

Effects of smell loss on daily life and adopted coping strategies in patients with nasal polyposis with asthma

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*Nasal polyposis and Asthma: effects of FESS and FPND; the Stockholm Study

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Running Head: Smell Loss, Daily Life and Coping

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Abstract

Conclusions: Results from prior studies of quality of life (QoL) in heterogeneous patient groups (regarding disorder type and etiology) with olfactory disorders may be useful also for understanding QoL in homogeneous patient groups. Diagnosis and treatment of smell loss should be given high priority in polyposis with asthma, and coping strategies can be suggested to these patients. *Objectives:* To investigate effects of smell loss on daily life and coping strategies in patients with smell loss without dysosmia and with nasal polyposis with asthma as the only primary etiology, and to compare these results with those from a prior study of a patient group with a heterogeneous olfactory disorder and etiology. *Methods:* Fifty patients with smell loss, and with nasal polyposis and asthma responded to questions about consequences of smell loss, QoL, psychological well-being and distress, and coping strategies. *Results:* Negative consequences of smell loss, associated risks, and diminished food enjoyment were commonly reported, and various aspects of QoL were rated as being deteriorated. Psychological well-being was found to be poorer than normal, and use of both problem- and emotion-focused strategies were common. The results from this homogeneous patient group are very similar to those previously obtained from a heterogeneous group.

Key words: *anosmia, clinical, hyposmia, olfaction, quality of life*

Introduction

The sense of smell is an important chemical warning system that regulates food intake and is involved in interpersonal relations. Consequently, adverse effects in patients with olfactory disorders have been reported with regards to poor safety, difficulties cooking and detecting spoiled food, decreased food enjoyment and poor appetite, change in body weight, worries about personal hygiene, depression and mood changes, feelings of vulnerability, and deterioration in work life, social interactions and sexual life [1]. However, with one exception [2], a limitation in these studies is that they have investigated rather heterogeneous groups. Thus, they have not differentiated the impact of different types of olfactory disorders or primary etiologies underlying the disorders.

Types of olfactory disorders include loss in sensitivity and qualitative changes. A sensitivity loss is typically described as impaired detection sensitivity, quantified in terms of either hyposmia (diminished smell sensitivity) or anosmia (complete smell loss). Quantitative changes, often referred to as dysosmia, include parosmia (qualitative odor distortion that typically is unpleasant) and phantosmia (odor sensation in the absence of an external odorant). It is possible that smell loss, without dysosmia, would be more strongly associated with poor safety than would dysosmia without smell loss. Furthermore, parosmia with an unpleasant distortion, but without smell loss, may affect enjoyment and intake of food to a larger extent than would an isolated smell loss.

The primary etiology underlying the olfactory disorder may also play a role in consequences of smell loss. Common etiologies are chronic rhinosinusitis with or without nasal polyposis and post-acute rhinosinusitis, and head trauma, toxins/drugs [3]. In many of these etiologies the patient is experiencing symptoms, in addition to the olfactory disorder, with consequences for daily life. For example, patients with polyposis and asthma would also have respiratory symptoms, and patients with head trauma may also experience paralysis and seizures. Hence, we need to understand to what extent the results from prior studies of quality

of life (QoL) in heterogeneous patient group with olfactory disorder can be generalized to patients with specific olfactory disorders and etiologies.

Coping strategies play a vital role in dealing with everyday problems and disorders, particularly in patients with olfactory disorders since treatment in many etiologies is limited or non-existing [3]. The strategies for coping are traditionally classified as problem- or emotion-focused. Problem-focused strategies aim at solving the difficulty/stressor that we may encounter whereas emotion-focused strategies are used to deal with the emotions that arise [4]. Only one study, to our knowledge, has investigated coping strategies used by patients with olfactory disorders [5]. In that study of patients with heterogeneous olfactory disorder and etiology, both problem-focused and emotion-focused strategies were found to be used by a considerable proportion of the patients. However, use of coping strategies by patients with a homogeneous olfactory disorder and etiology has not been documented.

