ORIGINAL CONTRIBUTION

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Olfactory disorders: the patients' view*

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SUMMARY

Objective: *To investigate the level of knowledge that patients had about their olfactory disorder at the time of presentation to a specialist Olfaction Clinic.*

Design: *Multi-centered, cohort study of consecutive patients presenting to specialist Olfaction Clinics surveyed using a standardized questionnaire.*

Setting: *Tertiary referral Olfactory Clinics in Geneva, Switzerland and Dresden, Germany.*

Main Outcome Measures: *The number of prior medial consultations, the number and type of doctors they had consulted, a rating of the information they had received from these doctors, whether prognostic information had been given and whether they felt their problems had been well managed by the doctor were factors surveyed. Olfactory assessment was measured by the Sniffin' Sticks kit.*

Results: *Eighty percent of patients had sought previous medical advice, with a mean 2.1 past consultations. Of these patients, 60 % reported that they had received either no or unclear or unsatisfactory information about their diagnosis, 30 % had received no information about their prognosis and 25 % felt they had not been managed well.*

Conclusion: *The majority of patients with olfactory disorders seek medical advice before presenting to a specialist Olfaction Clinic. However, the majority reported receiving no or poor information about their diagnosis and prognosis. Considering the significant prevalence and potential consequences of olfactory disorders, it is our duty as specialists to improve the knowledge and communication of our medical colleagues about these diseases, so that patient education or referral can be improved.*

Key words: education, communication, olfaction, diagnosis, patients view, Sniffin' Sticks, information, prognosis

INTRODUCTION

Although humans rely more heavily than other animals upon visual and auditory cues for information about their environment, the olfactory function is well-conserved from an evolutionary point of view. At a basic level, a healthy olfactory system enables humans to track odour sources [(1)] and recognize biologically important scents [(2)]. These abilities are common to most macrosmatic mammals, but contrary to popular belief, the human olfactory system is able to outperform other mammals in the detection of certain odours [(3)]. Indeed, humans have extended and specialized some aspects of olfactory function, which are present in other mammals: for example, retronasal olfaction [(4)]. Also, while humans have fewer genes which code for functional olfactory receptors than mice or rats have, some of these genes undergo selective pressure to be conserved during DNA replication in humans [(5,6)].

Severe olfactory loss is present in approximately 5 % of the general population [(7-9)]. It is generally reported to be less disabling than other sensory losses, such as blindness or deafness and, with a few reported exceptions, its consequences are rarely life-threatening [(10-12)]. Perhaps these facts have contributed to the commonly held belief within the general medical community that olfaction is a "lower sense" [(13)] and hence, olfactory disorders are relatively unimportant to the patients' health. Recent advances in our understanding of olfaction however, have made this traditional view untenable [(14)].

Indeed, human olfaction, viewed in the context of current data, has a significant impact on health and quality of life and the consequences of olfactory loss can be extremely wide-ranging. Physical consequences include the risks of illness from consuming contaminated or spoilt foods, injury or death from the delayed detection of environmental hazards (such as fire or noxious gases) and taste loss, leading to reduced nutritional intake [(10-12)]. Psychosocial consequences may include reduced quality of life, reduced food and wine tasting ability (with its

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personal, social and, for some patients, professional implications), and in extreme cases, a drop in personal hygiene levels, social isolation and depression [15].

Although the last twenty years have brought invaluable knowledge on epidemiological aspects of olfactory loss, no studies have addressed the issue of patient education and knowledge about their olfactory disorders. It is obviously important that patients are educated about their disorder, as well as the more serious consequences that may arise from it. It was our anecdotal experience that most patients presenting to our clinics had received prior medical advice, yet their knowledge about their olfactory disorders appeared to be poor. We designed this study to investigate the level of knowledge patients had about their olfactory disorders.

METHODS

Ethical Considerations

Informed consent was obtained from all patients. The study was approved by the institutional ethics review boards and conducted according to the Declaration of Helsinki on Biomedical Research Involving Human Subjects.

Patients

Two hundred and thirty consecutive patients presenting to the Smell and Taste Clinics of the Otorhinolaryngology Departments of the Dresden (60 % of the patients) or Geneva University Hospitals (40 % of the patients) were interviewed before the consultation began.

