

»Making Up Misophonic People« To popularize a medical category on social media

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Summary Misophonia is described by those affected as one of the first fully-fledged illness diagnoses of the Internet age. People gather in forums and platforms who feel an insurmountable hatred of specific noises. In this article we look at the emergence of the diagnosis of “misophonia” as a medical category in social media. We examine how misophonia becomes a popular diagnosis, how experts and laypeople refer each other and what resistance they are confronted with in this process. We see the emergence of the medical category as a “making up people”: as the emergence of a group of affected people who identify closely with the diagnosis and fight with great vigor for recognition as an illness.

Keywords Misophonia · Social media · Medicalization · Media sociology · medical sociology

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»Making Up Misophonic People«

On the Popularization of a Medical Category in Social Media

Abstract Those affected by misophonia describe it as one of the first full-fledged diagnoses of the internet age. People who feel an insurmountable hatred of specific sounds gather in forums and on platforms. In this chapter, we analyze the emergence of misophonia as a medical category on social media. We examine how misophonia becomes a popular diagnosis, how experts and lay people refer to each other, and what resistance they face in this process. We understand the development of the medical category as »making up people«: as the development of a group of affected persons who identify closely with the diagnosis and vigorously fight for its recognition as an illness.

Keywords Misophonia · Social Media · Medicalisation · Media Sociology · Medical Sociology

1 Introduction: The hatred of noises

Anyone who feels strongly disturbed by the everyday noises of other people and sometimes reacts with aggression or avoidance behavior to chewing and smacking noises, breathing, clearing their throat, foot tapping or finger drumming will quickly come across other sufferers if they do the appropriate online research. Thousands of posts on Instagram, Twitter or Reddit, in podcasts, self-help forums and YouTube videos report the psychological and physical suffering that everyday noises can cause. Those affected exchange ideas on the social web about which very different noises trigger the anger, what uncertainty, shame and sometimes decades of torment this is associated with, and to what extent the social environment is filled with helplessness, lack of understanding or even support - zung reacts, which coping strategies seem promising and what effects can occur, from social withdrawal to dismissals at work to massive partnership problems. Many of those affected continue to report the first time a certain noise bothered them so much, although it was usually only much later - and often on the social web - that they found out that they were not alone, that others felt very similar and that, which is perhaps the most important finding, their suffering has a scientific name: "Miso-phonia" – the hatred of noises.

Misophonia is generally understood to be a reduced tolerance to noise, which, triggered by a specific and usually everyday trigger noise, results in emotional reactions such as irritation, anger, aggression, disgust or flight behavior as well as physical reactions such as an increase in blood pressure on the part of those affected, breathing problems, sweating, muscle tension or even racing heart, whereby from the observer's perspective these reactions are in a "grotesque disproportionate to the perceived noise" (Schwemmle/Arens 2021, p. 4) (see also Ferrer-Torres/Giménez-Llort 2022). Misophonia is not a medically recognized or clearly defined disorder. she is



Little known, difficult to classify and therefore an essentially controversial category. Medically it is referred to as a subcategory of hypersensitivity to noise with overlaps with hyperacusis (general noise intolerance) and phonophobia (fear or anxiety of certain sounds). About that, since Hardly anything is known about when people suffer from misophonia and report it. Only a few famous personalities, such as Marcel Proust, A strong sensitivity to noise is reported. Misophonia only became an independent diagnosis through social media in the late 1990s popular, that is, noticed by many (Döring et al. 2021). This article examines this popularization of misophonia as a legitimate diagnosis by experts and laypeople on social media. We analyze how those affected discuss their hatred of specific noises on the social web and to what extent Experts refer to these online discourses on the Internet and what effects are associated with the production and distribution of the new category.

The starting point of our analysis is one outlined in the next section Concept of the science theorist and language philosopher Ian Hacking, who the social creation of a new category of people with the formula »making up people« describes. In contrast to hacking, which is of strong harm from groups of people through scientific expertise is shown in the case Misophonia requires a strong involvement of the affected lay people, for example under the hashtag #misophonie on YouTube, Instagram or Twitter and exchange ideas publicly. The self-designation and -Identification of laypeople online becomes an important element the creation of the disease and person category. We'll give afterwards a general overview of the exchange on health topics online This background led to the emergence of the misophonia debate in science and science to describe the (internet) public. Ultimately, we analyze the production and distribution of the personal category based on relevant online material misophonic people – in other words: “making up misophonic people” online. We assume that using the example of social media exchange Misophonia allows internet-driven changes in the expert-layperson relationship to break through as if through a prism, which is further spelled out in the conclusion

becomes.

2 »Making up people«: To produce and establish The person category

Since the beginning of the 1980s, the Canadian Ian Hacking has carried out a large number of scientific-philosophical studies on the origins and development in particular carried out by sociological and medical categories of people (hacking 2007, p. 285 ff.). For example, he is interested in how long and how long what criteria people are classified as “homeless,” “criminals,” “geniuses,” “poor,” “Homosexuals”, “prostitutes”, “suicidal people”, “obese people” or “ADHD people” are classified - and what effects are associated with these categorizations. Hacking claims that historically new categories each represent new foreign



and self-images implied what he referred to in the formula "making up people"¹ (Hacking 1986; 2006; 2007). "Making up people" is what this means social process from which not only a new category but also »a "new kind of person" (Hacking 2007, p. 285), that is, a previously non-existent species behavior and self-experience.