The aim of the study was to understand to what extent results from prior studies of impact on daily life and use of coping strategies in heterogeneous patient group with olfactory disorder can be generalized to patients with a specific olfactory disorder and etiology. Patients with smell loss without dysosmia and with nasal polyposis with asthma as the only primary etiology were investigated, and compared with results from a prior study of a patient group with a heterogeneous olfactory disorder and etiology, using an identical study protocol [5]. Polyposis is prevalent in up to 4% [6], and asthma in up to 10% [7] of the general population. In patients with nasal polyposis referred to ENT departments, asthma has been found in 30% [8]. Consequently, about 1% of this population suffer from concomitant nasal polyposis and asthma. The specific objectives were to study this homogenous patient population with respect to (i) consequences of smell loss, (ii) separate effects of smell loss and nasal polyposis on QoL, (iii) effects of smell loss on psychological well-being and distress, and (iv) strategies used to cope with smell loss.

Material and Methods

Patients

Fifty patients, aged 19-73 years (mean \pm SD = 50.5 \pm 13.1), with a diagnosis of NP and asthma were recruited from the ENT department at the Karolinska University Hospital, Huddinge, Stockholm, Sweden from January 2002 to September 2004. They were required to be hyposmic or anosmic, have bilateral nasal polyps upon endoscopic examination and asthma, diagnosed by history and lung function tests, evaluated by a pulmonologist. Our definition of nasal polyposis is in accordance with the European guideline definition “chronic rhinosinusitis with nasal polyps” [9]. Accordingly, nasal polyposis is an eosinophilic inflammatory disease characterized by bilateral nasal polyps that cause a severe nasal blockage and olfactory dysfunction. Nasal polyposis may be complicated by asthma and aspirin intolerance (Samters triad). Treatment of nasal polyposis is symptomatic and is based on antiinflammatory treatment with nasal and oral steroids. In patients with severe symptoms surgery may be a complimentary treatment (see also [10]).

Exclusion criteria included parosmia and/or phantosmia, polypectomy within the last six months, pregnancy and lactation. The patients are described in Table I (see [10] for further details).

The diagnosis of hyposmia or anosmia was based on a psychophysically determined odor detection threshold since this type of measure well represents sensory function and is commonly used in clinical settings for this purpose. The Connecticut Chemosensory Clinical Research Center Threshold Test [11] was used, which applies a two-alternative, forced choice ascending method of limits. A series of 15 aqueous dilution steps of butanol in deionized water was used, ranging from 4.0% (Dilution Step 14) to 0.0000008% (Dilution Step 0). Each successive dilution step was one third the concentration of the preceding dilution. The stimuli, vapour phase of 60 ml solution, were presented via 250-ml squeezable polyethylene bottles with pop-up spouts. Starting at Dilution Step 14, an incorrect choice led to a one-step increase

in concentration. A correct choice led to presentation of the same concentration to a criterion of five consecutive correct choices. Detection of Dilution Step 7-14 was referred to as normosmia, Dilution Step 3-6 as hyposmia, and Dilution Step 0-2 as anosmia [10,11].

The study protocol, the patient information and consent forms were reviewed and approved by the local independent ethics committee of the Karolinska Institute (Dnr 234:00) prior to the enrolment of patients, and the procedures were in accordance with the Helsinki Declaration of 1975, as revised in 1983.

[Table I about here]

Questionnaire instruments

The questionnaire used included (i) the questions pertaining to parosmia and phantosmia, nasal/respiratory symptoms, allergy, nasal/sinus surgery, and conditions with potential effect on olfactory sensitivity from the Multi-Clinic Smell and Taste Questionnaire [12], (ii) open- and close-ended questions about consequences of smell loss (Table II; of which many have been evaluated metrically and shown to be comprehensible and have good reliability [12]), (iii) questions about QoL (Table III), (iv) the General Well-Being Schedule (GWBS; [13]) for assessing psychological well-being and distress, and (v) questions about coping strategies.

The questionnaire was responded to under supervision at the ENT department.

The GWBS assesses a broad range of dimensions of psychological well-being and distress, including anxiety, depression, general health, positive well-being, self-control, and vitality [13]. It ranges in score between 0 and 110 (high score indicating positive well-being and low distress), and has been shown to have good internal consistency, test-retest reliability and validity and has normative data [14,15].

