

Reactions received by smell loss patients after revealing their dysfunction*

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Dear Editor:

The broad media coverage of olfactory loss due to “long COVID” has brought with it a much-needed awareness regarding the importance of our sense of smell. However, living with olfactory loss is largely a private experience⁽¹⁾ and the associated difficulties (e.g., reduced pleasure from sex⁽²⁾ and eating⁽³⁾), are under-reported, unrecognised and unappreciated⁽⁴⁾. Only 50% of those living with olfactory loss are receiving some form of treatment⁽⁵⁾ although encouragingly, helpful support is available online (e.g., fifthsense.org.uk; abscent.org), via social media (e.g., Twitter account @girlwhocant smell) and podcasts (e.g., The Smell Podcast). Like many disorders, people living with olfactory loss must consider whether and to whom they reveal their condition plus the potential impact of doing so. Therefore, the aim of the current study was to explore the reactions received by those living with olfactory loss when revealing their condition to friends, family members and colleagues.

One-hundred and eighty-six patients (107 females, 79 males; aged 19 to 86 years; Mage= 54.0 years, SDage= 15.87 years) with smell loss due to five etiologies (i.e., idiopathic, n=59; post-viral/post-infectious, n=56; sinonasal disease, n=28; trauma, n=22; other, n=15; not established, n=6) completed the study. Patients were attendees of the Smell and Taste Clinic at TU Dresden. This study was approved by TU Dresden’s Ethics Committee and all participants gave informed consent.

To determine a diagnosis, each patient was interviewed about the nature and duration of their olfactory dysfunction using a detailed, structured medical history and a physical otorhinolaryngological examination including nasal endoscopy⁽⁶⁾.

Olfactory function was tested using the three subtests of the “Sniffin’ Sticks” which measures odor acuity, discrimination and identification ability⁽⁷⁾. A total olfactory function score was calculated by summing all three subtests and termed the TDI score - higher scores indicate better olfactory function.

Patients were asked 12 open-ended questions in an interview format to explore the reactions received after disclosing their olfactory loss condition (Table 1, translated from German). The

interviewer recorded the patients’ responses and two of the researchers independently coded the responses, resolving any discrepancies with a discussion. Every patient did not answer every question, so the base rate of responses differs across questions.

After an initial consultation, patients had their physical otorhinolaryngological examination and nasal endoscopy performed by an ENT specialist, followed by the olfactory function test and reactions to olfactory loss interview.

The TDI mean score was higher for the post-viral/post-infectious group (M=22.13, SD=8.42), followed by the sinonasal disease group (M=20.07, SD=9.29), idiopathic (M=19.06, SD=8.36), other (M=16.05, SD=8.91) and trauma group (M=12.71, SD=8.54).

The reactions by family and friends after patients revealed their smell dysfunction were largely supportive (accounting for over 40% of the reactions) whereas the reactions by acquaintances were mixed, with expressions of support and a lack of understanding in similar percentages (Figure 1). In terms of helpful and welcomed reactions after disclosing one’s smell dysfunction, patients (N=87) received helpful responses (around one-third receiving helpful suggestions and one-third psychological support), although one-third of the patients also reported unhelpful reactions. In terms of the types of welcomed responses, fifty-three percent of patients said they would like psychological support, 22% said they were unsure or did not want any reaction, 15% said that would like research on a solution, 7% said they would like to be treated normally and 3% said they would like information about smells and tastes they cannot perceive. In terms of who was asked for help for their smell loss, 50% of patients (N=152) asked a physician, 30% asked multiple types of people (i.e., physicians, family and friends), and 12% of only asked family, friends or colleagues. Prior to attending the clinic, 7% of patients reported having never sought help before and only 1% of patients sought help from a psychologist or psychiatrist. When asked about discussing their smell loss in public, 44% had mentioned and 39% had not mentioned their smell loss in public settings (N=154). On a related question, 78% of patients

Table 1. Reactions to disclosure of olfactory loss – patient interview.

1.	How did your family react to the knowledge of your smell loss?
2.	How did your friends react to the knowledge of your smell loss?
3.	How did your acquaintances react to the knowledge of your smell loss?
4.	Which reactions have been helpful?
5.	What type of people have you asked for help?
6.	What type of people have you not asked for help?
7.	In public settings (e.g., work environment), have you mentioned that you have a problem with your sense of smell?
8.	Who around you knows you have a smell problem?
9.	Is it a problem for you to talk to other people about your olfactory disorder?
10.	If other people didn't exist, would your sense of smell problem still be an issue for you?
11.	What would be a reaction from those around you, or in conversation, that you would like to see?
12a	Is it best not to make public your sense of smell problem, because of possible difficulties at work or in your environment?
12b	If so, what difficulties would that be?

NB: All questions were open-ended.

(N=67) indicated that speaking about their smell loss in public would not be a problem for them.

When asked whether their smell loss should be kept private (N=117), 96% of patients said no, indicating it was best to reveal their smell loss. However, in response to a follow-up question (N = 24), 29% of patients anticipated some form of negative outcome and 17% indicated that people would not understand if they were to reveal their condition. Moreover, most patients (53%) indicated that only people they were close with knew they had a smell dysfunction, 27% indicated multiple types of people knew (e.g., physicians and family), 15% indicated everyone knew of their smell dysfunction.

Given olfactory ability declines consistently after the age of 60⁽⁶⁾, we compared the reactions received by patients 60 or under to those over 60 years. The findings indicated significantly more patients 60 or under received a supportive response compared to those aged over 60 (32% vs 21%; $\chi^2(5)=14.14$, $p=0.015$) and were more likely to reveal their smell loss in public compared to those over 60 (57% vs 31%; $\chi^2(3)=13.59$, $p=0.004$). Finally, a

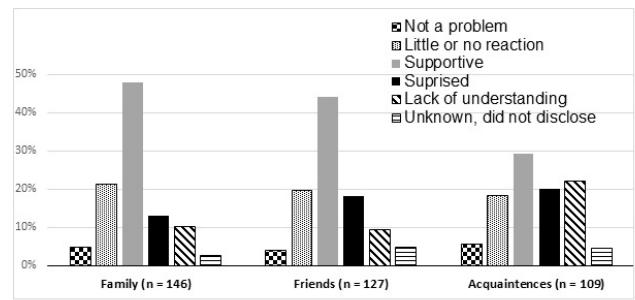


Figure 1. Percentage of reactions to disclosure of smell loss by family, friends and acquaintances.

higher percentage of patients who visited the clinic were 60 or under (62% vs 38%; $\chi^2(1)=11.39$, $p=0.001$).

The results showed that when revealing their smell loss to family and friends, the overwhelming response was one of support. Interestingly, patients reported the most desired response to revealing their condition was psychological support, yet only 1% of patients had sought help from a psychologist or psychiatrist. While patients receive psychological support from friends and physiological treatment from physicians, our findings suggest patients would also benefit from professional psychological support. Those over the age of 60 years may be especially uninclined to seek treatment for olfactory loss so health initiatives focussing on encouraging this cohort may help reduce their reluctance.

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Authorship contribution

MKM: data analysis, manuscript preparation and revisions. MM and MR: data collection and collation, manuscript revision. AH and TH: project design, manuscript revision and project management.

Conflict of interest

There authors have no conflict of interests.

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