From a sociological point of view, classifications are nothing new (cf. Durkheim/Mauss 1987): Processes of "making up people" can be observed in all societies, but only for two centuries, according to Hacking (2007, p. 305). the sciences are so central to our understanding of "who we are". Categories are therefore increasingly drawing on scientific ones. Classifications are generated, with hacking being particularly effective for classifications the social sciences, psychology and medicine.² A historical example is provided by the study "Sexual Behavior in the Human" published in 1948 Male" by the sex researcher Alfred Kinsey, which examines people's self-image, who have sex with people of their own gender has manifestly changed (Espeland/Stevens 2008, p. 413). The Kinsey Report, which was widely discussed in the public and scientific community at the time, states, among other things, that: a tenth of American men for long periods or permanently only have sex with men. These sober numbers had a profound impact. The people who had previously been stigmatized as criminals or sick felt confirmed by the statistics. The 10 percent figure was generalized, simplified and found in speeches, on posters and soon also in the Medien: »[T]he idea that 10% of any population is gay [...] became a taken for granted feature of how gay and lesbian people understood themselves« (Espeland/Stevens 2008, p. 413). Kinsey's works therefore forced a "making up people" that not only categorized homosexuals, but also public visibility, which ultimately led to the development of the gay rights movement (Espeland/Stevens 2008, p. 413). In the process of "making up people" therefore develops "a special dynamic of self-description and description of others [...]: assigned categories influence the categorized people, their self-perception and their actions, or they open up new ones Possibilities of self-identification" (Bennani/Müller 2018, p. 310). This will assumed that classifications and the classified interact in an endless loop, what Hacking (1986, p. 125) calls the "looping" effect, which is the type and manner, "in which a classification may interact with the people classified" (Hacking 2007, p. 285). This can be seen using the example of the »highly functional "Autistics" show that only with the creation of this category does an idea of it emerge

¹ The formula "making up people" was translated into German as "making people right," which means The social production process of the personal category only captures little. Due to the lack of our own translation suggestions, we are sticking with the original English version, which, however, can also have the potential for irritation, if not for social and historical reasons, but for one Contextless invention of the person category is assumed.

² Sociologically, the terms classification, categorization and typification can be distinguished from one another (cf. Zifonun 2018). In the following we use the terms category and categorization or classification and classification are largely synonymous in order to point out the general patterns of (scientific) classifications and their categories for "Making Up People".

corresponding ways of being emerged: »Before 1950, maybe even before 1975, high-functioning autism was not a way to be a person«, so Hacking, *der fortfährt*: »There probably were a few individuals who were regarded as retarded and worse [...]. But people didn't experience themselves in this way, they didn't interact with their friends, their families, their employers, their counsellors, in the way they do now" (Hacking 2006, p. 4). Before the scientific establishment of the category Those affected were therefore considered to be "high-functioning autistic people" (Asperger syndrome). incorrectly as "retarded", there was no suitable interpretive framework and consequently no adequate form of self-perception and external perception, what changed with the establishment of the new category.

In general, hacking assumes that it is the scientific experts who, legitimized by their membership in established institutions, drive the creation and development of categories and both

the scientific discourse as well as the manner of social

Determine how to deal with those classified. Expert communities therefore practice labeling "from above", that is, they construct through them

Attribution of categories to specific realities. Analytically differentiates

Hacking (2007, p. 305) describes seven specific scientific practices at this point, die sogenannten »engines of discovery«, die auf »the production of knowledge, understanding, and the potential for improving or controlling deviant human beings« (Hacking 2007, p. 310) to act as catalysts for "making up people". and will be explained here in brief:

The *counting* of classified people, as in the case of homosexuals outlined above, primarily aims at their data recording and numerical representation, as a statement of percentage shares or a representation of development trends over time.

Quantifying means the numerical derivation of the categories themselves , if, for example, obese people along the body mass index or gifted people can be determined based on their intelligence quotient.

The *normalization* is created by an orientation towards average values, which are called Gauges of normality apply and – as in the case of body size – the determination of deviations and thus enable the attribution of anomie along specific threshold values:

"The normal spectrum of the spectrum ends somewhere Height and begin the abnormal dwarfs or giants, but overall represent a vanishing minority" (Link 2014, p. 65).

Correlating is considered a central scientific practice for sociologists, who *are* more eager to search for connections the less they know.

Autism, for example, has been correlated with all sorts of things, "not excluding the relative lengths of the mother's fingers and testosterone in the fetus." (Hacking 2007, S. 309).

In contrast to the practices of statistical and social scientific analysis described so far, medicalization can be interpreted as *the* naturalization of social processes, for example around 1900

the negative effects of availability found in the female middle class

were observed in large department stores: agoraphobia and kleptomania were



den zu den »mental diseases du jour, discussed not only in the popular media, but also at great length in the weighty medical and legal journals of the day« (Lenz/MagSamhráin 2012, S. 280).

Biologizing *occurs* when biological causes of social practices in their importance be highlighted. Goffman (1994), for example, opposes the biologization of parenting practices and plausibly explains that the ability to give birth and breastfeed is by no means necessarily a primary responsibility for Care and housework leads: »Some organizational effort would be necessary if Even under modern conditions not too much, they wanted noticeable social “Prevent the consequences of these physical conditions” (Goffman 1994, p. 106). Ultimately , *geneticization* is understood as an enhanced form of biologization and the most recent scientific practice, for example in dealing with “Overweight” can be observed, which was once viewed as a weakness of the will first became the domain of medicine, then that of biology, »and at present “we search for inherited genetic tendencies” (Hacking 2007, p. 294). The fact that geneticization is accompanied by a decrease in attributions of responsibility is clear can also be seen in autism, for which, in the course of geneticization, previous psychoanalytic attempts to explain it, such as the alleged lovelessness so-called “refrigerator mothers” as a cause of childhood developmental disorders lost relevance.

