

***Hearing aids and cochlear implants***  
**– A study of the discourse of patients’**  
**English ENT online support forums**

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ABSTRACT

Lay medical language (Kokkinakis – Toporowska-Gronostaj 2006) tends to be simplified, to use non-specialised terminology, to be more emotional, and to resort to references to the experience of everyday life. Although ample research exists on the discourse of various thematic online (support) groups, the present authors know of no linguistic study of online communication among people with hearing impairment/loss. The goal of the present paper is to describe the main features of patients’ language as used in English ear, nose, and throat (ENT) support forums about hearing impairment/loss. These increasingly popular forums (Dosani et al. 2014; Neda et al. 2017) are spaces where patients and their families discuss particular medical conditions and treatment methods, as well as their own experiences. In doing so, they thus search thereby for both information and support (Karimi et al. 2011). The study shows that the lay language about hearing impairment/loss seems particularly emotional and the focus is on explaining specialist issues, which may prove to be useful, especially from the doctor’s perspective, the co-communicator in the doctor-patient dyad (Brown et al. 1997; Dobson 2003; Shoaib et al. 2016).

Keywords: computer-mediated communication, online group, support, emotionality, ENT forum, hearing loss/impairment.

## **1. Introduction**

The present-day role of the Internet as both a communication source and channel has been seen as the *next wave* (Eng et al. 1998) in the broadly

understood healthcare context. This communication may involve different configurations of users (doctor-patient, doctor-doctor and patient-patient). As a consequence, it can be varied in its character – professional vs lay communication – and it can have different purposes: it may be information-, support- or entertainment-driven. For instance, following the aforementioned divisions with respect to users and purposes, various online support groups for people with medical conditions and their families have appeared, which are seen as an alternative or complement to traditional healthcare communication (Braithwaite et al. 1999). Such online platforms are a source of support and contact for people with common experiences. This allows them to discuss similar problems, at the same time removing various communicative barriers (Dosani et al. 2014) as well as securing anonymity and sharing sensitive information. This is particularly important for members of online support groups in the context of stigmatisation, as well as lack of obligation of participation (the role of a reader only).

Although the discourse of various thematic online (support) groups has attracted keen interest among researchers (see section 2.2 below), the present authors know of no linguistic study of the online communication among people with hearing impairment/loss. The aim of the current study is to examine the computer-mediated communication (henceforth CMC) of patients with hearing impairment/loss, as it takes place on English language ENT support forums. Bearing in mind the expressive and informative functions of the communication in online groups in general, attention will be paid to the distinctive character of the discourse in communicating about the socially sensitive issue of hearing impairment/loss in particular. In this paper, the socio-cultural and theoretical aspects crucial to the investigation will be touched upon first, and a presentation of data and methods will follow. Next, a discussion of results will be offered, as well as implications for further research.

## **2. Socio-cultural and theoretical background for the study**

In the following section, firstly, the socio-cultural background for the study will be presented with a view to better understanding the discourses of ENT online (support) groups, Medicine 2.0 and personalised healthcare. Secondly, the theoretical backdrop for the present study will be discussed, i.e. such aspects as CMC communication and the genre of online forum

posts. An attempt will also be made to systematise the vast available research on CMC, in particular on online support groups and forums.

## 2.1 Medicine 2.0 and personalised healthcare

In order to understand the nature of communication among online medical (support) groups, it is necessary to discuss it against the backdrop of the unique context in which it takes place, so-called *Medicine 2.0* and *personalised healthcare*. Eysenbach (2008) defines Medicine 2.0 as “applications, services and tools [which] are Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies and/or semantic web and virtual-reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups.” These widely understood facilities can aid communication in different configurations of participants (patient-patient, doctor-doctor, doctor-patient), can be either professional or lay depending on participants’ levels of expertise, can serve different functions, and can be devoted to one of various topics (cf. the similar approach to online groups in section 1 above). What Eysenbach’s definition stresses, however, is its patient-oriented aspect, since Medicine 2.0 elevates the role of, and communication between, patients (social networking and collaboration) to the degree that used to be reserved only for medical professionals, thus granting access to professional knowledge (openness) and reevaluating patients’ experience as a source of valid information (referred to as apomediation, i.e. when patients seek information from other patients).

