

On the lack of self-concept and social representation of misophonia and their modulation by an intervention

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Research Article

Keywords: misophonia, social representation, lexicometry, mediational theory, semantic differential

Posted Date: August 2nd, 2022

DOI: <https://doi.org/10.21203/rs.3.rs-1914401/v1>

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Abstract

Misophonia is a poorly understood and underdiagnosed disorder. People who suffer from this condition without knowing it has a notable deterioration in their quality of life, affecting their personal and social relationships. The present study characterized the self-concept of 82 people (women:men, 3:2) attending a medical psychology center in Barcelona before and after their diagnosis of misophonia and intervention to raise awareness. The social representation of misophonia was also studied in their close relatives. A lexicometric analysis using IRaMuTeQ software qualified and quantified the 164 participants' words to describe the patient's behavior (associative cards method) in a list of situations reported but not yet identified as triggers of misophonic responses. The corpus of text, branching, and the word clouds of the most used words showed a high frequency of negative qualifiers (attributed to personality) from relatives [ranking: "irritable" (n=30), "narrow-minded" (n=24) and "anxious" (n=15)] and in the self-concept of patients [ranking: "irritable" (n=34) and "anxious" (n=26), tolerant (n=24) and frank (n=18)], with higher diversification in patients than relatives (14:8 qualifiers n>10), and an increased post-intervention (17:10 qualifiers >10). The intervention strongly modified the corpus since "misophonic" and "disorder" appeared in the self-concept post-intervention, but not the concept, suggesting relatives need substantial efforts to be aware of the nature/impact of the disorder. The distribution of misophonia levels differed among sexes (higher representation of women at level 2 [56%], while men mainly were diagnosed at level 3 [50%]) while age only showed trends. Interestingly, the intervention increased 2.71 points the misophonia score obtained in a self-administered questionnaire repeated seven months later and rescued 13.4% of positive diagnoses, suggesting that for the patients to recognize the diagnosis of misophonia in themselves, they must first be aware of this concept. The individuals with less self-concept stability more frequently recognized themselves as misophonic. Besides, 21% of the variance in the change in self-concept was explained by the change in the concept of a close relative. In summary, the lack of self-concept and social representation of misophonia have strong implications for all the actors and are relevant to design interventions to reduce their impact.

Introduction

First described in 2001 (Jastreboff and Jastreboff, 2001, 2002, 2014), misophonia is a recently identified disorder. Although its prevalence may be relatively high (Jastreboff and Jastreboff, 2014; Wu et al., 2014; Zhou et al., 2017; Naylor et al., 2020; Siepsiak et al., 2020b; Ferrer-Torres and Giménez-Llort, 2021a), it is considered underdiagnosed and is scarcely known to the general population. Scientific contributions on misophonia, also scarce, have increased in recent years, and the first consensus definition has been published (Swedo et al., 2022). This complex neurophysiological and behavioral disorder is characterized by more significant physiological and emotional responsiveness, triggered by intolerance to specific auditory stimuli (Jastreboff and Jastreboff, 2001, 2002; Möller, 2011; Wu et al., 2014). It is a state characterized by low tolerance to sound regardless of its physical characteristics (Jastreboff and Jastreboff, 2002). The stimuli that trigger misophonic symptoms can be of any nature, caused by other people, environmental, or produced by machinery or animals (Edelstein et al., 2013; Swedo et al., 2022). However, the most common are mouth or nose sounds, for example, chewing or heavy breathing (Wu et al., 2014; Edelstein et al., 2013). When faced with the stimulus, the symptoms that a person with misophonia experiences are varied, but the most frequent are anger, disgust, discomfort, and the need to escape from the stimulus (Zhou et al., 2017). Regarding physical symptoms, there is muscle constriction and increased heart rate (Edelstein et al., 2013; Siepsiak and Dragan, 2019; Ferrer-Torres and Giménez-Llort, 2021a). In general, intolerance of these sounds negatively influences the quality of life of those who suffer from it, mainly affecting their interpersonal relationships (Sánchez and da Silva, 2018; Ferrer-Torres and Giménez-Llort, 2021b). At present, there

are few diagnostic methods and no treatment for misophonia that have been validated. However, in recent years, different options have been proposed that allow an approach to diagnosing misophonia (Schöder et al., 2013; Dozier et al., 2017) with assessment tools based on the degree and diversity of symptoms of a person with misophonia (Wu et al., 2014; Siepsiak et al., 2020a; Rosenthal et al., 2021). On the other hand, the treatment proposals developed mainly focus on cognitive-behavioral therapy and auditory and pharmacological treatments (Haq et al., 2021; Sarigedik and Yurteri, 2021; Johnson, 2019).

It is known that the spectrum of bio-psychosocial health is critical for person-centered care (i.e., Molima et al., 2021), mainly in chronic conditions and mental health (Wood et al., 2021). Therefore, in parallel to the clinical relevance of misophonia in terms of origin, diagnosis, and treatment, research efforts are needed to address the disorder from a bio-psycho-social perspective. Thus, in parallel to the misophonia study's primary deficiencies, such as underdiagnosis and differential diagnosis due to the high comorbidity with other emotional and auditory disorders, the individual and social recognition of the problem will improve the situation and the quality of life of people with misophonia. The medical psychology and the social representation that define and classify misophonia are imperative to make it an accepted and recognized concept by individuals and society.