Overall, these social and natural science practices contribute to the establishment, clarification and stabilization of categories of people. This in turn is the prerequisite for three social connection practices, »each deriving from the engines of discovery and the knowledge that they produce, but each acting in its own specific way« (Hacking 2007, S. 310 f):

Normalization includes the measures, medications, aids and coping strategies, mostly suggested by experts, that are intended to eliminate the established anomie, alleviate the diagnosed illness or even thwart discrimination on the part of those classified .

Bureaucratization serves, among other things , to implement normalization measures, but also institutionalizes decisions about belonging to specific categories, standardizes processes for dealing with those classified or allocates financial resources. This is what political and social experts advise for example, to support the “homeless” in a certain way To treat “obese” people medically or to have “prostitutes” controlled by the state (Hacking 2007, p. 292).

Ultimately, the *resistance* (“resistance”) comes from those who are classified, who demand autonomy from the classifications controlled by science and bureaucracy and often respond to change through collective action

of categories and the improvement of their situation (Bennani/Müller 2018, p. 310). This means that those classified do not always agree with the scientific attributions made by the experts

According to Hacking (1986, p. 168), we partly counteract this “from below” and try “to take back control from the experts and the institutions, sometimes by creating new

experts, new institutions” (Hacking 2007, p. 311). The “rebellion” therefore represents a counter-reaction by the classified, which in the case of dysfunctional Defend classification practices against the experts.

We now assume that the process of “making up people” takes place through the possibilities of popularization on social media platforms have fundamentally changed. Both for social and natural science practices as well as for The social connection practices can be assumed that they are no longer alone are determined by the experts, but also by the social media exchanges of those affected and by the metrics of the platforms themselves are shaped.

In the next section we outline the general one against this background State of research on health-related Internet use by laypeople We dedicate ourselves to the empirical investigation of relevant online material on misophonia.

3 Popularization and medicalization in the social web

The importance of Internet services for communication on medical topics has been recognized since the late 1990s and discussed with regard to changes in the relationship between experts and laypeople (Hardey 1999) . For The questions of “making up people” are particularly interesting because the expansion and establishment of medical categories is often done by those affected Lay people are promoted (Conrad/Potter 2000). So has the sociological Research on medicalization processes (Conrad 2007) has shown that patients actively fight for the biologization or geneticization of their suffering. The social construction of medical categories is, as Conrad puts it: »collective action” (Conrad 2007, p. 9). This also means that popularization is not a simple simplification of medical terms with subsequent teaching represents the population, but a complex process that takes place over several Instances are distributed and shaped by them.

Social media therefore reinforces a process that was already apparent. On the one hand, self-help groups have not only achieved success since the mid-1970s social, but also scientific, usually medical, Recognition. Those affected organize themselves in self-help groups and, in turn, campaign for the recognition and alleviation of their suffering by science and the public (Kofahl et al. 2016) . On the other hand, we are already reporting Print media about new and vague disease categories (Kroll-Smith 2003). The connections between media and medicine are diverse and can hardly be combined force a uniform pattern. Studies on autistic people, for example, show that they benefit from social media communication because they are protected from the imponderables direct social interactions are somewhat relieved. Social media platforms help define what is meant by autism, and give those affected previously unknown opportunities for expression (Pinchevski/Peters 2016). So it is also questionable whether rebellion is still the central one



practice of the affected laypeople or whether the laypeople's practices have not changed fundamentally if the medical and social recognition of their illnesses is a central motivation.

If you look at misophonia from the perspective of medicalization and popularization, the question arises whether the hatred of noises should be recognized as a clinical picture or not. Rather, the media practices come to the fore through which those involved postulate a medical category, locate themselves within it and fight for its recognition. Such emancipatory communitization processes to create a shared category of people are more common in social media, but particularly in the case of rare and controversial diseases. In the case of the vague diagnosis of "excessive daytime sleepiness" (Kroll-Smith 2003), it becomes clear that medical authority comes under pressure due to the popularized claims of those affected. In these cases, "Making-up-people-online" is operated by those affected themselves, which does not mean that medical expertise is irrelevant. Medical authority remains necessary to establish the legitimacy of the illness, but it is no longer the primary driver for establishing the person category. The groups of laypeople and experts cannot always be clearly distinguished. Experts from health professions can also be affected or work online to recognize misophonia and support those affected. Discourses from specialists and those affected sometimes overlap, overlap, reinforce each other and can thereby accelerate the popularization of the medical category.

However, the shifts in the relationship between experts and laypeople in relation to disease knowledge point to the specific role of social media. In particular, they allow those affected to generate and maintain attention. They receive attention not only among themselves, but also in the medical community and among relatives and friends. At the same time, they have to deal with critical opposing voices. The fight over the personal category "misophonic" brings together different interests and people who formulate heterogeneous bodies of knowledge and claims: from the experiential knowledge of those affected and their history of suffering to the medical classification and description of the symptoms to the incomprehension of the opponents, consider misophonia to be an invention or imagination or not take it seriously as a disease. Misophonia can also be counted publicly via social media metrics: in forums, posts, likes or retweets. We will examine in more detail how these different configurations of knowledge and people, experts and laypeople interact in the case of misophonia in the next section.