Five problem-focused and six emotion-focused questions about use of coping strategies for smell loss were used to respond to with “yes” or “no” (Table IV). The emotional strategies and the problem-focused strategy about seeking information are commonly used for coping

with situations in general, whereas the remaining four problem-based strategies can be considered as specific for smell loss. The patients were instructed to respond to all strategies that they use.

[Tables II-IV about here]

Statistical methods

One-sample Sign tests were applied to analyze the QoL data, and Chi-square to analyze the data on psychological well-being and distress, using SPSS 15.0 for Windows (SPSS Inc., Chicago, IL, USA). The α -level was set at 0.05.

Results

On the open-ended questions about consequences of smell loss, negative effects were reported by 72%, positive effects by 38%, associated risks by 65%, interference with daily activities by 33%, and effects on well-being by 21%. On the close-ended questions about food intake, 68% reported diminished ability to taste or enjoy food, and 27% reported worsened appetite.

Distributions of the specific responses are given in Table II.

Median (interquartile range) ratings of the importance of the aspects of QoL are shown in Table III, suggesting that all seven aspects were important for QoL, which was confirmed by one-sample sign tests of significant differences from zero ($p < 0.001$). Table III also shows median (interquartile range) ratings of effects of the smell loss and nasal polyposis on the aspects of QoL. One-sample sign tests of differences from zero (“No change at all”), separately for effects of smell loss and nasal polyposis, yielded significant differences for effects of both loss and polyposis on financial security ($p < 0.01$) and on the remaining six aspects of QoL ($p < 0.001$). Note that although the median rating for some aspects of life quality were zero, the number of cases for which the rating was smaller than zero (rating of

deterioration) was for all aspects larger than the number of cases for which the rating was larger than zero (rating of improvement).

Mean \pm SE GWBS score of psychological well-being and distress was 69.40 \pm 20.63. According to these scores and cutoff values [14], 50% of the patients can be referred to “positive well-being” (scores 73-110), 20% to “moderate distress” (scores 61-72), and 30% to “severe distress” (scores 0-60). For comparison, normative data [14] are 71%, 15%, and 14%, respectively. Compared to the normative data, the patients showed a significant difference in distribution across the three health categories, shifted towards lower well-being and more distress [$\text{Chi}^2(2) = 10.48, p < 0.01$].

The percentage of patients who reported having adopted the problem- and emotion-focused strategies for coping with their smell loss are presented in Table IV. Three of the five problem-focused strategies were reported being used by a fairly large proportion of the patients ($\geq 19\%$), of which letting a family member taste food that might be spoiled dominated (58%). In a similar vein, four of the five emotion-focused strategies were fairly commonly reported ($\geq 18\%$), dominated by trying to accept the situation and do the best of it (73%).

Discussion

The aim of the study was to better understand to what extent results from prior studies of effects on daily life and use of coping strategies in heterogeneous patient group with olfactory disorder can be generalized to patients with specific olfactory disorders and etiologies. The results, when compared with those of a prior study [5], support such a generalization, at least regarding olfactory loss without dysosmia, and with nasal polyposis with asthma as the only primary etiology.

The consequences of smell loss in this homogeneous group are in some respects strikingly similar to those previously reported by patients with heterogeneous olfactory

disorders and etiology, of whom 34% had parosmia and/or phantosmia, but only 11% had nasal polyposis as etiology [5]. In both studies, with identical study protocol, unawareness of personal hygiene and less interest in food were the two most common negative effects; not being bothered by unpleasant odors was the most common positive effect; failure to perceive fire/smoke and rancid food were the two most common associated risks; difficulties in cooking was the most common interference; and depression was the most common effect on well-being. The proportions of patients reporting these consequences were in general very similar as well. The two studies were also comparable with respect to proportions reporting diminished food enjoyment (53 vs 68%) and worsened appetite (32 vs 27%). This suggests that patients with a smell loss without dysosmia and a homogeneous etiology of nasal polyposis with asthma experience consequences of the smell loss very similar to patients with heterogeneous olfactory disorder and etiology.