Since its initial formulation by Serge Moscovici in 1961, the Theory of Social Representations (TSR) has been widely used in psychology and sociology, the disciplines in which it originated. Currently, it is also developed and studied in disciplines such as psychiatry and neurology, particularly in interpersonal relationships and the concept of illness and the sick (Bone Montoro, 2006). The affirmations, values, and definitions within a social representation help people orient themselves and function in the social environment (Halbwachs, 1992). In other words, social representation provides a common code that names and classifies different aspects of the world. In this way, individuals obtain a common perception of a specific topic and act according to it (Jedlowski, 1997). Moscovici (Moscovici, 1981) defined Social Representation as a socially elaborated and shared knowledge whose function is to elaborate behaviors and communication between individuals. On the other hand, social representation could not be complete without considering the effect of collective memory, which refers to the memories that society collects as a whole (Halbwachs, 1992). The collective memory is shared, transmitted, and constructed by the social group (Jedlowski, 1997). This allows social representation to be developed based on these sets of memories. It is important to note that individuals' social representations of specific people, objects, or situations allow us to glimpse what they think or imagine about them (Delval, 1995, Morgiève et al., 2021)

In the current work, the above definitions and statements hypothesize that the existing social ignorance of misophonia could augur a distorted perception of the disorder, the people who suffer from it, and their behaviors. If this is added that living with a person suffering from misophonia is often uncomfortable and, in some cases, challenging (Ferrer-Torres and Giménez-Llort, 2021b), it is evident that giving visibility to both the disorder and the people suffering from misophonia becomes a fundamental need to improve the quality of their life and their interpersonal relationships. This is why, in this study, misophonia was approached from the social representation, which requires responding to the needs of classification and understanding complex or painful events; justification of actions planned or committed against other groups; and differentiation of one group from the others (Tateo and Iannaccone, 2012). That is, classify misophonia as a neurophysiological disorder and understand its symptoms, justify the perception that the population has about misophonic people's behavior, and finally differentiate the behavior of a misophonic person from that of a person non-misophonic person in social development.

On the other hand, the present study performed a lexicometric analysis. From this approach, it is expected to know the meanings and their representations in the experiences of misophonic responses, as well as in the apprehension

of the concept as a disorder. At this point, researchers have highlighted the role of language as a catalyst for man's relationship with the community and with culture as its product (Tateo and Iannaccone, 2012). Hence, through language, it is possible to establish social representations according to the inhabited culture or society.

Finally, the research evaluated the effects of an intervention under the hypothesis that it may increase the disease's social representation in patients and rescue a significant proportion of negative diagnoses in the baseline A-MISO-S test (Schröder et al., 2013) when this social representation was not present yet. We also tested the hypothesis that the intervention is associated with changes in the value of self-concept and that the increase in social representation changes the self-concept that the patients have when they are under triggering events and the concept of their close relatives.

In summary, this research aimed to demonstrate that the lack of social representation of misophonia determines the negative way to qualify the disorder, as well as the self-concept of the patient with misophonia and the concept that relatives have of them. Also, to study the effects of an intervention on these psychological constructs and the misophonia assessment.

Materials And Methods

Participants

This prospective descriptive study was carried out in three phases, from September 2019 to March 2020, and consisted of three phases according to a pre-post analysis and an intermediate intervention. The initial sample was 123 people regularly attending a Medical and Psychological Center in the city of Barcelona (Spain) and their close relatives. At the end of phase 1, the diagnosis of misophonia was confirmed or not, and the study sample was reduced to 82 people with a positive diagnosis and their close relatives. The information about the study and the instructions were equal for both groups. The data were analyzed in a double-blind manner to eliminate the confirmation bias. For the present study, only the results of the pre-post analysis of this 82 M+ and relatives sample population are presented.

The inclusion criteria for patients were defined as follows: Women and men over 18 years of age; Be a regular patient of the Centre; Agreement to participate in the study and that signed the informed consent; Have performed the clinical anamnesis; Diagnosis of misophonia (M+) through the Amsterdam Misophonia Scale (A-MISO-S); At least mouth and nasal sounds identified as triggering stimuli in the patient's diagnosis; Having a minimum of four triggering stimuli.

Exclusion criteria were: History of phonophobia, hyperacusis, tinnitus, tympanic membrane perforation, or temporomandibular disorders (TMDs); Having any degree of hearing impairment, from mild to severe, following the Bureau International d'Audio-Phonologie (BIAP) criteria, which indicates mild hearing loss starting at 20dB; Have received treatment for misophonia.

Each of the patients asked a close relative to participate in the study. The relative had to be the closest person who lived with the affected person daily since the objective was to evaluate the patient's reaction to misophonic triggers. The other inclusion criteria for family members to participate were: Over 18 years of age; Agreement to participate in the study, and sign the informed consent.

Study design, procedures, and evaluation too

Phase 1 – Pre-analysis

1.1. List of Situations, Self-concept and Concept (pre-intervention)

A clinical anamnesis was carried out individually with the initial 123 patients over two sessions, one hour each. In these interviews, misophonia was not mentioned at any time. Patients were asked about situations that the researcher knew could show the presence of misophonia, the history and evolution of the symptoms, and the presence of possible symptoms in other family members. Besides, patients were asked to describe situations in which they felt uncomfortable or upset for no specific reason and how these situations affected their quality of life. Then, a qualitative-interpretive analysis was done of their anamnesis. From these interviews, a document was prepared for each patient with five situations described by themselves (List of Situations, LS), which the professional valued as possible misophonic situations.

The patients and their families had to assess, using adjectives or qualifiers, the perception they had of the patient in one (chosen by the technician) of the five situations they described in the LS. These adjectives and qualifications were answered anonymously using the associative cards method (Abrieu, 1994; 1996), which consists of reproducing a set of free associations or associative chains concerning a so-called 'basic inductor term'. In this case, the primary inductor referred to the situation chosen by the technician. This task aimed to make a list of adjectives and qualifiers with directionality in the meaning of the responses, which were initially misophonic. Subsequently, five professionals analyzed all the adjectives and words described by the patients and their relatives: only common expressions and those contemplated by the Royal Spanish Academy (RAE) were taken as valid. Once the final list was made, they were classified into three categories: positive qualifiers (value: 1), negative (value: -1), and neutral (value: 0). Those with a frequency less than or equal to 5 were eliminated; only "misophonia" was included even though the concept had less frequency (2 times). Subsequently, this list was used to evaluate the psychological and semantic meaning (concept of the family member and self-concept of the misophonic patient described in the situations).

The quantitative and qualitative textual lexicometric analysis was carried out (Moreno and Ratinaud, 2015) through the program "Iramuteq, version 0.7. Alpha 2". This program is designed to perform differentiated textual analyses according to sociodemographic characteristics aimed at studying the similarity or proximity between the textual elements of a set (Ruiz Bueno, 2017).