4 Misophonia in the Social Web – An Empirical Approach

The medical exploration of noise hatred began around 25 years ago: the American ear doctor Marsha Johnson is credited with the early description of "selective sound sensitivity syndrome (4S)", which she diagnosed in 1997



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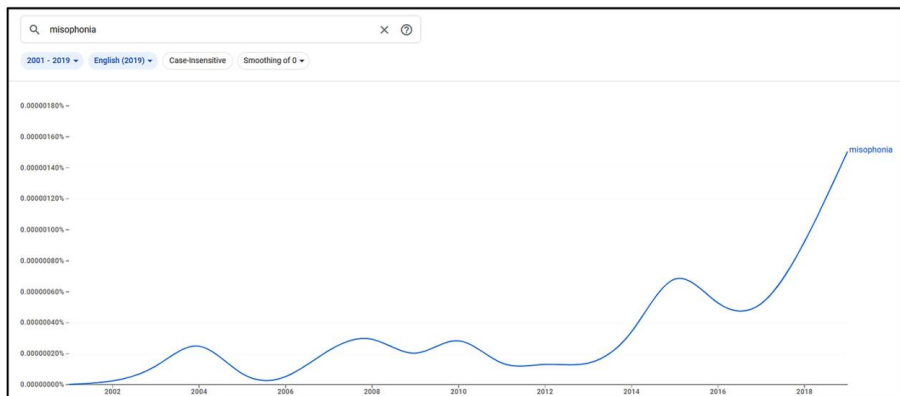


Fig. 1 Search term “misophonia” in the Google Ngram Viewer. Source: Google Ngram Viewer, own Creation, English corpus 2019, as of: March 9, 2023

in one of her patients and diagnosed it hundreds of times by the turn of the millennium (Bernstein/Angell/Dehle 2013, p. 2; Ferrer-Torres/Giménez-Llort 2022, p. 5). The label “misophonia” was first published in 2001

Newsletter article by Margaret, a biologist with a doctorate in tinnitus research Jastreboff and the Professor of Ear, Nose and Throat Medicine Pawel Jastreboff: In their clinical work they had noticed that the pathological hypersensitivity to noise known as hyperacusis and the fear of specific noises known as phonophobia occurred in some of their patients *innership could not be adequately located, which is why they are responsible for the outright hatred of noises invented the specific term “misophonia”:

»After reviewing various Latin and Greek prefixes, and consulting with a distinguished expert in classic Greek and Latin from Cambridge University UK, we selected the term ›misophonia‹ which translates into ›strong dislike (hate) of sound‹. As such it is close to the patients' description of their symptoms and can encompass a variety of negative emotions generated by the sounds in question.« (Jastreboff/Jastreboff 2001, S. 1 f.)

Although the Jastreboffs identified an urgent need for research in their small newsletter article, in the following decade only a few scientists were interested in the new medical category. Analyze below

As a first step, we will determine when a more intensive discussion of the hatred of noises can be identified in the scientific discourse and which ones to observe social and natural science practices in the sense of hacking before we take a closer look at misophonia-related online practices.

The popularization of the medical category “misophonia”, that much can be said anticipate is closely related to the development of social media.

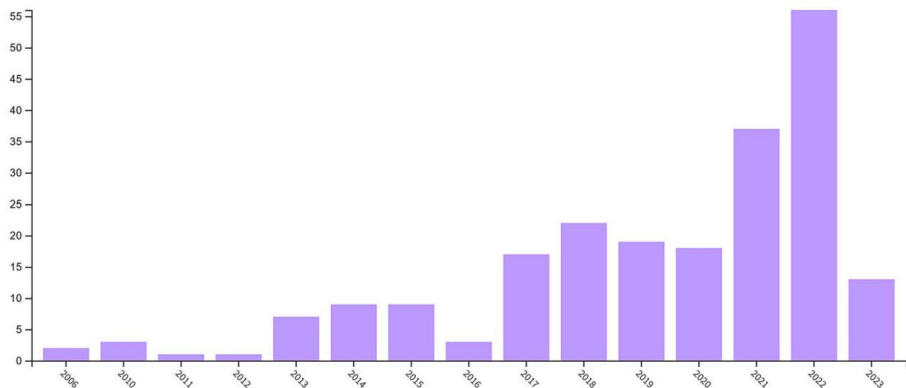


Fig. 2 Search term "misophonia" in the Web of Science Core Collection. Source: Web of Science Core Collection, own creation, as of April 27, 2023

4.1 The scientific discourse on misophonia

The Jastreboffs' new word creation in 2001 initially generated little response in science. This means that the scientific practices described by Hacking have not yet occurred - at least if you follow a corresponding analysis with the "Google Ngram Viewer": Using data mining, the "Google Ngram Viewer" can be used to view the text corpora of a digital collection of different Evaluate books printed in languages for the occurrence of specific words. The curve diagram (see Fig. 1) shows the relative frequency with which the word "misophonia" can be found in the English-language text corpus of books printed between 2001 and 2019. With reference to the methodological specifics of corresponding big data analyzes (Pettit 2016), the data generated by the online tool used are interpreted here with all caution as evidence of the way in which the discourse on misophonia develops. It turns out that the term appeared for the first time in 2001, but was only found in low frequency, which remained largely the case for a whole decade. It was only from 2012 onwards that "misophonia" was mentioned more and more frequently in English-language books - the curve continued to rise until 2019.

Even though the text corpus analyzed here only covers the period up to 2019, a supplementary analysis suggests that publication activity on misophonia continues to grow today. The search engine "Google Scholar", designed for scientific literature research, refers to a total of almost two thousand scientific documents after entering the search term "misophonia". Almost half of these documents date from 2000 to 2019, while the other half date from 2020 to mid-2023. This means that there are as many scientific documents on "misophonia" linked in Google Scholar for the last three and a half years as for the previous twenty years. Research in the Web Of Science shows a similar picture with a total of 217 documents (see Fig. 2).