The other component of the socio-cultural background, *personalised healthcare*, can be seen as a direct consequence of Medicine 2.0, through which attention has been redirected to patients. It involves developing ways in which medicine can be more “personal”, which, at the technological level, can mean using various tools and applications to measure every possible parameter of the functioning of the body (Alessi – Snowdon – Schnarr 2014). Personalised healthcare is part of a greater whole, i.e. the personalised industry. It deals with health systems, and, at the interactional level, is involved with achieving one of its main aims, i.e. to “democratise information to empower people to take charge of their health and wellness”, which is aimed at acquiring feedback about clients’ preferences and needs on a global scale (Alessi – Snowdon – Schnarr 2014).

## 2.2 Online (support) groups

The users of/participants in online groups or forums “interactively produce and consume [a particular] discourse” (Hunt – Harvey 2015: 135-136) regarding a given problem or ailment, seeking and providing relevant information as well as support. This type of discourse can be subsumed under the label of *computer-mediated discourse* and constitutes “the communication produced when human beings interact with one another by transmitting messages via networked computers” (Herring 2001: 612). Among the various text-based forms of computer-mediated communication, Herring (2004a) enumerates e-mail, forum discussion, chat, internet communicator, blog post, and others. These may occur in a non-synchronous or synchronous manner (Kiesler et al. 1984), in real-time, either face to face or not. In particular, forums and social networking sites allow users to post messages (Christensson 2011). In both environments, users can form different groups which share particular interests, experiences, etc. Online support groups exemplify those groups where the primary rationale behind the existence of the grouping is to provide others with various forms of help, e.g.: giving information, sharing common pastimes, or relating events people have experienced (Dosani et al. 2014: 1).

Online support groups have been described in the theoretical literature as *communities of practice* (Lave – Wenger 1991) or *virtual communities* (Herring 2004a). Communities of practice are understood as a form of engagement in certain practices, complying with certain rules, for a given period of time and in a specific milieu. In virtual communities, this milieu is online and its participants are involved in particular activities focused on a particular topic/theme/problem, and they follow a certain code of conduct which new members need to learn about before participating. Other features of communities of practice include: “solidarity, support, reciprocity; criticism, conflict, means of conflict resolution; self-awareness of group as entity distinct from other groups; and emergence of roles, hierarchy, governance, rituals” (Stommel 2008: 2). In this paper, the present authors subscribe to Stommel’s (2008: 2) claim that each of these features needs to be considered by the researcher, and evidence of each sought. Admittedly, the nature of such phenomena presents “interpretive challenges” (Herring 2004a: 359) and requires careful analysis, as well as an individualised approach in the case of each community.

In the medical context, the activity of these communities is “organised in threads of postings on [for instance] an affliction” (Stommel – Koole 2010:

358) and help is understood as the possibility of communicative exchanges of a particular type (expressing/sharing some messages and possibly also receiving feedback on them), which, additionally, may be seen as a form of therapy (Haidet – Paterniti 2003; cf. Frank 1995; Borkan – Reis – Medalie 2001; Sharf – Vanderford 2003; Pawelczyk 2011). Moreover, those exchanges are typically connected to previously mentioned personalised healthcare due to their patient-centred and motivational character, which encourages participants to take charge of their own health. This action also constitutes a part of the already mentioned Medicine 2.0, since online (support) groups primarily concern patient-patient interaction with a view to exchanging information (not necessarily expertise, but also individual experience) outside the professional context. Additionally, the element of personal experience, to some extent legitimises offers of support (Morrow 2006: 542), which means that lay participants can be seen as experts with regard to their experience, which itself is raised to the status of expertise, something ordinarily reserved for professionals.