Many of the present findings on consequences also agree with other prior studies of patients with heterogeneous olfactory disorder and etiology, for example, regarding person hygiene, eating and drinking, failure to perceive fire/smoke and rancid food, difficulties in cooking, and depression [16,17]. As in the study by Hedén Blomqvist et al. [5], the proportions reporting consequences of the olfactory disorder were somewhat lower than in these other studies, which may be due to the fact that we asked only about the main effect, rather than about all possible effects.

The results further suggest that physical health, financial security, work life, partnership, friendship, emotional stability, and leisure are important for QoL, and that both the smell loss and the polyposis negatively affect all seven aspects. The median ratings imply modest effects in general, and that the polyposis has a larger effect than smell loss on these aspects of QoL, with the exception of financial security.

Psychological well-being and distress was studied from a broad perspective with the GWBS. The questions in this instrument ask about well-being and distress without respect to

any particular medical condition. Thus, it is not possible to differentiate the effects of smell loss, nasal polyposis and asthma. Nevertheless, the results suggest that patients with smell loss caused primarily by polyposis secondary to asthma have poorer well-being than the normal population. Considering the present result of 21% reporting affected well-being due to the smell loss, and prior findings of polyposis with and without asthma affecting health-related QoL [18,19], it is likely that both smell loss and the polyposis secondary to asthma are underlying this poor well-being and distress.

The results show that the patients use both problem- and emotion-focused strategies to cope with their smell loss. The most common problem-focused strategy was letting a family member taste food that might be spoiled, followed by looking for information about the smell loss and asking a family member about just enough perfume or after shave. Regarding emotion-focused strategies, the most common strategy was trying to accept the situation and do the best of it, and trying not to think about the smell loss.

The current homogeneous group was very similar to the heterogeneous group [5] also with regards to QoL, psychological well-being and distress, and use of coping strategies. Whereas the life-quality aspect financial security did not show a significant deterioration ($p = 0.07$), all other six aspects were reported to deteriorate in that study [5], very similar to that found in the present study. Regarding psychological well-being and distress, we reported in this earlier study that 51% of the patients were referred to positive well-being, 21% to moderate distress, and 28% to severe distress [5]. These percentages are very similar to those found in the present study (50, 20, and 30%, respectively). The order of how commonly the different coping strategies were used was almost identical in the two studies, and the percentages of usage were in general very similar. No gender differences were observed in the current study, but in response to stressors men tend to use problem-focused strategies more than women, and women tend to use emotion-focused strategies more than men. This may be

noted since the proportion of women in the present study (42%) was lower than in the study with the heterogeneous group (60%) [5].

Certain caution should be taken when interpreting the results. First, regarding the questions of the smell loss having affected well being and QoL, it might have been difficult for the patient to differentiate between the effects of smell loss and of nasal polyposis. It is probably even more difficult to differentiate between effects of asthma and polyposis since both affect respiratory function. Future studies of effects of smell loss may therefore, if possible, focus on patients with smell loss as the only medical condition. Secondly, although it is reasonable to assume that the primary etiology of the smell loss is nasal polyposis with asthma, it cannot be excluded that secondary etiologies may be involved. Although a number of potential causes of smell loss were found not to be reported by the patients, conditions such as diabetes mellitus (reported by 6%) and high age may have contributed to the loss.

The findings have clinical implications. The similarities in results between this homogeneous patient group and a heterogeneous group [5] implies that results from a relatively large number of prior studies of QoL in heterogeneous patient group, referred to above, may be useful also for understanding QoL in more homogeneous patient groups with olfactory disorder. However, further studies are needed to better understand to what extent such generalizations can be made. Other implications are that diagnosis and treatment of olfactory disorder should be given high priority, and that use of both problem- and emotion-focused coping can be suggested by the healthcare provider to these patients.

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Table I. Patient characteristics (%).

