
Over-the-counter medications	14.1
Alternative medicine tried	19.5
Counseling for depression/anxiety	12.1

185, 243, 288, and 130 members for those topics, respectively, and a number of key themes were identified as detailed with frequencies in Table 3. Professions most affected by smell disorders included those working in the food industry, the medical profession, childcare, and the housing and engineering industries. Many comments were made about respondents' concerns about personal hygiene at work and about

Table 2 Members responses for impact questions

Impact question	Mean	Median	Standard deviation
Has your smell disorder had an impact on your professional life?	4.3	4	3.15
Has your smell disorder had an impact on your social life?	5.7	6	2.83
Has your smell disorder had an impact on your domestic life?	6.6	7	2.79
Has your smell disorder had an impact on your sex life?	3.9	3	3.07

difficulties with eating with colleagues. The latter also ran through into social circumstances, whereby many respondents described annoyance at the lack of understanding by family and friends in social gatherings and hence avoidance of these situations. Other social and domestic issues encountered included birthdays, food preparation, for example, spoilt and burnt food, dinner parties, gas leaks, reliance on partners for their sense of smell, room/pet odors, body

Table 3 Free text themes in response to professional, social, domestic, and sexual issues (number in brackets = respondents entering comments)

Professional	Social	Domestic	Sexual
Housing/engineering (5)	Birthdays/family events (10)	Lack of enjoyment of (preparation of) food (107)	Missing smelling partner (6)
Food industry (22)	Dinner parties/eating out (160)	Gas leaks, burnt/spoilt food, etc (133)	Loss of libido/desire (23)
Hazardous chemicals (27)	Embarrassment (16)	Reliance on partners for their sense of smell (45)	Concern about smelling appealing to the opposite sex (14)
Medical and allied professions (13)	Annoyance at lack of understanding by others (17)	Room/pet odors (63)	Loss of intimacy (53)
Childcare/teaching (9)	Concern about personal hygiene (30)	Children, e.g., nappies (8)	Cessation of dating/relationship (3)
"Do I smell at work?" (19)	Loss of nice environmental odors (27)	Personal hygiene/household smells (63)	Concern about not being able to detect sexually transmitted diseases (1)
Avoidance of eating with colleagues (9)	Relationship difficulties (9)	Hobbies (4)	Anxiety (2)

secretions smelling foul (parosmia sufferers), concern about personal hygiene, children, for example, nappies.

Among the other free text entries into the survey are a number of examples of key messages of impact to these sufferers.

Emotional

The key issue for me is one of frustration, and the future regarding my anosmia feels dismal. It's difficult to quantify and I can see how some people might easily become depressed by it. It removes colour from a life.

I am devastated that I have not regained my sense of smell and upset that we're expecting our first child and I won't be able to smell them. Life is totally unenjoyable. Is full of odours and tastes that make us aware of dangers and delight. This has been removed from me and my life. Something needs to be done to help us.

Input from the medical profession

One of the most depressing issues is the lack of concern by the medical profession. Getting help from GP and then being told by specialist that there was "nothing that could be done" and sent away to live the rest of your life missing one of your vital senses. If I had lost my hearing, sight, a limb or had been disfigured more help would have been given. More training should be given on this issue for GPs and especially ENT students, with more smell and taste clinics provided. I saw a consultant at my local clinic who said he'd never heard of the symptoms I have experienced over the last 20 years.

Even a specialist from a large teaching hospital could give me no hope of any form of self or professional help I was just told it was something I had to live with

When I was told my anosmia was permanent, the doctor who told me became very embarrassed and possibly threatened by my reaction and actually told me that I should consider myself lucky it wasn't my sight. It's over 9 years later and I am still very angry at the medical response.

Professional

It can be dangerous in the construction industry as unable to smell leaking gas etc

I am a chef and it has undermined my confidence in my ability to create new recipes

Working with children I am fearful that I cannot smell things of danger

I'm a psychiatric nurse ...so I can't tell if somebody has been drinking or if they have tell-tale smells of certain conditions.

Isolation and danger

As a lone elderly man with few interactions other than with his family... Above all smell is the sense which makes reality different from a highly sophisticated TV facsimile. Its absence thereby gives a feeling of isolation as well as depriving one of a myriad of pleasures, and, as I have personally experienced following a gas escape, can put one - and others - in very dangerous situations.

My house is rigged full of fire alarms and carbon monoxide alarms as I'm scared of not smelling fire.

I lost my sense of smell 34 years ago. I have still not come to terms with it. I remember what pleasure and learning I got through smelling things. I used to be an avid cook and perfumes were a serious interest. Because it is an invisible disability, most people do not know I have it and do not understand.

Personal interaction and sex life

So much of sexual closeness is wrapped up in smell. It's how you know who you are with when the lights are off. It has reduced my interest / desire.