The discourse of online (support) groups/forums has attracted keen interest among researchers, partially as a follow up to the introduction of CMC in the 1960s. Studies adopting the discursive perspective (Stommel – Lamerichs 2014) have examined online (thematic/support) groups devoted to eating disorders (Stommel 2009), anorexia (Stommel – Koole 2010), and Alzheimer's (Kruk 2015), as well as those devoted to particular common diseases/conditions like breast cancer (Sharf 1997; Gustafson et al. 1998; Radin 2006), irritable bowel syndrome (Coulson 2005), and New Daily Persistent Headache (Plastina 2015) or rare diseases, such as primary biliary cirrhosis (Lasker et al. 2005) and sleep paralysis (Weisgerber 2004). Other more theoretically-oriented studies include Herring (2004b) and Stommel (2008). Inquiries related to these, but not specifically investigating online (support) groups (rather computer-mediated healthcare communication) include research on online narratives – of addiction (Jodlowski et al. 2007) and mental illness (Giles – Newbold 2013; see also Dosani et al. 2014), as well as of Internet health advice columns for teenagers (Harvey 2013). Recent surveys of CMC perform computer-assisted analyses of larger corpora of texts, wherein, importantly, frequencies of various linguistic items, such as keywords, can be considered (see Harvey – Koteyko 2013: 165-211). Of note here are Harvey's (2013) and Mullany et al.'s (2015) examinations of electronic health messages by adolescents concerning sexual health and eating disorders, respectively, as well as Plastina's (2015) study of online support groups.

In general, the literature shows that communicating in online groups means support or even treatment for many people (see Pawelczyk 2011), especially in medical contexts where interactants are chronically or even terminally ill. Support can be realised via both epistemic messages (i.e. sharing of information) and affective messages.

Messages posted on forums can also be classified as *high person-centred*, *moderately person-centred* or *low person-centred*, depending on the level of understanding and sympathy expressed. In general, participants favour high person-centred messages (Burlison 2003: 212-215), which suggests that a certain level of involvement on the part of the author is preferred, perhaps even expected. This involvement may have to do with interactivity and building relations, which can be conveyed by means of specific linguistic resources for eliciting information or advice such as employing questions as requests (Morrow 2006; Vayreda – Antaki 2009) and expressing acceptance, empathy and support, respectively.

Another avenue to explore may be the nature of the lay language as used by the participants of online (support) groups, in order to determine whether they differ in the allocation of communicative accents, i.e. what is important from their perspective, as well as in the nature of their language use.

### 2.3 Lay language

*Lay language* is understood here as the everyday language used by non-experts who try to discuss or explain specialised issues. Such a variety may be characterised by lay equivalents for professional terms, lack of abbreviations, references to the experience of everyday life, etc. In contrast, as Kokkinakis and Toporowska-Gronostaj (2006) show in their comparison of two corpora of publications related to the cardiovascular disorder subdomain in Swedish<sup>1</sup>, professional texts may have a higher token/sentence ratio, longer nouns, more acronyms, more terms (in this case medical ones), and more Latin and Greek loan words.

The lexical aspect seems to be the feature that makes the understanding of such texts particularly difficult for a lay audience; this is the consequence of a lack of familiarity not only with the terms but also with the very content matter (Gotti 2008: 16; see also Ownby 2005). Professional terminology

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<sup>1</sup> a professional corpus with texts from a news site for medical experts as well as from a weekly online journal vs a lay corpus featuring texts from online daily newspapers and other health information sources

as one of the main reasons why lay users of language find it difficult to communicate is also mentioned by Janicki (2010)<sup>2</sup>. In his qualitative study, non-linguists were asked whether they had ever experienced language comprehension problems. Janicki observes that in order for lay people to understand competently, more words of a lower level of abstraction are required, for instance 'car' rather than 'vehicle', or 'sausage' rather than 'meat product' (the first instances can be "coupled with tangible experience (...) [and are typically] easier to grasp", Janicki 2010: 86). Also, examples, especially from one's everyday context are facilitative, as are various visualisations, e.g. gestures. Kokkinakis and Toporowska-Gronostaj (2006) point to two more differences between professional and lay texts. Apart from sentence complexity and common use of the passive voice (see also Ownby 2005), in their study, the six most frequent keywords (terms related to the discipline), and their occurrence in the two sets of data, show different patterns of use, characteristic of the groups, stemming from the tendency of lay people to emphasise symptoms and of professionals to focus on diagnoses, respectively (cf. Tse – Soergel 2003: 676). Other differences between lay and professional varieties include the complexity of professional terms (see also Ownby 2005), greater variability of meaning or less precision in lay language (Brown et al. 1997: 917; Tse – Soergel 2003: 674, 676), and the idiosyncratic character of many lay expressions (Brown et al. 1997: 917; Tse – Soergel 2003: 674; Shoaib et al. 2016: 426).