1.2. First evaluation of Misophonia (pre-intervention)

The Amsterdam Misophonia Scale (A-MISO-S) was used to assess whether the initial sample of 123 patients was suffering from misophonia (M+) (Schröder et al., 2013). For the only purpose of this study, to facilitate data collection and analysis, the five levels of this numerical scale [9] were labeled as follows: level 0, not misophonic (for a score of 0-4, subclinical); level 1 (5-9, mild); level 2 (10-14, moderate); level 3 (15-19, severe); level 4 (20-24, extreme).

2. Phase 2. Intervention

Patients M+ and their close relatives participated in an intervention that started with a three-hour group intensive session about the misophonia disorder, its characteristics, etiology, types of triggers, and responses. After that, as part of this intervention, the patients had to record all those situations that produced misophonic responses for a month. They had to score them from 1 to 10 according to their physical and emotional reactions. They also had to

describe the event and the agents involved. During this task, their close relatives were requested not to intervene in any way, directly or indirectly.

3. Phase 3 – Post-analysis

3.1. Second evaluation of Misophonia (post-intervention)

Seven months later, the third phase of this study began, and the 82 people M+ were administered the test of misophonia A-MISO-S again (Schröder et al., 2013).

3.2. Self-concept and Concept (post-intervention)

The patients and their families were interviewed again using their corresponding List of Situations from Phase 1. Patients and relatives were asked again to provide five qualifiers (adjectives, nouns, and verbs), and the post-analysis was carried out in the same manner described for Phase 1.

Data and Statistical analysis

The statistical program R (V 4.1.1) was used. Data are expressed as raw data, means, and SEM or percentage. A proportions test with continuity correction was used to estimate the proportion of patients initially diagnosed without misophonia. To evaluate the effect of the intervention on people with misophonia, the pre-post difference in the diagnosis of misophonia (A-MISO-S score) was taken as the primary clinical outcome and analyzed using paired *t*-statistics. Other clinical outcomes of interest were the difference in self-concept before and after the intervention. The number of selected adjectives that remained the same before and after the program was defined as a measure of self-concept stability. For each individual, the average of the positive, negative, and neutral values of the adjectives was computed, and the change in the value of the self-concept was calculated as the difference before and after the intervention. The same analyses were performed with the concept of their close relatives and the correlation of the self-concepts of patients and relatives. Two-tailed paired *t*-test was used to analyze the diagnostic changes, self-concept stability, and self-concept value with the intervention.

Results

1. Demographics and Diagnosis of Misophonia

The demographics and diagnosis of Misophonia of the initial and the target samples are depicted in Table 1.

Table 1. Demographics and diagnosis of Misophonia in the patients' population

Variable	Variable classification	Patients n [%]
<i>Phase 1- Pre-intervention</i>		
Sex	Total sample	123 [100]
	Women	78 [63.41]
	Men	45 [36.59]
Age	18 to 34 years old	35 [28.46]
	35 to 50 years old	48 [39.02]
	51 to 87 years old	40 [32.52]
Awareness	Aware about misophonia	2 [1.62]
<i>Phases 2 and 3– Intervention and Post-intervention</i>		
	Total sample pre-post analysis	82 [100]
Sex	Women	48 [58.54]
	Men	34 [41.46]
Age	18 to 34 years old	23 [28.05]
	35 to 50 years old	36 [43.90]
	51 to 87 years old	23 [28.05]
Awareness	Aware about misophonia	82[100]
	Level 0 (absence M+, 0-4)	52 [42.27]
<i>Phase 1</i>	Level 1 (mild M+, 5-9)	6 [4.87]
Misophonia		
(M+)	Level 2 (moderate M+, 10-14)	36 [29.26]
Pre-intervention	Level 3 (severe M+, 15-19)	25 [20.23]
	Level 4 (extreme M+, 20-24)	4 [3.25]
	Level 0 (absence M+, 0-4)	41 [33.33]
<i>Phase 3</i>	Level 1 (mild M+, 5-9)	5 [4.06]
Misophonia		
(M+)	Level 2 (moderate M+, 10-14)	37 [30.08]
Post-intervention	Level 3 (severe M+, 15-19)	31 [25.20]
	Level 4 (extreme M+, 20-24)	9 [7.31]

Note: Assessed using the Amsterdam Misophonia Scale (A-MISO-S) (Schröder et al., 2013). The authors adapted the levels for the only purpose of facilitating analysis in the present work.

The total number of people with clinical anamnesis suspicious of misophonia and accepting to participate in the study was 123 clients (Sex: 78 women (63.41%) and 45 men 45 (36.59%); Ages: 35 (28.46%) were 18 to 34 years old; 48 (39.02%) were 35 to 50 years old; 40 (32.52%) were 51 to 87 years old). Only two out of 82 patients, 2 females 25 and 27 years old, with an extreme misophonia level according to A-MISO-S, were aware of the misophonia disorder and their condition when starting the study, although they did not yet have an official diagnosis. They went to the center requesting help for the issue of misophonia. The rest of the patients, unaware of the disorder and suffering from it, attended the center to request help for depression or anxiety, among other issues.

On Phase II, forty-one (33.33%) of them (30 women and 11 men) were excluded because their diagnosis of misophonia was negative (A-MISO-S, score 0-4). The demographics of the final sample of 82 patients had a sex ratio of 3:2 women to men.

For the present study, only the results of the pre-post analysis of this 82 M+ sample population are reported in the following subsections.

2. Self-concept and Concept – Pre-intervention

The first time the participants provided the five qualifiers to describe the behavioral and psychological profiles of the patients in misophonic situations, neither the patients nor their relatives were aware of misophonia as a disorder except for two.