On this empirical basis it can be assumed that the expert discourse misophonia began around the turn of the millennium, at the latest since intensified in 2012 and has increased significantly again recently has. These surges of attention within the professional public show that Establishing the category is not linear and that's not all the recognition of misophonia as a disease. First of all shows up just that the new medical category is also increasing in professional discourse receives attention.

However, Ian Hacking can show, as detailed above, that specific scientific practices can contribute to the establishment of new categories, A distinction can be made between social and natural science practices. Social scientific practices for the production and establishment of misophonia as a category of people, for example, when experts research the frequency of occurrence of misophonia (counting, see e.g. Jager et al. 2020; Rouw/Erfanian 2018; Schwemmler/Arens 2021) if they are carried out in particular through tests strive for quantifying diagnostic criteria (quantification, see e.g. Jast-reboff/Jastreboff 2002; Remmert et al. 2022; Swedo et al. 2022), along these lines Criteria define normal ranges (normalization, see e.g. Schröder et al. 2013) and put the occurrence of misophonia into a statistical connection with sociodemographic characteristics or other illnesses (correlate, cf. e.g. Schröder et al. 2019; Siepsiak et al. 2020). Scientific practices to establish misophonia as a category are generally present when the hatred sounds are predominantly thought of in medical terms (medicalizing, see already Jastreboff/Jastreboff 2001 with the term "misophonia" and that Claiming the responsibility of medicine for the identified disorder) and if (neuro)biological (biologizing, see e.g. Schwemmler/Arens 2021) or genetic causes (geneticizing, see e.g. Sanchez/Silva 2018) of Hatred of noises should be highlighted.

After hacking, as also explained above, social connection practices are: the practices of normalization, bureaucratization and rebellion. practices of Normalization consists of measures, medication and coping strategies that aim to alleviate the suffering caused by misophonia and to achieve a cure as well as the reduction of anomic attributions to others and to oneself. Practices of bureaucratization continue to aim at the institutionalization of tests and diagnostic criteria as well as the allocation of public research funds. With the Rebellion ultimately describes hacking as a specific follow-up practice of those affected or classified, which arises in the case of dysfunctional classifications turn against science and bureaucracy "from below".

In the following, we assume that a significant proportion of the above-mentioned scientific and connection practices now take place online initiated, flanked, advanced and helped to be shaped by laypeople on the social web become. This means that we analyze the social process using the example of misophonia of "making up misophonic people online" as interest-driven popularization a medical category. We proceed analytically in two steps: In a first step, we examine to what extent social media exchanges on misophonia variants of the social and natural sciences described by Hacking



scientific practices can be found. In a second step, we focus on social connection practices on the Internet, assuming that the practices of normalization, bureaucratization and rebellion outlined by hacking need to be modified or expanded in the digital age.

4.2 Social and natural science practices online

Due to the quantifying logic of social media, the social scientific practice of counting, which aims to record and represent those who have been classified, is omnipresent on the Internet. Since the use of the social web continually leaves traces of data, the use of social media is simultaneously accompanied by the production and presentation of corresponding numerical material: »[E]very trace we enter into the digital environment of social media platforms, whether direct or indirect, visible or invisible, provides information about us" (Casagrande 2022, p. 153). In this sense, in the social media negotiation of specific topics, for example the number of posts, the number of likes, the number of followers, friends or members, the number and frequency of comments or even the extent of redirects in the context of the corresponding online -Interpret counting practices. Unlike the standardized surveys of empirical social research, such as the Kinsey Report, this data was not specifically collected, does not follow any methodological system and does not claim to be representative. Rather, this "specifically digital way of knowing" (Marres 2017, p. 37) has explicit distortions, which can potentially also be turned productively (Marres 2017, p. 123). And if not representative, those affected by misophonia and their families at least gain a certain level of representation and visibility, which is reflected in the sheer volume of agreement, comment and support.

With a view to misophonia-related online counting practices, for example, the development and size of social networks on the topic can be interpreted as a relevance marker: the largest English-speaking Facebook group on misophonia, for example, currently has 25,000 members, the largest German-speaking Facebook group now has over 3,000 members, who largely are likely to consist of (self-)classified people and their social environment. It can be assumed that this membership strength of the misophonia-related networks alone contributes to a new understanding of self and others for those affected in the sense of the looping effect. Accordingly, for example, the website "Misophonia UK" states that misophonia is "one of the first fully-fledged diagnoses of the Internet age": While the disease was previously "invisible", patients were not taken seriously and did not receive medical attention did not exist, this changed with the exchange and mobilization of those affected on social media.

What is central in this context is that those affected learn online that the hatred of noises can be identified with a technical term that not only allows for self-localization, but also for community and normalization: »A common refrain is "I thought I was the only one in the world, until I discovered my condition had a name. I'm so glad there are people out there

who understand what I am going through«³. That those affected exchange information online Recognizing that they are not alone, that their suffering has a name and that there are other people who experience a similar fate is therefore quite typical for the medical histories documented on the Internet (see Goldstein Jutel 2011 for medical diagnoses in general).

A well-received TikTok video from Connor begins with this in mind DeWolfe: The protagonist looks at an ice cream spoon raised to his mouth to his counterpart an urgent, urgent request: "Don't do it! There's not enough noise in this room..."⁴ The idea of being exposed to the licking noises of eating ice cream without background music or similar background noise being is obviously perceived as unbearable. After a short conversation the interlocutor, who was prevented from eating ice cream, records in the 19-second video: »If you have such a strong dislike towards sounds like that, then you have Misophonia!«, whereupon the astonished answer of the person diagnosed in this way is: "Oh, there is a name for that?". In the more than ten thousand comments on the video, which has been shared almost thirty thousand times, there are countless self- and external diagnoses, short ones Stories of illness, reports of experiences and countless communitarian announcements like those from @whoskaroline.22: "I've found my people."