Also in this context, Gotti (2008: 17-18) makes a useful distinction into three scenarios in which specialised discourse is used, depending on the configurations of participants – *scientific instruction*, *scientific exposition* and *scientific journalism*. While the first situation involves the use of specialised discourse solely among specialists, the second and the third scenarios seem of particular interest for the current study, since they feature the explanation of scientific issues, possibly also with the use of everyday language, which, though performed by specialists is meant for lay people, and thus has to bear the features of lay language. Such a configuration was researched for example by Lopez (2007: 7), who shows how "a musical metaphor – nucleotide-bases-as-musical-notes that produce the 'music of life'" was used in an exhibition to educate the public about genetics.

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<sup>2</sup> A reverse situation is also reported in the literature, when medical professionals resort to online forums, for instance to learn more about adverse effects of particular drugs, and find it difficult to extract relevant information due to the heavy idiosyncrasy of the lay language used there (see for example Karimi et al. 2011).



Elsewhere, the present authors have discussed the different ways in which professionals and patients talk about the same disease event in the so-called interactive case reports. As a written medical genre, often appearing as a publication, interactive case reports combine a standard medical report on some new disease or its novel aspects as well as the narrative by a patient who is being treated for that disease. The study shows that apart from different communicative accents (which were also observed by Kokkinakis and Toporowska-Gronostaj [2006], as mentioned above), at a very basic level, the two groups use different vocabularies, i.e. the patients resort to lay vocabulary (as shown in patients' narratives), while the doctor exchanges it for specialist terminology (as used in the report part). Relevant examples may be "difficulty breathing" vs "dyspnea", "bowels were slow" vs "constipation", "muscle and joint pain" vs "myalgias, arthralgias" (Zabielska – Żelazowska 2017: 74), "tarry stools" vs "melena" (Donnelly 1988: 824), or longer phrasings, e.g. "jaundice" vs "Once you turn yellow (...)" (Zabielska – Żelazowska in press). Fleischman (2001) refers to it as the "translation process", which takes place between the patient and the doctor during a patient's interview, when the patient's verbal account is translated into some form of a record (Donnelly 1997). With respect to these changes in vocabulary, according to Donnelly (1988), specialist terms may contribute to the effect of the text appearing as more objective as they tend to be perceived as neutral.

### 3. Analysis

#### 3.1 Data and approach

The aim of the current study is to determine the main features of the discourse by/about patients with hearing impairment/loss. The data analysed constitute threads of comments derived from three open support forums available from *Action on Hearing Loss*, as well as from the two closed Facebook support groups *Cochlear Implant Experiences* and *Hearing Loss Community*. They were followed and carefully read by both authors in order to identify the topics touched upon. These were the issues discussed by the members of the groups, and some of them indeed sparked emotions, as opposed to issues addressed in purely information-related posts. The topics were classified as those invoking emotions in the users if they themselves were expressed by emotionally-laden linguistic resources (e.g. words such as



'stupid', or punctuation such as exclamation marks) or the responses to them were expressed this way. Following this, the fragments chosen were also examined for textual realisations of their emotional triggers and grouped into lexico-grammatical as well as discursive ones. Ultimately, 20 threads (20,102 words) containing 151 posts (M=89.86 words) were chosen for the corpus. The analysis was qualitative in nature and thus cannot be treated as representative; however, following Sinclair (2001: xi), "[even] a small corpus is seen as a body of relevant and reliable evidence". Additionally, the search results – both topics and their emotional triggers – were verified by a third reader, a person with a hearing impairment, who also has experience in participating in similar online support forums.