The answers of those two females and their close relatives are detailed below. Since qualifiers are very specific and some may be bivariant (Emergencias.Portalsemes.org, 2015), the qualifiers are reported in Spanish, the language used by participants, followed by its translation into English. Both patients aware of misophonia qualified themselves or their behavior as (in order of citation): Women 1: *Misofónica*-Misophonic, *Irritable*-Irritable, *Ansiosa*-Anxious, *Alterada*-Altered, *Hipersensible*-Hypersensitive; Women 2: *Misofónica*-Misophonic, *Inquieta*-Restless, *Impaciente*-Impatient, *Nerviosa*-Nervous, Irritable-Irritable. Their respective close-relatives provided the following qualifiers: *Ansiosa*-Anxious, *Misofónica*-Misophonic, *Trastorno*-Disorder, Irascible-Short-tempered, *Nerviosa*-Nervous; and *Misofónica*-Misophonic, Irritable-Irritable, *Nerviosa*-Nervous, *Ansiosa*-Anxious, *Impaciente*-Impatient.

The results from the rest of the participants, unaware of the disorder, are depicted in Table 2. The original qualifiers (in Spanish) and their translation into English are provided for the self-concept (patients) and concept (close-relatives) of behavioral and psychological profiles of the patients in misophonic situations before (Table 2AB) and after (Table 2CD) the intervention. A total of 2,368 adjectives and qualifications were registered by the 164 participants (patients and relatives). Once the technicians carried out the evaluation process, 222 words remained. Only frequencies over 10 were considered representatives and used for further analysis. This data analysis was complemented with the branching analysis and the word cloud generated by the IRAMUTEQ software, as illustrated in Figure 1.

Table 2. Self-concept and concept pre- and post-intervention

A. People M+ pre-intervention

Self-concept		Frequency	Percentage
Total number of qualifiers		231	[100]
Spanish	English		
<i>Irritable</i>	Irritable	34	[14.72]
<i>Ansiosa/o</i>	Anxious	26	[11.26]
<i>Tolerante</i>	Tolerant	24	[10.39]
<i>Franca/o</i>	Frank	18	[7.79]
<i>Nerviosa/o</i>	Nervous	16	[6.93]
<i>Intolerante</i>	Narrow-minded	16	[6.93]
<i>Asertiva/o</i>	Assertive	15	[6.49]
<i>Directa/o</i>	Direct	14	[6.06]
<i>Correcta/o</i>	Polite	14	[6.06]
<i>Tranquila/o</i>	Calm	11	[4.76]
<i>Perfeccionista</i>	Perfectionist	11	[4.76]
<i>Indiferente</i>	Indifferent	11	[4.76]
<i>Adaptable</i>	Adaptable	11	[4.76]
<i>Exigente</i>	Demanding	10	[4.33]

B. Close-relatives pre-intervention

Concept		Frequency	Percentage
Total number of qualifiers		122	[100]
Spanish	English		
<i>Irritable</i>	Irritable	30	[24.59]
<i>Intolerante</i>	Narrow-minded	24	[19.67]
<i>Ansiosa/o</i>	Anxious	15	[12.30]
<i>Directo</i>	Direct	12	[9.84]
<i>Exigente</i>	Demanding	11	[9.02]
<i>Nerviosa/o</i>	Nervous	10	[8.20]
<i>Intransigente</i>	Intransigent	10	[8.20]
<i>Claro</i>	Clear	10	[8.20]

C. People M+ post-intervention

Self-concept		Frequency	Percentage
Total number of qualifiers		340	[100]
Spanish	English		
<i>Misofónica/o</i>	Misophonic	79	[23.24]
<i>Irritable</i>	Irritable	37	[10.88]
<i>Trastorno</i>	Disorder	30	[8.82]
<i>Ansiosa/o</i>	Anxious	21	[6.18]
<i>Nerviosa/o</i>	Nervous	19	[5.59]
<i>Hipersensible</i>	Hypersensitive	19	[5.59]
<i>Sensible</i>	Sensitive	18	[5.29]
<i>Asertiva/o</i>	Assertive	16	[4.71]
<i>Tolerante</i>	Tolerant	14	[4.12]
<i>Vulnerable</i>	Vulnerable	12	[3.53]
<i>Inquieta/o</i>	Restless	12	[3.53]
<i>Irascible</i>	Short-tempered	11	[3.24]
<i>Susceptible</i>	Touchy	11	[3.24]

D. Close-relatives post-intervention

Concept		Frequency	Percentage
Total number of qualifiers		167	[100]
Spanish	English		
<i>Intolerante</i>	Narrow-minded	32	[19.16]
<i>Irritable</i>	Irritable	31	[18.56]
<i>Malcaracter</i>	Bad character	21	[12.57]
<i>Asertiva/o</i>	Assertive	15	[8.98]
<i>Iracunda/o</i>	Irate	13	[7.78]
<i>Egoísta</i>	Selfish	13	[7.78]
<i>Refunfuñón/a</i>	Grumpy	12	[7.19]
<i>Severa/o</i>	Severe	10	[5.99]
<i>Maniática/o</i>	Manic	10	[5.99]
<i>Impaciente</i>	Impatient	10	[5.99]

<i>Correcta/o</i>	Polite	11	[3.24]
<i>Miedosa/o</i>	Fearful	10	[2.94]
<i>Franca/o</i>	Frank	10	[2.94]
<i>Respetuosa/o</i>	Respectful	10	[2.94]

The lexicometric analysis evaluated the similarity between the adjectives or qualifiers that the patient described during Phase I on their misophonic behaviors/responses during the 5 situations described in the List of Situations (LS) (Figure 1A) three dimensions or lexical representational nuclei (*Spanish-English*): *Irritable-Irritable*, *Franca/o-Frank* and *Tolerante-Tolerant* in the case of the nucleus of *Irritable-Irritable*, it was associated with *Ansiosa/o-Anxious*, *Intolerante-Narrow-minded* and *Nerviosa/o-Nervous*. It was also associated with *Perfectionista-Perfectionist*, *Exigente-Demanding*, and *Directa/o-Direct*, although less frequently. In the case of *Directa/o-Direct*, it was associated with *Franca/o-Frank*, which, in turn, was associated with *Correcta/o-Correct* and *Asertiva/o-Assertive* associated with the nucleus of *Tolerante-Tolerant* whose constellation of words constituted by *Tranquila/o-Calm*, *Adaptable-Adaptable* and *Indiferente-Indifferent*.