Questionnaire

A one page questionnaire was completed during the interview. It consisted of four main questions requiring "yes/no" answers and further parts to some questions, as follows:

1) Have you previously consulted other doctors because of your smell problem?

   If "yes": how many doctors have you consulted, what was their field of practice (general practitioner, ENT surgeon, neurologist, etc.), how many consultations did you have with each doctor?

2) Did you receive information about your olfactory disorder and its potential consequences?

   If "yes": how clear was this information (clear, satisfactory, unsatisfactory, unclear)?

3) Did you feel your olfactory complaint was well managed by the doctor(s)?

4) Were you given prognostic information about your olfactory disorder?

   If "yes": was it that your sense of smell will return quickly, slowly or never?

Clinic Consultation

After completing the questionnaire, the patients underwent the regular work-up for olfactory disorders at our clinics. This involves a complete medical history, otorhinolaryngological examination, nasal endoscopy, and chemosensory testing (for details concerning olfactory work-up, see reference [16-18]). Assessment of olfactory function was performed using the "Sniffin' Sticks" [19] tests for odour threshold, odour discrimination and odour identification. Results from these tests were presented as a composite "TDI score" which was derived from the sum of the results obtained for threshold, discrimination, and identification measures. Each patient was then categorized as having anosmia (TDI score $\leq$ 15), hyposmia (TDI $>$ 15 but $<$ 30) or normosmia (30 $>$ TDI score) [19].

Statistical Analysis

Results were analysed using SPSS 12 for Windows™ (SPSS Inc., Chicago, IL, USA). Descriptive statistics were presented as means and standard errors of the mean (SEM). Analyses of variance (repeated measures-ANOVA) were used to investigate differences in numbers of consultations depending on the cause of the olfactory disorder. Student's t-tests for independent samples were used to investigate differences between patients who felt their problem had been well managed or those who had received an explanation, on the one hand, versus those who did not fit into these categories, on the other. The alpha level was set at $p < 0.05$.

RESULTS

Patient Demographics

Of the 230 patients in the study, 99 were men and 131 were women. The mean age for men and women did not differ (men 53.2 1.2 years, women 52.3 1.6 years; $p = 0.6$).

Questionnaire Results

Completion of the questionnaire took between 5 and 10 minutes in all cases.

<u>Previous Consultations and Doctors (Question 1)</u>

Eighty percent of patients (n = 184) had consulted doctors about their olfactory symptoms prior to presentation at our clinic, leaving 20% (n = 46) who had received no medical advice previously. Of the group who had received prior medical advice, a mean of 2.1 $\pm$ 0.1 doctors had been consulted (Figure 1). Most patients had consulted an ENT surgeon (n = 95; 52 %), their general practitioner (n = 8; 4 %), or both (n = 81; 44 %; Figure 2). The degree of olfactory loss (expressed as TDI score) did not correlate with the number of previous consultations ($r = -0.08$; $p = 0.23$) nor was the mean number of consultations related to the diagnosis (anosmia-hyposmia-normosmia) given ($F = 0.058$, $p = 0.94$).

<u>Information Received (Question 2)</u>

Among those patients who had sought prior medical advice (n = 184), 58% (n = 107) had received information about their olfactory disorder and its potential consequences, while 42 % (n = 77 patients) had received no such information. Patients

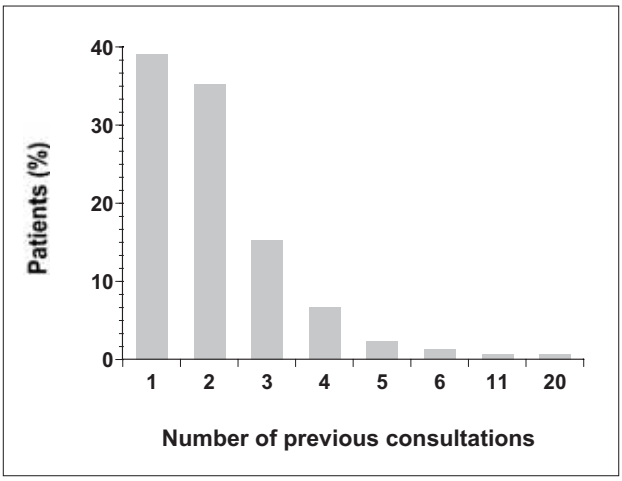

Figure 1. Number of consultations in those patients who already saw another physician before coming to our outpatient clinic. On average these patients had consulted two times before being referred to our outpatient clinic.