The criteria according to which membership in this group is determined is unclear The case of misophonia is still in the negotiation process. There is currently no medical definition and diagnosis according to DSM-V or ICD-11 (Schwemmler/ Arens 2021, p. 7). An example of an online variant of the social science practice of quantification, that is, the numerical determination of Attribution criteria for specific categories, however, can be found on one British misophonia website. Anyone who opens the »Misophonia UK« homepage comes across a small survey entitled "What is your worst trigger?" As Possible answers include breathing noises, eating noises, repetitive noises and an other option is listed. The linked analysis of the over 14,000 answers shows that a good 60 percent of those surveyed heard eating noises and ten percent repetitive ones Noises, almost eight percent breathing noises and the remaining 20 percent something see something else as the worst trigger. Find below the survey results There are almost 200 older comments, most of which contain your own trigger noises be explained again in more detail. This is also often in the comments

The relief documented by misophonia sufferers on their first visit the website because by reading the available misophonia information they learned for the first time that others feel similar things and experience. By identifying both the most common triggers (eating noises) and the variation of the Triggers (including breathing noises) are revealed, to which those affected can then relate, normalization and community initiated, while normalization practices in the sense of an orientation towards average values or adherence to specific limit values in the case of misophonia are (so far) less observed. Interesting to illustrate Correlating practices that can be observed online are still the work of experts

³ <http://www.misophonia-uk.org>.

⁴ <https://www.tiktok.com/@connordewolfe/video/6973172078879067398>.



initiated misophonia platforms such as the online presence “Patients-like-me”: here can be searched for people with a similar diagnosis. Whoever does this receives not just an opportunity to contact and exchange ideas with other affected people, but also also aggregated data, for example on the connection between misophonia and indicate age. In summary, the social sciences

Practices of counting, quantifying and correlating note that these respectively can be observed in specific online variants and in public exchange play a central role in misophonia as a whole.

The scientific practices (medicalization, biologization, geneticization) that serve to establish misophonia as a category, however, take place in Online exchanges provide more indirect support. The naturalization of misophonia is undoubtedly in the interest of those affected: the scientific one Proof of a physiological cause makes it easier to recognize misophonia as a serious illness and legitimizes the suffering of those affected. The social media exchange on misophonia is often characterized a high level of expertise: scientific theses, for example of geneticization find their way into lay discourse and in particular Help pages are often updated on the current state of medical research referred.⁵ In addition, there are repeated calls from those affected to engage more intensively and on the basis of scientific findings to deal with the disorder. Conversely, it is also noticeable that, especially in More recently, social media exchange on the topic has been a relevant reference point in scientific work on misophonia: With reference to The studies illustrate the everyday problems associated with misophonia using discussion contributions in online forums (Siepsiak/Dragan 2019). Terms common on social media to describe the triggering sounds checked for plausibility (Brout et al. 2018, p. 1) as well as respondents in social networks also recruited materials for content analysis studies (Rouw/Erfanian 2018).

All in all, it shows that experts as well as (expert) those affected demonstrate social and scientific practices on the social web, that serve the misophonia-related “making up people”: That’s how they exist However, scientific practices in the form described by hacking will continue increasingly as cooperative practices between experts and laypeople on and carried out offline. The production of the appropriate category of people will be is therefore largely influenced by the extensive social media discourse of those affected. Regarding social connection practices, we assume The availability of the social web is even more consequential: the practices of normalization, bureaucratization and rebellion themselves are changing.

4.3 Social connection practices online

Parallel to the establishment of a new category of people, as outlined above, social connection practices emerge that normalize and bureaucratize hacking

⁵ <https://www.self.com/story/misophonia-pandemic-tips>.



and rebellion describes. In the following, we will use the example of misophobia to show that and how these practices change qualitatively as a result of the extensive social media exchange between those affected.

4.3.1 *From normalizing to popularizing*

The normalization of misophonia can largely be seen as an effect to understand the online popularization of the phenomenon. This means that while normalization practices previously came from experts and included suggestions for measures, medication and coping strategies, in the logic of the social web it is particularly the popularization practices that come from those affected, which is aimed at reducing anomic self-attributions and external attributions prove effective.

Anecdotally, one of the well over one hundred interviews from the “Misophonia Podcast” can be cited here⁶ in which one respondent says that the Discovery of a Facebook group on misophonia marked a breakthrough in dealing with it with her illness represented:

»I don't know what made me think of this, but the big breakthrough five years ago was thinking, ›Oh my gosh, I wonder if there is anything on Facebook« [...] I didn't look too much into like what the group was about. I just posted these pictures and introduced myself. And the response was overwhelming. And then I was like, ›Okay, wow, this is like, this is my world« (Jennifer C., S6E5, 15:30).

Twitter user *@TheAmberPicota* also gets an insight into this unknown world when she asks on the social network whether others too felt attacked by eating noises: »Tell me the truth, I can handle it. Do you feel rage when people chew food in videos/near you? I'm trying to see something«.⁷ This is followed by a large number of comments, misophonia diagnoses and our own “discovery stories,” such as those of Twitter user *@SusannahElyse*, who answers minutes after the question: “Yes it's a real thing! I felt so vindicated when I found out it was a real disorder, take that, family who always got mad at me for getting mad at them for eating!”⁸

By “discovering” the misophonia classification, those affected feel relieved and confirmed because they can now be sure that they are suffering from a “real” disorder, that their anger has an explainable cause and that it is happening. Lack of understanding of the social environment can now be countered by a scientific explanation. In the spirit of hacking, the classification of your own Suffering creates a new self-image and external image of those affected, a visible and countable group whose online presence alone creates identity-forming effects. This means that the misophonic feeling is deprived of its anomic character through documented dissemination and measured attention by many.