Regarding their close-relatives (Figure 1B), before the intervention, two representational nuclei of certain relevance can be found: *Irritable-Irritable* and *Intolerante-Narrow-minded*. A third nucleus has a lower frequency. The best-defined set was that of *Irritable-Irritable*, which in turn was directly related to two nuclei *Intolerante-Narrow-minded* and *Directa/o-Direct*. On the other hand, *Irritable-Irritable* is associated (in frequency) with *Ansiosa/o-Anxious*, *Intransigente-Intransigent* and *Nerviosa/o-Nervous*, whereas *Intolerante-Narrow-minded* is related to *Exigente-Demanding*.

After the intervention, the lexicometric analysis of the qualifiers provided by the patients (Figure 1C) showed a large representational core standing out and two less representative lexical cores derived from it. In the most representational group, the word *Misofónica/o-Misophonic* appeared first and associated with this, in order of frequency, appeared *Irritable-Irritable*, *Trastorno-Disorder*, *Ansiosa/o-Anxious*, *Nerviosa/o-Nervous*, *Hipersensible-Hypersensitive*, *Sensible-Sensitive*, *Tolerante-Tolerant*, *Vulnerable-Vulnerable*, *Inquieta/o-Restless*, *Irascible-Short-tempered*, *Susceptible-Touchy*, *Miedosa/o-Fearful*. In turn, *Misofónica/o-Misophonic* was associated with *Asertiva/o-Assertive* and this was related to *Franca/o-Frank*. A third nucleus associated with *Misofónica/o-Misophonic* was *Directa/o-Direct* and, in relation to this, *Respetuosa/o-Respectful*.

The fourth lexicometric analysis (Figure 1D), referring to the close relatives after the intervention, showed a much more dispersed representation, which consisted of four small groups. The most frequent concept was *Intolerante-Narrow-minded*, a process interconnected with the nuclei corresponding to *Irritable-Irritable*, *Malcaracter-Bad character* and *Severa/o-Severe*. On the other hand, *Intolerante-Narrow-minded* was related to *Refunfuñon/a-Grumpy* and also *Irritable-Irritable* that in turn was related to *Maniática/o-Manic* and *Impaciente-Impatient*. The qualifier *Malcaracter-Bad character* was related to *Iracunda/o-Irate* and *Egoísta-Selfish*. Finally, *Severa/o-Severe* was related to *Asertiva/o-Assertive*.

3. Diagnosis of misophonia after the intervention

As a result of the study, 82 individuals were ultimately diagnosed with the A-MISO-S program, with a mean of 14.97 (sd=5.51). The number corresponding to the observed misophonic degrees is shown in Table 1 (post-intervention).

In particular, women had a higher representation at level 2 [56%], while men were mainly diagnosed at level 3 [50%]. The difference in the distribution of misophonia levels between both sexes was statistically significant (Fisher exact test, $P=0.03$). We found age differences that tended to be statistically significant between high (>1) and low ($=1$) levels of misophonia (Odds Ratio=1.08, $P=0.061$).

For these 82 misophonic individuals, we reviewed their initial diagnosis by A-MISO-S values before the intervention. There, 11 of the 82 patients were initially diagnosed without misophonia. Therefore, the proportion of positive diagnoses rescued after the intervention was 13.4% (proportion=0.13, 95%CI=0.07, 0.23). To measure the increase in the level of diagnosis, we compared the A-MISO-S scores before and after the intervention (Figure 2A). We observed that no individual had a higher score before the intervention than after and confirmed that patients with a high degree of initial misophonia had a high degree of final misophonia ($R=0.58$, $P=1.36 \times 10^{-8}$).

Regarding the increase in the score given by the difference in the A-MISO-S score before and after training (Figure 2B), we observed a significant increase of 2.71 points (paired t-test, 95%CI=1.72, 3.71). Concerning the differences in misophonia levels, we observed that although the misophonia levels of the majority of patients (60) did not change, 22 of them increased the final classification level (Figure 1C). Finally, we observed that the level difference was correlated neither with gender differences (Figure 1D) (Fisher exact test, $P=0.89$) nor with age (OR=0.96, $P=0.10$).

4. Changes in self-concept after the intervention

The patients' self-concept of their disorder was given by 5 adjectives or qualifiers selected from their LS triggering situations. Within the adjectives, there was that of being misophonic. We analyzed the change in the adjectives of the 82 patients with a positive diagnosis at the end of the study. While in the pre-intervention analysis, only 2 individuals identified themselves as misophonic, a total of 78 did so in the post-intervention analysis.

Regarding the self-concept stability, in general, terms, taking into account all the adjectives used, there was little stability in the adjectives given for the same situations before and after the intervention. One patient kept the same list of 5 adjectives, 2 patients kept 4 adjectives, 7 patients kept 3, 21 patients kept 2, 27 patients kept only 1, and 24 patients changed all the adjectives. Interestingly, the individuals with less self-concept stability more frequently recognized themselves as misophonic (OR=0.42, $P=0.007$).

To assess the psychological attitude of misophonic patients towards the triggering events, we calculated the mean value of self-concept for each individual according to the value given to adjectives or qualifiers. The mean value of self-concept before training in patients with a positive diagnosis at the end of the study was 0.10 (sd=0.63) (Figure 3A). Although patients generally had an initial positive self-concept, this value changed its sign after the intervention (-0.24, sd=0.40) (Figure 3B). The reduction in -0.34 of the self-concept value was significant ($t(df=81)=-5.22$, $P=1.34 \times 10^{-6}$). This pattern in the reduction of self-concept was also seen in the concept given by relatives. In the case of relatives, the mean value of the concept before the intervention was markedly negative (-0.31, sd=0.70) (Figure 3C). After treatment, this score fell to -0.62 (sd=0.54). The reduction of -0.31 was significant ($t(df=81)=-5.10$, $P=2.16 \times 10^{-6}$), and although less than the self-concept value, it should be noted that it occurred at already very low levels of family approval.