Women	42
Olfactory diagnosis ¹	
Hyposmia	32
Anosmia	68
Chronic/frequent nasal/respiratory symptoms (within past 2 years)	
Nasal discharge	68
Coughing	52
Sneezing or itchy nose	44
Attacks of breathing difficulties/wheezing	40
Colds	34
Sinus infection	30
Lower respiratory mucus	30
Sinus pain/headache	28
Lower respiratory infection	24
Nose bleeds	22
Allergy	
Drugs ²	20
Food	8
Prior nasal/sinus surgery (within past 2 years)	
Nasal polypectomy	42
Sinus surgery	8
Deviated nasal septum repair	8
Other nasal surgery	4
Conditions with potential effect on olfactory sensitivity	
Smoking	6
Diabetes mellitus	6
Stroke	0
Alcohol or drug abuse	0
Cystic fibrosis	0
Alzheimer's or Parkinson's disease	0
Sjogren's syndrome	0
Multiple sclerosis	0

¹Based on odor-detection threshold. When adjusting for age-related loss in sensitivity, 38% were hyposmic and 62% were anosmic

²Without specific analysis of NSAID-intolerance

Table II. Questions and responses about consequences of smell loss and importance of olfaction (%).

Has your smell loss had any negative effects? If so, what is the most negative effect? ¹	
Less aware of personal hygiene	19
Less interested in food and beverages	15
Less satisfied with work life	15
Poorer quality of life in general	13
Less appreciating of nature	4
Unable to perceive fire/smoke	2
Less emotional satisfaction	2
General feeling of insecurity	2
Has your smell loss had any positive effects? If so, what is the most positive effect? ¹	
Not being bothered by unpleasant odors	38
Do you perceive any risks associated with your smell loss? If so, what is the main risk? ¹	
Failure to perceive:	
fire/smoke	38
rancid/ill-smelling food	15
dangerous chemicals/gases	6
Risks at work	6
Does your smell loss interfere with your daily activities? If so, what is the main type of interference? ^{1,2}	
Difficulties in cooking	13
Reduced ability in work life	8
Eating problems	6
Difficulties interacting with friends	4
Feeling obliged to wash myself/my home more often	2
Has your smell loss affected your well-being? If so, what is the main effect? ^{1,2}	
Depression	15
Tired	4
Poorer general well-being	2
How has your smell loss affected your ability to taste/enjoy food? ²	
Improved	4
No change	28
Diminished	68
How has your smell loss affected your appetite? ²	
Improved	0
No change	73
Worsened	27

¹Open-ended question²Evaluated regarding comprehension and reliability (Nordin et al. 2003)

Table III. Questions and responses as medians (interquartile range) about quality of life.

How important are the following aspects for your quality of life? ¹	5.0 (1.0)
Physical health	5.0 (1.0)
Financial security	4.0 (2.0)
Work life	4.0 (2.0)
Partnership	5.0 (1.0)
Friendship	4.0 (1.0)
Emotional stability	4.5 (1.0)
Leisure	4.0 (1.0)
To what extent has your <i>smell loss</i> affected the following aspects of your quality of life? ²	
Physical health	-1.0 (2.0)
Financial security	0.0 (0.0)
Work life	0.0 (1.0)
Partnership	-0.5 (1.0)
Friendship	0.0 (2.0)
Emotional stability	-0.5 (2.0)
Leisure	-1.0 (2.0)
To what extent has your <i>nasal polyps</i> affected the following aspects of your quality of life? ²	
Physical health	-2.5 (2.0)
Financial security	0.0 (0.0)
Work life	-1.0 (2.0)
Partnership	-1.0 (3.0)
Friendship	-1.0 (2.0)
Emotional stability	-1.0 (2.0)
Leisure	-2.0 (3.0)

¹Rated on a 6-point scale ranging from “not important, 0” to “very important, 5”

²Rated on an 11-point scale ranging from “very extensive deterioration, -5” to “no change at all, 0”, to “very extensive improvement, 5”

Table IV. Questions and responses about use of problem- and emotion-focused strategies to cope with smell loss (%).

Problem focused	
Do you let a family member taste food that you suspect is spoiled?	58
Have you looked for information about your smell loss?	20
Do you ask a family member whether you have just enough perfume/after shave?	19
Do you avoid meeting other people?	2
Have you found solutions to problems caused by your abnormal sense of smell?	2
Emotion focused	
Do you try to accept the situation and do the best of it?	73
Do you try not to think about your smell loss?	30
Do you compare your problems with those who are worse off?	18
Do you seek support from family members?	18
Do you seek advantages of your smell loss?	18
Do you try to reprioritize how important different things are to you?	2