⁶ <https://www.misophoniapodcast.com/episodes/s6e5-jennifer-c.>

⁷ <https://twitter.com/TheAmberPicota/status/1596304387114405890.>

⁸ <https://twitter.com/SusannahElyse/status/1596306442268676097.>



Not being crazy and not alone, as well as having a nameable illness, creates a space in which recognition of one's own feelings is possible.

The fact that this knowledge normalizes one's own perception is also exemplified by a comment on the online survey explained above, in which the user Deidre states: »I am so glad that I finally know that I am not insane and that this is an actual issue for others as well as me«⁹ The visibility due to the popularization of the category therefore has a positive effect on successful self-diagnosis.

However, such self-diagnoses are also discussed negatively, especially on social media. In the misophonia group on Reddit, for example, one of the almost 60,000 group members complains that on the social network Facebook, many people make low-level claims that they suffer from misophonia:

»Why does everyone think they have Misophonia?? As a misophoniac who's had it pretty severe since I was 12, I can't fucking stand it when I see articles about Misophonia and people quote it by saying ›Omg I definitely have this haha‹. Why? Because every time I see it shared as an article on facebook and I see who quoted it by saying that, it's someone I've met irl and THEY'RE PART OF THE PROBLEM. This cannot just be me, I also know that Misophonia is a pretty rare neurological problem and don't get me wrong, meeting people who've also self diagnosed themselves with it for years is pretty extraordinary because it's fairly unheard of, but every time without fail on Facebook I'll see at least 6 people shared the same article about it and quote it by saying ›I just found out I have this lol‹ but most of them are irl's that I'm like nooooo you don't buddy, every time I meet you, you chew on your nails and smack your gum with your mouth open Kind of a rant post and maybe some misophoniacs can't relate, but I hope some people get what I'm trying to explain.«¹⁰

Based on this post by the user *pOcha*, a heated discussion is developing about the extent to which the observation is correct and how, if necessary, the popularity of self-diagnosis should be dealt with. The undesirable popularity, as criticized here, can also be understood as a debate about reliable diagnostic criteria - and thus ultimately as part of "making up people".

The layperson's normalization practices therefore partially coincide with those of the experts: avoidance strategies and therapy options are exchanged in order to be able to lead as normal a life as possible with misophonia.

However, through popularization on social media, normalization is gaining new momentum. The communal experience of shared suffering, the common identification under #misophony, creates a feeling of belonging to a specific group. The popularization via social media forms the basis for the layperson's normalization of misophonia as a community-building dialogue.

gnosis.

⁹ <https://poll.fm/2934468/results>.

¹⁰ https://www.reddit.com/r/misophonia/comments/9mt0nf/why_does_everyone_think_they_have_misophonia/.

4.3.2 Bureaucratize and commercialize

The social connection practices of bureaucratization serve in Hacking's concept the implementation of normalizing measures, the institutionalization of diagnostic criteria, the standardization of treatment paths, for example Allocation of research funds. Appropriate experts will be involved Bureaucratization practices supported online, for example when complaining about the lack of recognized classification criteria according to ICD or DSM on Reddit¹¹ or online Monetary donations are called for, which will be used, among other things, to promote misophonia-related research.¹² The self-help organization "soQuiet", a "nonprofit built by people with misophonia for people with misophonia"¹³, calls for donations that go beyond supporting science serve more specifically to support those affected.

In addition to these donation options, a kind of misophonia merchandising can be found on several platforms. By 2022, ¹⁴ were on the website of the For example, the already mentioned "Misophonia Podcasts" sells bags, T-shirts and socks with "Misophonia" lettering, which serves several purposes dienen sollte: »Wearing the logo supports the podcast and helps raise awareness of Misophonia. Plus, it lets other misophones know you're one of them. All pro-ceeds go toward production of the podcast, promoting it to a wider audience, and supporting Misophonia research." The already mentioned organization "soQuiet" also offers similar products¹⁵. To what extent on the part of the relevant It is difficult to determine whether providers are dominated by the idea of support or profit. In any case, the misophonia-related products can be described as expressive Identification with the corresponding (self-) diagnosis as well as support Understanding popularization. That is, as long as there is still institutionalized recognition of misophonia due to the relatively weak bureaucratization to date is outstanding, those affected gain (internet) public visibility and recognition themselves - not least through commercialization practices.

This is how the increase in relevance of social media strengthens the position of laypeople: The Commercialization and popularization of misophonia comes primarily from Social media exchange between those affected, which also expands the content of social connection practices. That is, the dominance of experts The bureaucratization and normalization carried out are interlinked with the commercialization and popularization practices of the lay people. Ultimately changed the relationship between the two groups as a whole, which will be explained in conclusion.

¹¹ https://www.reddit.com/r/misophonia/comments/10iiytu/is_misophonia_a_disorder_or_a_symptom/.

¹² <https://misophonia-association.org/donate-today/>.

¹³ <https://www.squiet.org/>.

¹⁴ <https://web.archive.org/web/20221030034719/https://www.misophoniapodcast.com/>.

¹⁵ <https://www.squiet.org/shop>.