Finally, we calculated the differences between the self-concept values before and after the intervention and compared them with the differences in the values given by the relatives. We observed a high correlation between the

two (Figure 3E) ($R=0.46$, $P=1.23 \times 10^{-5}$), suggesting that 21% of the variance in the change in self-concept can be explained by the change in the concept of a close relative.

Discussion

The present report provides evidence of the lack of awareness, self-concept, and social representation of misophonia in a sample of Spanish patients and their close relatives. The qualitative and quantitative lexicometry analysis also described the main concepts and their branching, showing that relatives' perception was worse than that of the patients, both before and after the intervention.

First, the results regarding lexicometry concluded, both in the pre- and post-analysis, considerable disqualifications both by the patients towards themselves and by their close family members towards the patients.

Before the interventions, patients perceived themselves as irritable, anxious, tolerant, frank, nervous, narrow-minded, assertive, direct, correct, calm, perfectionist, indifferent, adaptable, and demanding. On the other hand, the most frequent attributes of family members at that time were: irritable, narrow-minded, anxious, direct, demanding, nervous, intransigent, and clear. The ranking highlights that the family members consider the patient more intolerant and demanding than the patients, and the most frequent qualifiers did not include any that could be considered with positive valence, despite appearing with low frequency in the branch analysis. Thus, it can be seen that the patients' self-concept and the concept that family members had of them mostly alluded to negative aspects of personality. The patients and the family members attributed the behaviors to personality aspects, and only two patients (aware of the disease condition) attributed them to misophonia.

During the post-analysis, the patients' representations of themselves after the diagnosis and intervention on misophonia were Misophonic, irritable, disorder, anxious, nervous, hypersensitive, sensitive, assertive, tolerant, vulnerable, and restless short-tempered, touchy, fearful, correct, frank, and respectful. In contrast, the representations of their close relatives in this phase were: narrow-minded, irritable, bad character, assertive, irate, selfish, grumpy, severe, manic, and impatient.

It is important to note that in Phase 1, there were no records on the word misophonia nor allusion to any disorder when patients were asked to rate the behaviors and psychological status during the 'misophonic situations' described during the anamnesis, except for only two occasions. These particular couple of cases referred to an illness and a disorder, respectively, and were recorded by the only two people who knew about misophonia. Interestingly, the diagnosis of misophonia in these two patients was extreme misophonia. As reported in previous work, the education level of the sample population attending this clinical center is medium (High school) to high (University) (Ferrer-Torres and Giménez-Llort, 2021b). Therefore, it could be feasible that the severity of their condition was the main reason for their awareness.

Another noteworthy fact is that in Phase 3, once the intervention was completed, contrary to what might be expected, the word misophonia only appeared in the group of patients, this being the most referenced qualifier since only three patients did not use this word to describe themselves. It should also be noted that the word 'Disorder' appeared in this subgroup, so it was an indirect reference to Misophonia. In contrast, the rest of the qualifiers alluded to the symptoms, but not to the disorder itself, despite knowing their diagnosis of Misophonia and having been recognized. This result could be justified because patients share general beliefs and stereotypes about mental disorders or illnesses but do not attribute them to themselves (Cockherham, 1979). In addition, most of the population is not represented in mental illness, despite having it (WHO, 1959; Nunnally, 1961; Halpert, 1963;

Townsend, 1975; Farina and Fisher, 1982). It should also be noted that in this post-analysis phase, and for the group of patients, other words also appeared, which despite being classified as negative (-1), could be interpreted as more self-indulgent.

On the contrary, regarding the representations that close-relatives made of misophonic responses after learning about the disorder and the patient's diagnosis, only three close-relatives qualified the behaviors of patients as Misophonia, a fact that is not reflected in Table 2D because their frequency was less than ten. As can be seen in the same Table, the relatives did not represent the patient's behavior with other words that indirectly alluded to the Misophonia, such as Disorder, Illness, among others. These data may be justified because the relatives of people mentally ill tend to interpret the symptoms as normal expressions of stress (Cockherham, 1979). It should also be noted that the references made by family members at this stage were generally considerably more negative than those made during the pre-intervention phase. This is possible because the social representation of psychological illness conceives the patient as responsible for their situation, a fact that does not occur with the bio-medical representation, which exonerates the family and the patient and eliminates all personal responsibility for their situation (Farina and Fisher 1982). In addition, at a general level, mental illness is qualified as an abnormality, or a disorder, only when the behavior is strange, that is, when the deviations are extreme (Nathan and Harris, 1983).

Finally, it should be noted that the group of patients, both in the pre- and in the post-analysis, were more accepting than their relatives were with them. In addition, in both groups, the misophonic behavior was represented by negative ratings, and the relatives were much more emphatic. The classification highlights that relatives consider the patient more intolerant than patients. Another noteworthy fact is that in the pre- and post-analysis, positive attributions appear above a frequency greater than or equal to ten in the group of patients. On the contrary, neither in the pre- nor post-analysis did any positive words equal to or greater than ten appear in the family group.

In both groups, after the intervención, an increase in the social representativeness of the misophonia disorder was observed. With this, it can be concluded that the self-concept that patients have of themselves was determined by the absence of knowledge of the disorder. The same occurred with family members who, by not knowing the concept of misophonia, devalued the symptoms that the patient has and considered her/him intolerant and with a wrong attitude. This reaffirms the idea that the unknown can be threatening when one doesn't have a category to classify it (Moscovici, 1981). From these results, it is important to consider that the psychological meaning that each one has of certain representations is fundamental in the cognitive organization, being these constituted by two elements: knowledge and effects (Szalay and Bryson, 1973). These two elements will determine the behaviors, relationships, and actions a person maintains in their emotional, social, work-life, and with themselves (Szalay and Bryson, 1973).