To study both the emotional content presented and the language used, Ungerer's (1997) *emotional inferencing system* approach – originally developed to study news discourse in general and the reader's perspective in particular – was chosen and modified (see also Ryberg 2013). The model assumes that readers' emotions can be evoked by appropriate selection of topics which are realised by means of concrete linguistic resources and these resources can be detected with the help of a number of principles addressing different aspects of news discourse (Ungerer 1997: 307). In the context of the current analysis, the modification of the model involved the selection of relevant principles, i.e. those that could be used to examine the emotional character of the discourse of patients' English ENT online support forums and that matched the particular themes discussed in the sample collected. Ultimately, the so-called *Principle of Emotional Content* and the *Principle of Intensity of Presentation* (Ungerer 1997: 317-319) were selected for the study.

According to Ungerer (1997: 318-319), following the former principle, the so-called thematic emotional triggers are usually of high relevance to the readers. In the current sample, these are descriptions of the users' experiences (often shared for therapeutic reasons), requests for information/advice, or expressions of support/anxiety/opinion, etc., as well as acts of venting feelings and humorous comments.

Following the second principle, the *Principle of Intensity of Presentation* (Ungerer 1997: 317-318), for content to be emotional, particular resources for expressing it are needed. These include: words with positive or negative connotations, words without such connotations but requiring some evaluation on the part of the receiver, and metaphors. The current sample included adjectives, adverbs, and interjections. Emotive messages were also supported by means of punctuation, symbols, and (rarely) pictures.

The analysed data are divided below into themes which repeat themselves in the sample, and their concrete linguistic realisations will be discussed there. Additionally, the lay nature of the language as used by the contributors will also be touched upon, which, in general, will be in line with the observations commented on in the theoretical background above (see section 2 above).

### 3.2 Results and discussion

In general, the data appear to be relatively emotion-laden, which can be seen at first glance through the use of punctuation such as multiple exclamation or question marks and ellipsis, as well as symbols. This seems to resonate with Burleson's observation (2003: 212-215) that there is a preference towards high person-centred messages, that is, those which convey high levels of sympathy and involvement, which is actually the case, as can be seen in both form and content in the current sample.

#### 3.2.1 Thematic groups

The first thematic group of emotional triggers is *sharing experiences*, which is one of the main ones, reflecting the functions of and rationale behind the phenomenon of Medicine 2.0 as well as its particularly patient-oriented character. It is here in such online support groups that participants can share their experiences, only for the sake of doing so, knowing that there is someone else who understands, or in order to receive some comfort or confirmation that such experiences are not isolated.

In the dramatic instance below, the user informs readers that her brother committed suicide because of the condition of tinnitus (ringing or buzzing in the ears). She admits that she has not reconciled herself to that yet and wishes she had known about the site earlier as it might have helped him somehow. She explicitly names her current emotional state – “saddened”, which is in line with Ungerer's (1997) *Principle of Intensity of Presentation* discussed above. Below there is a response sympathising with the original post (1a), informing the previous user that the author is not the only one going through this and offering some comfort. In the second response, the author describes the same dramatic experience that the post relates and hopes for support for a family member they will potentially leave behind (1b).

- (1) **I am saddened** that I have only just found this site. Unfortunately it is too late for my brother who committed suicide nearly 3 weeks ago.

He had suffered from severe tinnitus for 3 1/2 years and this had led to depression and severe anxiety. He was amazing at managing it for periods but would have several periods of severe depression linked in with his tinnitus suffering. It was clear from what he told us that his action to end his life was ultimately down to the incessant noise in his head caused by the tinnitus.<sup>3</sup>

Comments:

- (1a) **I can totally sympathize with what you must be going through.** I have Tinnitus in both ears from a work incident in September 2011. **I have struggled with depression and anxiety as of this and at times when its been bad I have been close to suicide.**
- (1b) Hi prob not around now seeing as this post is 6 years old just hoped that you could be **some kind of support** for my little sis Im thinking of jumping ship and she's goong to need support tinnitus has gotten me I'm afraid x

In a similarly emotional instance below, there are some responses sympathising with the original post (2a, 2c), but also showing interest in some more detail (2a), informing her that she is not the only one going through this (2b), offering some comfort (2c), complimenting the child as well as the mother (2d) or simply agreeing with the mother (2e).