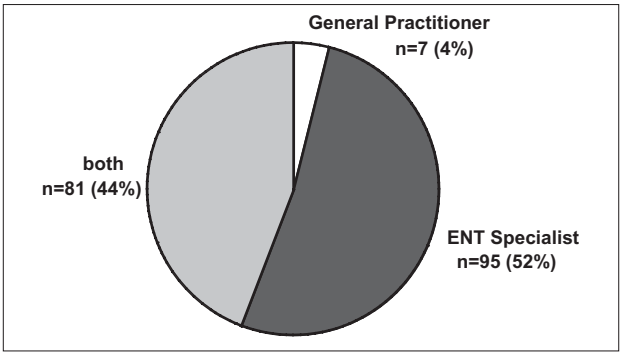

Figure 2. Distribution of the physicians who have been visited by the patients who previously consulted for their olfactory problem.

who had received information had not attended significantly more consultations than those who had not received any (1.9 ± 0.2 visits versus 2.3 ± 0.2 visits; t = 1.5, p = 0.13). The number of consulted doctors was not significantly different between patients who received information and those who had not (Chi square test, p = 0.43). Among those patients who had received information (n = 107), 42 % (n = 45) described it as clear, 26 % (n = 28) as satisfactory, 23 % (n = 24) as unsatisfactory and 9 % (n = 10) as unclear (Figure 3). In summary, 111 patients (60 %) out of 184 who had previously seen a physician received unclear, unsatisfactory or no information.

Management of past doctor(s) (Question 3)

Among those patients who had previously seen doctors (n = 184), 141 (75 %) reported their disorder had been well managed, while 25 % (n = 43) reported the feeling it had not (Figure 4A). There was a significant difference in the number of consultations attended by these groups, with the former group having fewer consultations (2.0 ± 0.1 visits versus 2.6 ± 0.4 visits; t = 2.2, p = 0.048; Figure 4B).

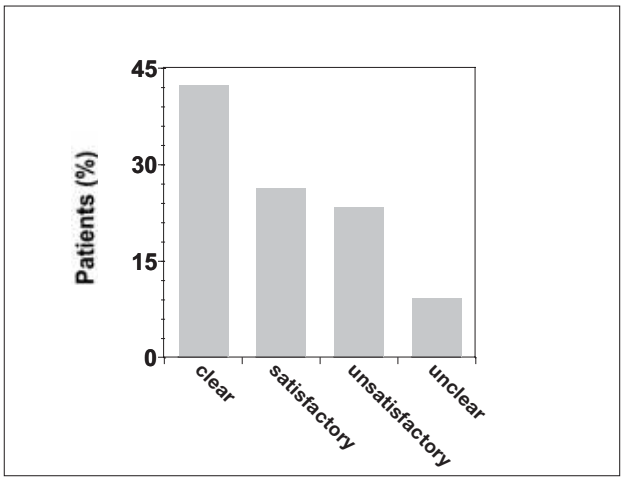

Figure 3. Levels of patient's perception of the clearness and degree of satisfaction of the physician's explanation.

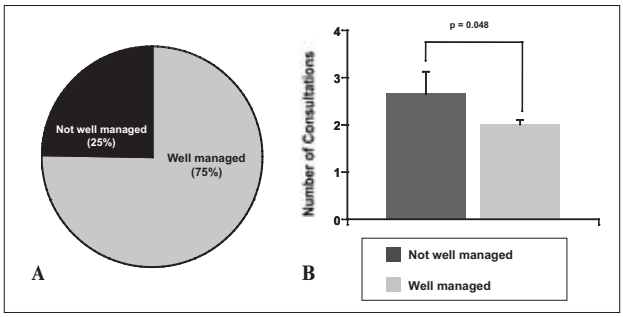

Figure 4. A) Percentage of the patients who felt their olfactory problem was well managed during the previous consultation. B) Number of previous medical consultations for the olfactory problem in patients who reported their problem had been well managed versus patients who felt their problem had not been well managed.