The evaluations of misophonia before and after the formative sessions gave very different results. This fact was not unexpected since, from the author's clinical experience, the personalized interviews with participants already allowed us to estimate that there were more patients with this disorder than those identified by the A-MISO-S test. Thus, the diagnoses increased once the patients were aware of the existence of misophonia. It is known that the reliability of a test administered for the second time depends on the time that elapses between the first test and the retest. However, in the current study, the discrepancy may be due to the lack of awareness of the concept of misophonia, since the A-MISO-S tool is a self-administered questionnaire (Schröder et al., 2013), which means that the patient will respond according to their experience, knowledge, and self-perception. Besides, the time elapsed between both tests was seven months. This work does not detract from the efficacy of the test. Rather, it shows that, because it is a self-assessment test, misophonia's lack of social representation may affect the results.

We hypothesize that once the patients are aware of misophonia, they are more perceptive in identifying the disorder. Therefore, the formative sessions are likely to be the main reason for the differences observed. In this way, the importance of social representation as a tool for self-concept and recognition of misophonia would be confirmed. Conversely, the diagnosis of patients should be reaffirmed with other tests, for example, the MISOQUEST test (Siepsiak et al., 2020a) and the Duke Misophonia Questionnaire (DMQ) (Rosenthal et al., 2021). That is why using the social representation theory, which serves two main functions: to make the strange familiar and the invisible perceptible (Farr, 1994), people have the necessary knowledge through which they can place themselves within what they know (Moscovici, 1981), in this case, to be able to recognize the diagnosis of misophonia in themselves.

From what has been described so far, it should be taken into consideration that the psychological meaning that each one has of certain representations is fundamental in the cognitive organization, these being constituted by two elements: knowledge and affection (Szalay and Bryson, 1973). These two elements will determine the behaviors, relationships, and actions the person maintains in their affective, social, work-life, and with themselves. Therefore, from what has been described so far, it is essential to ask how the perceptions of misophonic responses influence socio-family interactions and concerning oneself if we also take into account that living with a person suffering from misophonia often becomes an uncomfortable fact, and in some cases, excessively difficult, both for the person who suffers it and for all the members of the family.

Regarding the social representation of misophonia, we can conclude that the comprehension of this disorder can help reduce the problem for the patient. In addition, it can improve their self-concept, and the perception and the influence on the people with misophonia exerted at the social level. This knowledge will also promote interest and increase the research on this disorder.

The development and achievement of the social representation of misophonia have several implications since it will be important to perform the following points: 1) To categorize people and their behaviors. In this case, to categorize people with misophonia and their behaviors when subjected to misophonic stimuli. 2) As a training process in social representation, anchoring is the instrument to interpret reality and act on it. That is, once the concept of misophonia is anchored, it will become a reality, and with it, the need to act on it arises, for example, by proposing diagnostic or treatment methods. 3) Since one function of social representation is to provide operational guidance for social life, for the resolution of problems and conflicts, the application of social representation of misophonia would mean having a guide that recognizes the symptoms of misophonia in a social environment, with which people who do not suffer from the disorder accept the situation and act accordingly.

The present work provides a picture of a singular scenario where a lack of self-concept and social representation has been captured. However, since both self-concept and social representation are dynamic constructs in constant evolution, this can be considered a limitation. As recently discussed by other authors (Rosenthal et al. 2021), there is a diversity of sampling; therefore, studies considering other settings will be of interest as providing a specific picture of these constructs. One would expect that the self-concept and social representation from community samples (McKay et al., 2018; Cassiello-Robbins et al., 2020, 2021) and students (Wu et al., 2014; Zhou et al., 2017; Naylor et al., 2020) be more alike, while it may slightly differ from those found in specialized scenarios such as clinical settings (Schröder et al., 2013; Quek et al., 2018; Jager et al., 2020; Siepsiak et al., 2020b; Ferrer-Torres and Giménez-Llort, 2021) or misophonia support forums (Rouw and Erfanian, 2018) with higher awareness about the disease. Other aspects derived from the intrinsic characteristics of the clinical sample can be a limitation since the

level of Misophonia, but also sociodemographic factors such as the age, sex, education, and culture of the participants (people M+ and relatives) may model the studied psychological and sociological constructs.

The previous results show that the importance of expanding the knowledge of misophonia in the general population becomes tangible. In this way, we may expect that the quality of life of misophonic patients who usually are emotionally abused because the people around them do not understand them could be improved. Getting a better perception of people with misophonia at the social level will contribute to increasing interest and research on this disorder. In this way, the social representation of misophonia will then fulfill its mission: 'By giving a name to things, they are more readily accepted.

Declarations

Data Availability Statement

The raw data supporting this article's conclusions will be made available by the authors, without undue reservation, to any qualified researcher.

Ethics Statement

All procedures were approved by the ethics committee of Centro Médico Psicológico L'Alfatier. All participants were informed of this study's objectives and signed an informed consent form before participating in it. They also confirmed that they accepted the General Data Protection Regulation (GDPR) policy.

Author Contributions

Interviews, data collection and analysis, manuscript draft: AFT. Both authors, AFT and LGL, contributed equally to the concept, design, and scientific discussion, as well as manuscript writing and approval.

Conflicts of Interest

The authors declare that the research was conducted without any commercial or financial relationships that could be construed as a potential conflict of interest.

Acknowledgments

We are grateful to the participants for their trust and their willingness to contribute to fighting Misophonia through scientific research.

Footnotes

Funding. This work did not receive financial support.