Well many of us deal with it because there is no choice...and make the best of it...but it's like seeing the world in monochrome and I worry I will never be able to share again properly in my social and sexual life. I feel like I'm just an observer.

Postoperative bliss

My sense of smell returned 5 days post-op and my life has since improved immeasurably. Every aspect of my life is happier having regained this very important sense.

Discussion

The findings of this survey have clearly demonstrated that British sufferers of olfactory disorders suffer significant physical, social, psychological, and emotional impacts. Fifth Sense, as a patient support organization, has clearly illuminated the largely unspoken voice of these sufferers through this survey, demonstrating the need for these conditions to be taken seriously by medical practitioners in the NHS as well as the need for more research into treatment and coping strategies for these patients. This paper is by no means the first to demonstrate these issues. Tafalla (2013) in her recent article on congenital anosmia has summarized many of these issues from her own perspective and from those with and without smell disorders who she has consulted. A more reaching perspective of the hidden consequences of olfactory dysfunction was encapsulated by Keller and Malaspina (2013) who used an online study of 1000 subjects internationally including free-form reports and a questionnaire also adapted from that produced by Frasnelli and Hummel (2005). They similarly had two thirds of respondents being female but primarily provided a qualitative analysis of the reports returned. Hazard avoidance was discussed by 72% of their respondents but lack of food enjoyment (72%), weight loss/gain (25%), and the sense of isolation (47%) were less prominent than in our British cohort, perhaps a reflection on cultural differences whereby British sufferers are more reserved in coming forwards with their problems. In exploring the issues of social isolation, the authors also discussed the role of medical practitioners managing these disorders, commenting that while most doctors handle the discussions in a professional and empathic manner, there are some doctors who have clearly not heard of anosmia, thus suggesting there is a bigger issue of educating the medical profession; the quotations cited above were chosen to highlight the dismissive response given by a minority of healthcare professionals. This problem with poor medical advice has been seen elsewhere. Landis et al. (2009) found that patients in their study reported receiving either no or poor information about their diagnosis and prognosis.

The frustration with medical professionals is certainly a key problem faced by many respondents in this survey, but judging by the responses in other areas clearly reflects a societal view of the value of olfaction in daily life, a subject broached more widely in the book *Aroma: The Cultural History of Smell* (Classen et al. 1994). Indeed a quick look at the NHS website for disability (<http://www.nhs.uk/livewell/disability/Pages/Disabilityhome.aspx>) does not provide any mention of olfactory disorders as a disability and examination of the guidance as to what constitutes a disability in the 2010 Equality Act (Anonymous 2010) does not reveal any mention of loss of the ability to smell as a disability either. This is not solely confined to the

United Kingdom, as the American Medical Association's Guide to the Evaluation of Permanent Impairment suggests that smell loss is considered as a 1–5% impairment as compared with deafness (35%), blindness (85%), and even tinnitus (5%). American citizens do however have the advantage of having a number of well-established Smell & Taste Clinics such as that run by Prof. Richard Doty at the University of Pennsylvania Smell and Taste Center in Philadelphia (Deems et al. 1991). Similarly, a number of European countries also have centers dedicated to these disorders, such as that run by Prof. Thomas Hummel in Dresden (Landis et al. 2004), but smell disorders are not mentioned on European Disability Forum website (<http://www.edf-feph.org/>).

In other studies that have examined the quality of life impacts of olfactory disorders have also found similar themes. In 2002, Temmel et al. found that in most patients, olfactory loss caused food-related problems, younger patients had more complaints than older ones, and women had more complaints than men (Temmel et al. 2002), which has clearly been demonstrated in the Fifth Sense survey. In a Swedish study, sufferers attending one of 2 outpatient clinics were asked to state what the most negative effect of their disorders was; “less aware of personal hygiene” was rated as the top complaint (36%) and being less interested in food and drink, second (21%) (Blomqvist et al. 2004). In a study using the Becks Depression Inventory, it was reported that signs of depression were found in 29% of patients with chemosensory disorders (Deems et al. 1991). In a Japanese study, Miwa et al. (2001) found, in their subjects, that the most common cited impairments were ability to detect spoiled food (75%), gas leaks (61%), or smoke (50%), eating (53%), and cooking (49%). In Taiwan, Shu et al. (2011) found that the impact of olfactory loss is more significantly felt by younger patients. Interestingly, the issue of not recognizing hazardous odors in the elderly was reported back in 1957 by Chalke et al. (1958).