Prognostic information (Question 4)

Among the 184 patients who had sought prior medical advice, 30 % (n = 55) reported that they did not receive any information about their prognosis. Twenty percent (n = 37) had been told that their olfaction would never improve, while 31 % (n = 57) had been told that it would recover slowly and 13 % (n = 24) had been told that it would recover quickly. A few patients (6 %, n = 11) felt that their disorder had been trivialized by the doctor with comments to the effect that their olfactory loss would not significantly impact upon their quality of life or health and that they should not worry about it any further (Figure 5).

Causes of Olfactory Symptoms

The assessments from our clinics found the causes of the olfactory disorders in this cohort of 230 patients to be upper respiratory tract infections in 33 % (n = 75), head trauma in 21 % (n = 48), inflammatory sinonasal diseases in 16 % (n = 37), idiopathic olfactory loss in 18 % (n = 42), congenital olfactory loss in 3 % (n = 8) and miscellaneous causes in 9 % (n = 20; for

example, neurodegenerative disease, iatrogenic from surgery or medication, or tumour; Figure 6A).

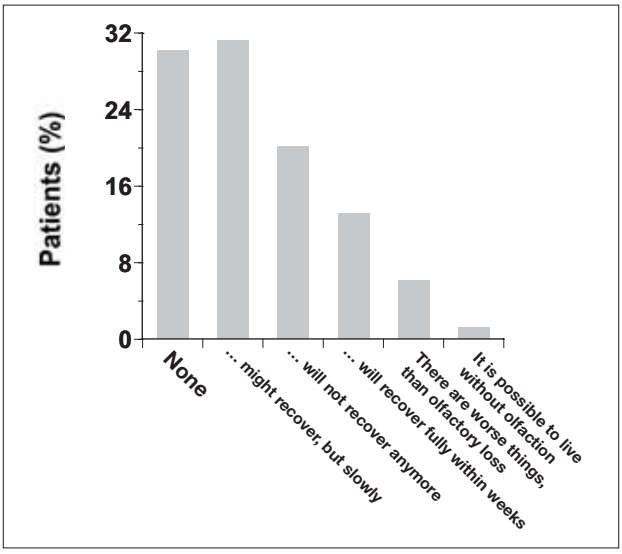

Figure 5. Explanations received by the patients concerning the prognosis and evolution of the olfactory dysfunction.

Olfactory Scores

Results of our clinic tests showed 15 % (n = 35) of patients had normal olfaction, 39 % had hyposmia (n = 90) and 46 % had anosmia (n = 105, Figure 6B). All patients who were found to have normal olfactory scores (n = 35), complained of subjective olfactory impairment. Most of them were diagnosed as idiopathic (n = 13), sinonasal (n = 9), post-viral (n = 6), neurological and psychiatrical diseases (n = 3), post-surgery (n = 3) and post-radiotherapy (n = 1).

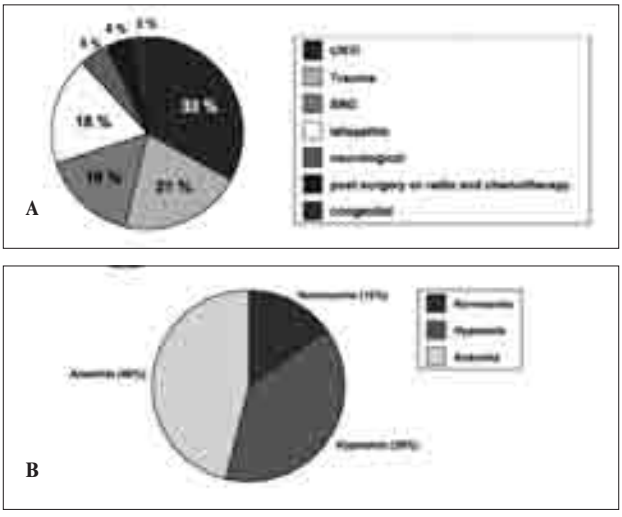

Figure 6. A) Distribution in percentage of the causes of olfactory disorders. The majority of patients presented with a dysfunction occurring after an upper respiratory tract infection (URTI), head trauma and chronic sinonasal disease (SND). B) Percentage of patients which had been diagnosed to have normosmia, hyposmia or anosmia according the TDI scores.