Supplementary Material

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Figures

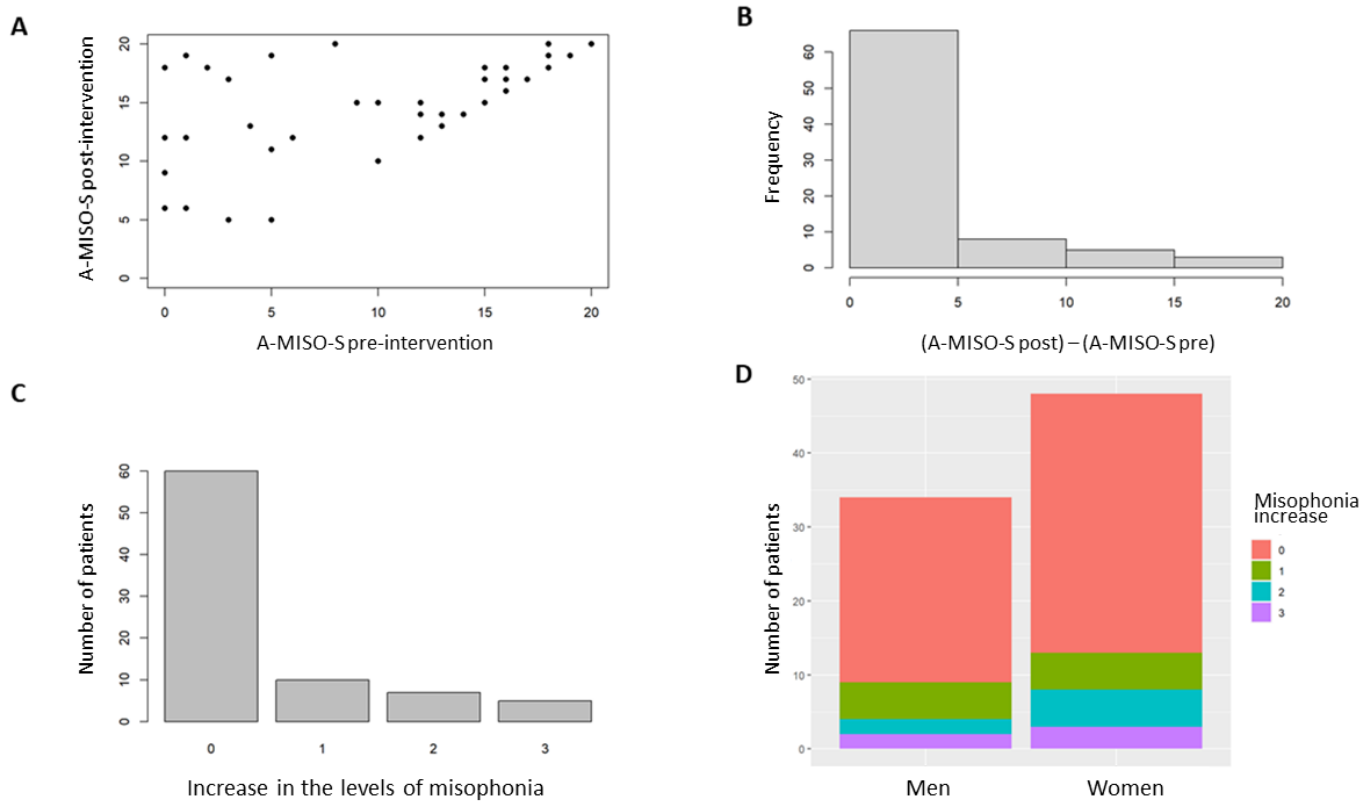
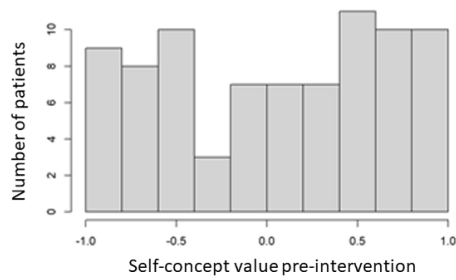


Figure 2

Changes pre-post intervention in the A-MISO-S scores. A. Diagnosis of misophonia before (A-MISO-S pre) and after (A-MISO-S post) the intervention; B. Histogram for the difference between A-MISO-S post and A-MISO-S pre-intervention; C. Distribution of the differences between the levels of misophonia before and after the intervention. D. Distribution of differences in misophonia stratified by sex.

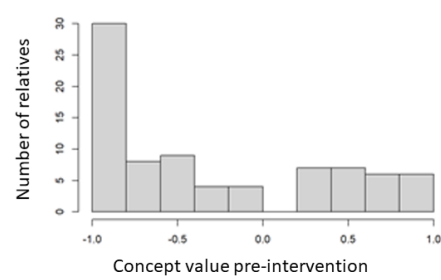
A. SELF-CONCEPT

Pre-intervention
People M+



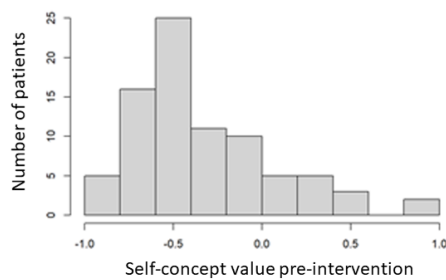
B. CONCEPT

Pre-intervention
Close-relatives



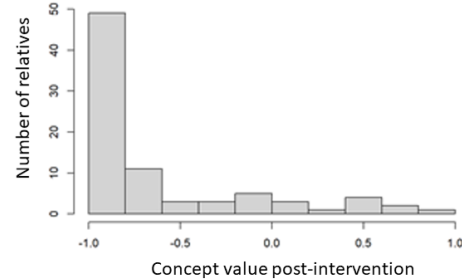
C. SELF-CONCEPT

Post-intervention
People M+



D. CONCEPT

Post-intervention
Close-relatives



E. Correlation between the change in SELF-CONCEPT and that in the CONCEPT

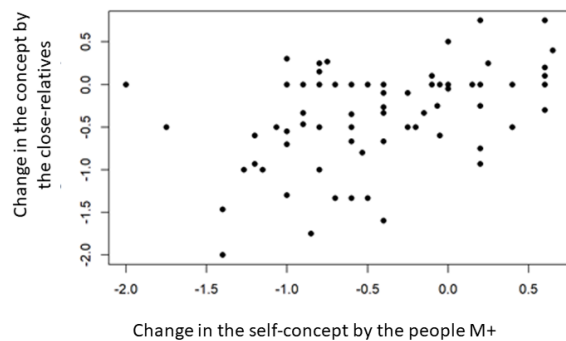


Figure 3

Distributions of Self-concept and Concept pre- and post-intervention. A. Self-concept values pre-intervention in people M+; B. Concept values pre-intervention in close-relatives; C. Self-concept values post-intervention in people M+; D. Concept values post-intervention in close-relatives; E. Correlation between the change in self-concept, pre- and post-intervention and the change in the concept by the close-relative.