Fig. 3 Search term "misophonia" in Google Trends. Source: Google Trends, own creation, worldwide, as of: 11/14/22

4.3.3 From rebellion to alliance formation

In Hacking's conception, the resistant practice of "rebellion" represents the central follow-up practice on the part of those affected: the assumption is that laypeople will rebel against the responsible experts in the event of inadequate categorizations. However, against the background of our exemplary analysis of social media exchanges on misophonia, we would like to claim that rebellion no longer adequately describes the common connection practices of those affected. Instead of a confrontational relationship, it can be observed that alliances of lay people and experts are forming in order to jointly promote the creation and establishment of a new category of people.

In this sense, we compare the above presentation of the scientific misophonia discourse with an analysis of the (internet) public exchange on the topic. It turns out that the popularization practices on the social web fuel the scientific discourse on misophonia. An evaluation using the analysis tool Google Trends provides a first impression of the (internet) public interest in the topic of misophonia. Since 2004, Google Trends has been able to show how the weekly volume of search queries in the Google search engine for the term "misophonia" relates to the total volume of corresponding Google searches, so that the popularity of the search query can be seen over time. Public interest in "misophonia" was therefore very subdued until the middle of 2011, but then rose sharply at the end of September 2011 - and has remained at least at this level to this day (see Fig. 3).

The fact that the number of Google searches on the subject of misophonia suddenly increased massively in September 2011 can most likely be explained by an article published in the New York Times on September 5th, 2011. This article was entitled "When a chomp or a slurp is a trigger for outrage" (Cohen 2011), put the topic of misophonia on the media agenda and quickly spread, especially in the USA. Marsha Johnson, mentioned above, is mentioned as an expert in the New York Times article, not only mentioning her pioneering medical work, but also her founding of the Yahoo group "soundsensitivity," which was already used by 1,700 people at the time. So it is an expert who is responsible for networking those affected with one another

started at an early point in time (2005). Even if this online group isn't today more exists, social media exchange about misophonia is still high relevant. The New York Times article may have served as the initial spark public misophonia debate, but ultimately it is social media that has led to a significant increase in attention to the condition since the end of 2011 at the latest have contributed. With this in mind, we now assume that from the end 2011 increasing (internet) public popularity of misophonia also from 2012 growing scientific publication activity on the topic (see Fig. 1 & 2) has forced. Accordingly, it is less a rebellion by the (self-)classified than rather, to observe an alliance formation between experts and laypeople.

Nevertheless, misophonia is still reported in a recent review study als eine »little-known and poorly studied disorder, which still has many information gaps" (Ferrer-Torres/Gimenez-Llort 2022, p. 18). This incompleteness of scientific knowledge could also be precisely what has given impetus to the public debate on misophonia. A current overview article In any case, Misophonia states that there is an "imbalance between popular media Internet entries and scientific literature." Above all Misophonia forums may be so present because the exchange of Those affected always play a major role when the scientific and medical discussion and therapy on this topic are rather rare." (Schwemmler/Arens 2021, p. 6). The expert and lay discourse on misophonia is therefore closely interwoven, the scientific and the media Agendas strengthen each other, and in some cases the social media debate even precedes science.

5 Conclusion

The internet-driven popularization of misophonia as a medical condition has been observed for over a decade. The diagnosis has now also become known beyond the Internet, with the awarding of the so-called Ig Nobel Prize representing a current high point in public visibility. "Ig Nobel" means "unworthy" in English. Accordingly, since 1991, the "Anti-Nobel Prize" has been awarded year after year in a ceremony at Harvard University for research work that at first glance might seem somewhat ridiculous.

However, upon closer inspection they can prove to be highly relevant. The price will According to the self-description, it was awarded "for achievements that first make people LAUGH then make them THINK". In 2020, the Ig Medical Nobel Prize went to a Belgian-Dutch research team. The award went to Nienke Vulink, Damiaan Denys and Arnoud van Loon "for diagnosing a long-unrecognized medical condition: Misophonia, the distress at hearing other people make chewing sounds" 16. One of the honorees, Damiaan Denys, admitted that the I was a little irritated by the award at first: »Yet we accepted it because we think it is

¹⁶ <https://improbable.com/ig/winners/>.



important that this condition gets the attention«.17 Even if the scientific one Although the award did not go unquestioned, the nominees obviously understood it as a value in itself, the category of misophonia in public to gain further attention.

However, on the whole it is less the experts, but rather primarily affected laypeople who are responsible for popularizing the We believe that the present analysis shows that people hate noise have. Especially for relatively new and indefinite medical categories, it can be seen that that those affected have just as much, if not greater, interest than the experts in recognizing a condition as a scientific fact (cf. Fleck 1980). Accordingly, we are establishing misophonia as a new one Category of people primarily aims at popularizing their own experiences Social Web back. The popularization on social media thus at least partially paves the way for professional access by medicine. The one there Self-classification of those affected awaits, so to speak, legitimation and certifying confirmation by the classic gatekeepers of the health system, which ultimately holds the prospect of institutionalizing financing and therapy can put. The medical experts typically bring the social capital of the profession, while for the laypeople concerned, that they bring the popularizing potential of social media into play. The This means that when it comes to misophonia, there is less a powerful assertion of professional interpretation and expertise than it is of affected lay people to observe the self-promoted production and popularization of misophonia as a personal category. In the process of popularization, they become intertwined Practices of laypeople and those of experts stabilize each other and ultimately create a functioning category of people.

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¹⁷ <https://nltimes.nl/2020/09/18/amsterdam-research-misophonia-wins-ig-nobel-prize>.



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