- (2) Finally... After 13 months waiting for the test and 2 months for results, we spoke with the ENT yesterday. Axel is not a candidate for Cochlear implants. At some point far from now, that could change, but I don't know how likely positive change is. All I usually hear of are negative changes... We totally got this but that doesn't mean my heart isn't little bit broken... the moments of overwhelming sadness for the beautiful things he won't ever be able to hear are ever present and plentiful... – feeling emotional.

Comments:

- (2a) **I'm really sorry! It's frustrating** to go through the process and not get the results. What kind of hearing loss does he have?

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<sup>3</sup> All the data will be provided in their original form, including spelling and grammar mistakes.

- (2b) very interesting **my son has similar hearing loss** and eventually will go through the process.
- (2c) I'm so sorry for your grief. It's very hard to know your child will not experience certain things in his life. **Understandable that you would be upset. Gradually you and he will adapt and find different kinds of joy. His beautiful brain will learn other ways and you will help him to do it.**
- (2d) **Your son is perfection**, exactly how he is – CI or not. Grief is such a difficult part of parenting. **In several years you'll look back and remember this time, combined with "and then we..." and remember some of your greatest joy. He is beautiful**, and is lucky that he has a loving mama to do life with.
- (2e) you couldn't possibly be more right!

Thus, the sister's (1) and the mother's (2) acts of sharing rather sad stories from their perspective receive not only a comforting "It will be okay", but they trigger responses that ensure understanding and emphasise common experience or even offer compliments. This may all contribute to the therapeutic effect of the sharing act (Haidet – Paterniti 2003), when the sharing reflects not only the awareness that someone else understands and may have had similar experiences, but also generates various forms of comfort. Language-wise, the words key to these acts are the emotion-laden adjective "saddened", the verb "struggle", the nouns "depression" and "anxiety" and the common expression "I can totally sympathize with what you must be going through".

The second thematic group can be broadly labelled *requesting for advice/information* and refers to the other main rationale behind online support groups where their users perceive other members as potential experts in the field, though not in the common sense of the word, and therefore ask questions directly, or frame them in a more subjective manner attempting to say "what would you do in my case?", thus differentiating between information and advice. (3) is an example of the first instance, a mere request for information, while in (4) the author is experiencing the adverse effects of a diagnostic test and emotionally expresses their need for some information ("I am a bit scared... Should I check anything else?"), whilst at the same time looking for some common ground ("Did this happen to anyone else?").

- (3) With Audiology appointments like gold dust and a 20 mile drive to hospital, plus taking time off work, **I;d appreciate recommendations on anything I can do or request** to increase the likelihood the new moulds will be a better fit?
- (4) **Please**, what happened? I am going through the same thing and **I am desperate for a solutoon**. Had an MRI/MRA and US of my carotic arteries and everything was OK. It's been a week now, that my pulsatile tinnitus switched sides and it's continuous now! **I m a bit scared** to be honest. **Should I check anything else? Did this happen to anyone else?**

Another thematic group is *expressions of support/anxiety/opinion*, where the authors attempt to show others that they are there for them, acknowledge the help they get, show their concern, or simply express their position.

(5) is a narrative presenting the positive results of a course of treatment, which is supposed to encourage other users; (6) is a similar case, but this time the narrative is explicitly referred to as being motivating; in (7) there is the additional element of a religious reference. (8) constitutes an expression of anxiety ("afraid" and "scared"). Finally, (9-11) are explicit expressions of the patients' dissatisfaction with their audiologists' performance which they regard as ineffective, with (10) being the most emotional and representing open criticism via evaluative words such as "stupid", an exclamation mark, multiple question marks, and a rhetorical question.