DISCUSSION

About three quarters of olfactory disorders are due to sinonasal inflammatory diseases, traumatic injury or upper respiratory tract infections (URTI). The remaining one quarter of patients either have rare causes or remain undiagnosed as "idiopathic olfactory disorder" [20-22]. While the olfactory deficits due to sinonasal inflammatory diseases usually improve with treatment of the underlying disease, the other causes lack effective treatment [16,23]. Although olfactory impairment is not life-threatening, most patients suffer considerably on a social and psychological level [15,20,24] and have to adopt coping strategies to overcome the lack of normal olfactory function [25]. Despite that almost half of them experience domestic accidents such as eating spoiled food or non detection of fire or gas leaks [26]. Consequently, since treatment cannot always be offered, education and follow-up becomes a central management aspect in order to reduce the patient's distress. Of course, it has become part of routine practice in all fields of medicine to educate patients about their disease, its potential consequences and natural history, especially for chronic diseases or as part of informed consent prior to surgery [27]. Olfactory disorders are no exception, particularly as they carry significant potential consequences on life quality. Despite this, it was the impression of our staff that, even though most patients had received medical advice about their olfactory disorders prior to presenting to our clinics, they usually had a poor understanding of their diagnosis, its consequences and prognosis. The present data seem to confirm this impression. With regard to prognosis for example, it is important that patients are informed that the olfactory epithelium does have the capacity of spontaneous regeneration after injury [28]. Both post-traumatic and post-URTI olfactory disorders exhibit much higher rates of regeneration than olfactory loss from other causes: 15 % and up to 50 %, respectively, within two years [29-31]. In the context of the current paucity of effective treatments for many causes of olfactory disorders, this information may offer some hope of natural recovery in the long-term.

The concerning statistics from this study are that 60% of patients had received no or poor information about the nature or consequences of their diagnosis, 30% had received no information on prognosis and 25% felt that their problems had not been well managed. The possible reasons for these statistics include lack of knowledge about these facts by the doctor, ineffective communication by the doctor or poor recall by the patient. The fact that those patients who felt their case had not been well managed were motivated enough to seek more consultations and visit more doctors, suggests that it is the doctors who need to address their role in the communication process. Improvements in patient education should also provide an economic benefit, by reducing the number of consultations sought by these patients.

The results of this study suggest that significant improvements are needed in patient education about olfactory disorders by doctors in a non-specialist outpatient setting. This actually means that the onus is upon specialist olfactologists to educate our medical colleagues about olfactory disorders and, in particular, what information needs to be given to patients and the manner in which it should be delivered. For example, consideration should be given to the publication of patient information sheets about olfactory disorders and their consequences. These may be written as a consensus, by a group of specialist olfactologists. Such an information sheet could be available for distribution to patients through practitioners of all medical specialties that treat olfactory disorders. This may be a useful method to improve patient knowledge about this group of diseases, which can have a significant impact upon patient safety and quality of life. In addition, awareness needs to be raised within the medical community about the presence and location of specialised Olfaction and Gustation Clinics.

This is the first study that assesses the education of patients about their olfactory disorders, as performed by doctors in settings other than specialist Olfaction Clinics. It contains a large group of 230 patients, 85 % of whom had hyposmia or anosmia on testing in our clinics. A standard data collection method was used in a prospective manner, before consultation at our clinic.

The questionnaire was designed to be short for reasons of efficiency, but this limits the data available. The data is subjective in its nature and will be affected by patients recall bias. There has been no attempt at correlating the data by other methods, for example, contacting the doctors who had been previously consulted, to confirm whether information about diagnosis and prognosis had been given to the patient. The suggestion that patient information sheets may be useful in improving patients' knowledge needs to be assessed with a randomized controlled to study to prove its efficacy.

CONCLUSIONS

Eighty percent of patients had consulted doctors, usually ENT surgeons, prior to presentation at our Olfaction Clinics. The majority of patients (60 %) reported receiving no or poor information about their diagnosis and its potential consequences at these consultations. One quarter reported that their disorder had not been well managed. This group of patients sought significantly more consultations and consulted a greater number of doctors. Thirty percent of patients reported receiving no information about prognosis. It is evident that doctors need to improve their communication with patients about olfactory disorders. Olfactologists need to be active in facilitating this process and raising awareness about specialist Olfaction clinics to manage these patients.

CONFLICTS OF INTEREST

None Declared.

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