Overall, considering the domains explored by the Fifth Sense survey, previous studies have shown impact on these areas as shown in Table 4 (Ferris and Duffy 1989; Toller 1999; Miwa et al. 2001; Temmel et al. 2002; Blomqvist et al. 2004; Santos et al. 2004; Brämerson et al. 2007; Aschenbrenner et al. 2008; Nordin et al. 2011; Croy et al. 2012; Haxel et al. 2012; Keller and Malaspina 2013). The findings are generally that British subjects are more adversely affected than those in other countries. However, limitations of the Fifth Sense Member Survey include a paucity of detailed medical information such as diagnosis, duration, and etiology, as well as a reporting bias, as it is likely that those affected most by olfactory disorders will be Fifth Sense members and among the 496 respondents, therefore more likely to be proactive about their plight. Furthermore, the survey represents subjective opinion by those affected but on the other hand has the advantage of providing information about the effects of these disorders without the influence of medical

Table 4 Evidence of impact of olfactory disorders on quality of life from the literature and comparative Fifth Sense survey findings

Quality of life domain	Percentage of sufferers affected	Percentage of Fifth Sense respondents affected
Reduced enjoyment of food or reduction in appetite	27–69 (Ferris and Duffy 1989; Toller 1999; Nordin et al. 2011)	95
Problems with cooking (spoilt or burnt food)	37–73 (Miwa et al. 2001; Temmel et al. 2002; Santos et al. 2004; Croy et al. 2012)	46–86
Eating more/weight gain	3–20	36
Eating less/weight loss	20–36 (Ferris and Duffy 1989; Aschenbrenner et al. 2008; Keller and Malaspina 2013)	33–40
Social interaction issues	19–36 (Temmel et al. 2002; Blomqvist et al. 2004; Nordin et al. 2011)	59
Problems detecting hazards such as smoke	20–42 (Blomqvist et al. 2004; Nordin et al. 2011; Haxel et al. 2012)	86
Depression	25–33 (Miwa et al. 2001; Blomqvist et al. 2004; Nordin et al. 2011)	49
Professional issues	8–33 (Temmel et al. 2002; Brämerson et al. 2007; Haxel et al. 2012)	41

professionals, as might be experienced in a formal study from a clinical setting.

Conclusion

This first survey of British sufferers of olfactory disorders has revealed that there is a significant and previously unquantified problem with those affected in many ways from professional to emotional and nutritional issues. However, there is also a greater problem of the understanding of the role the sense of smell plays in everyday lives, both in the general public and among the medical profession. Fifth Sense is moving toward charitable status and will have, as its mission statement, the goals of improving treatment for patients, understanding of the sense of smell, and aiming to help generate more research into treatments for affected sufferers. It is hoped that this paper will highlight this neglected group of patients and empower relevant clinicians to be more empathic in their dealings with them.

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Appendix 1

Fifth Sense Members Survey

How old are you?

What is your gender?

How do you feel about the following statements relating to your smell disorder?

1. I often perceive a bad smell, regardless of whether a potential odor source is present
2. My biggest problem is not that odors are less intense (or absent), but that things smell different from the way they used to
3. I am aware of my problem all day long
4. It reduces my appreciation of food and drink
5. Food tastes different from what it used to
6. I now eat less than I used to
7. I now eat less healthily than I used to
8. I am now more careful about the food I eat
9. I have gained weight
10. I have lost weight
11. I go to restaurants less often than I used to
12. I am wondering if I will ever be able to live with this problem
13. I am more stressed than I used to be because of this problem
14. Sometimes I have thoughts and ideas I would not want other people to know of
15. Most of my problems are due to the difficulties with my sense of smell
16. I visit friends, relatives, or neighbors less often

17. I find it harder to relax
18. The difficulties with my sense of smell make me feel alone and isolated
19. I avoid groups of people
20. This problem is just one of the many problems in life one has to live with
21. I am scared of getting exposed to certain dangers (e.g., gas, rotten food)
22. I have problems taking part in many of the daily activities of life
23. The difficulties with smelling make me feel angry and/or frustrated
24. My relationship with my partner/family/friends is affected by my difficulties with smelling

Have you suffered from the following in relation to your smell disorder:

- Depression – Yes/No
- Anxiety – Yes/No

If you have suffered depression or anxiety as a result of your smell disorder, have you...

- Taken any medication prescribed by your GP (e.g., anti-depressants, sedatives, anxiolytics)?
- Taken an over-the-counter medicine?

- Taken an alternative medicine remedy?
- Received counseling?
- Other (please specify below)

Has your smell disorder had an impact on your professional life? (0–10 scale)

- Please provide details of any specific issues here

Has your smell disorder had an impact on your social life? (0–10 scale)

- Please provide details of any specific issues here

Has your smell disorder had an impact on your domestic life? (0–10 scale)

- Please provide details of any specific issues here

Has your smell disorder had an impact on your sex life? (0–10 scale)

- Please provide details of any specific issues here

Do you think there are any key issues that have not been covered by the above questions? If so, please provide further details here.