- (5) More importantly, after only two days of not taking the pills, my tinnitus level has reduced significantly. My GP has assured me that it should subside completely within a couple of weeks **and judging by the improvement I've already experienced, am confident**.
- (6) If I am honest, the main thing to aid your recovery is believing that you will heal and live your life as full as possible. This is a very powerful thought set to have. In fact it was when I was feeling really positive, happy and calm that I managed to see clearly, and could think what the problem might be – which started me on the journey to recovery. **Hope my story helps some of you**.
- (7) Wish everyone well and **God Bless!**
- (8) So I was ofcourse afraid of any T or hearingloss, I didn't notice anything that day, then the next morning I woke up I noticed the

ringling and tinteling in my ears, It's been almost 2 weeks now, and I'm having a hard time focussing, and last night I stayed awake for 7 hours. Shaking and being afraid. I keep reading these T-stories that make me even more **scared**.

- (9) My latest adventures, Just had a brain MRI, doctor found no issues; ear doctor and **Audiologist weren't much help either and couldn't find anything wrong, infact they said my hearing was great.** In my case, the Tinnitus is a constant low pitched hissing sound, in scale of 1-10 varies between 4-6 out of 10 depending on the time of day.
- (10) Hello All, I appreciate you all sharing your experiences and stories, **maybe we one day we will figure out a solution together, not our Doctors.**
- (11) I did mention the constant popping in my ears to my ENT but to no great response. **He just suggested** putting some sort of device in my ears that meant making a hole in my eardrum to allow the pressure to be released??? **I've never heard of such a stupid idea? He had only just checked** the pressure of my ears and said that it was fine! So why would I want to do my ears more damage and put them a risk of infection etc.? **This is why I don't trust some doctors!** Well some at least.

*Humour* is another thematic group that can be distinguished in the posts analysed. In detail, it is humour about oneself, one's own abilities, resourcefulness, etc. and may be treated as a specific form of *venting emotions* in the oftentimes very dramatic situations or circumstances that are reported by the users of the groups.

The example below is actually only a commentary on the picture featuring a man's back part of the neck with a hearing aid attached to a clothes peg clipped to the man's collar. That it was interpreted as a good joke can be seen in the comments (12a-d), where the users exchange different views on how the author may be referred to, based on his abilities, as seen in the photo.

- (12) When your mic clip breaks and you need it for work... you improvise. I have my ifb hooked up to it so I cna hear our control room cue me to go on air.

Comments:

- (12a) Now that's a real MacGyver solution!

(12b) hat should be my middle name

(12c) ...father of invention!

(12d) A meteorologist always has to know how to improvise; it's the nature of the business ♥

On the basis of the analysis of the above-given examples of online forum posts, it can be concluded that the two main features of this discourse are emotionality and expositoriness, referring to the experience-sharing and informative functions of such groups, respectively. In each case, there is a variety of topics touched upon by online group members, depending on the group theme. In this particular context of ENT forums, the subjects included the users' experiences, requests for information/advice or expressions of support/anxiety/opinion, etc., as well as acts of venting feelings and humorous comments. What is more, regardless of the seriousness of the topic/condition discussed, the authors may resort in their narration or exchanges to humour, which may be seen as comic relief. Finally, different forms of expression may be used to communicate, strengthen, or just complement a message.

### 3.2.2 Lay vocabulary

As pointed out in section 2.3 above, in contrast to experts, lay users are likely to employ terms and explanations from everyday language. This is recommended by Janicki (2010) as a way to reduce misunderstandings in communication. The sample at hand contains relevant examples, such as the one below, where the author of the post clarifies what seems a very basic distinction in this particular context.

(13) An observation about your questions: you seem to be assuming that **"deaf" means "no hearing at all"**. This is not the case. Deafness is a range of hearing loss, not a total loss of hearing.

In the following examples, one deals with a situation where potentially complex professional matters are discussed/clarified with reference to patients' everyday experience. In (14), the author, in a rather emotional manner (i.e. with the use of exclamation and question marks), tries to explain what it means to be deaf, referring to a popular politician, a TV series (see also a reference to a popular 1990s TV series and its main character in (12a) above) and a footballer, comparing their lack of familiarity with these issues to dementia and referring to it explicitly as being "isolated from the mainstream". (15) is an example of how professional patients may appear in



their use of terminology, yet with a bit of hesitation (i.e. with the question mark used following the term).

- (14) If anyone asked you about what is the most popular record in the last 20 years or the singers, we would have little idea, we haven't heard them, so don't attempt to listen to them, can you name any of **Cameron's** cabinet members in any depth (Without rushing to **google**), have you dementia if you don't know? if someone asked you about '**Downton Abbey**' in on the TV would you have any idea if you never watched the TV program, what is what about, or who is in it, and you said 'don't know, **have you dementia?** I cannot name anyone apart from **wayne rooney** who plays football for the England team, have I dementia? (NO just a memory of convenience I hate football!), on the face of it the AOHL and these drs would assume yes? People who are **isolated from the mainstream** cannot be expected to be as aware of things they have no access to either!
- (15) I've seen a specialist about this and they stated they can **perform a tympanoplast** and they seemed quite confident it'd be successful because 'the **perforation** is tiny' and 'the position of the hole is in an accessible position' i.e. in the middle of the **ear drum** and not close to the side of the **ear canal** or the '**malleus**'(?). I'm also in reasonable health.

In sum, the lay language used in the present sample is characterised by more descriptive explanations of specialist matters or references to everyday experience, which, in general, complies with what has already been established in the studies referenced in the literature review above (section 2.3). Such posts, in contrast to those discussed in section 3.2.1, are classified as performing an informative function, imparting knowledge rather than giving support. Yet, some of them appear to be relatively emotional at the same time.

#### 4. Conclusion

The aim of this paper has been to analyse the nature of patient language as used by the contributors to three English open ENT support forums available from *Action on Hearing Loss*, as well as those to the two closed Facebook support groups *Cochlear Implant Experiences* and *Hearing Loss Community*, both about hearing impairment/loss. The threads chosen for the analysis

were classified with respect to the themes touched upon by their users, and then the lexico-grammatical as well as discursive resources to express these issues were examined, following Ungerer's (1997) *emotional inferencing system* approach. Firstly, the study points to the particular emotionality of the posts analysed, which is realised at the level of the topics selected by the users (following the *Principle of Emotional Content*), but also at the level of the linguistic resources employed (following the *Principle of Intensity of Presentation*).

Regarding the former, the users openly discuss the issues that bother them from the first- or second-person perspective, and do not hesitate to directly express their perceptions and preferences with the use of particular emotion-laden words and expressions. Some of the posts are only one or two sentences long, they and seek reactions from the community; others are longer, some lengthy narratives, and their very sharing can be perceived as therapeutic on the part of the authors. The briefer posts tend to be requests for information/advice or expressions of support/anxiety. The lengthier ones are often stories about particular experiences, and they may be told for others who wish to express their opinions on some particularly sensitive issues relevant to the community.

An additional aspect observed in the sample was the use of humour in the form of comments or particular stories, as shared by the contributors, which may be considered relieving given the stressful or even dramatic nature of the issues discussed in the groups. Moreover, the emotionality of the posts/comments is emphasised with the use of punctuation or symbols. Some users also decide to post photos, very often featuring themselves, illustrating their equipment and/or the particular circumstances discussed.

Finally, the present authors would like to emphasise a few points regarding the lay character of the language used by the contributors of the groups. While they seem well-versed in the issues regarding the variety of the dedicated equipment, and they utilise the vocabulary regarding their conditions and symptoms rather skilfully, some users offer more everyday terms/clarifications for some specific conditions/diagnoses if these are inquired about. In other cases, they resort to particular everyday expressions in order to bring closer experiences which may be new to some contributors.

No doubt the study has implications for the medical profession. The reading of such posts can be significantly informative to professionals who wish to know which aspects of their patients' conditions are of particular interest to them (if not necessarily medically essential), what the causes of anxiety in their patients are, and how their patients describe those causes in the relatively stress-free context of online support groups.

## REFERENCES

**Sources***Action on Hearing Loss*

<https://www.actiononhearingloss.org.uk/live-well/our-community/our-forums/>, accessed February 2019

*Cochlear Implant Experiences*

<https://m.facebook.com/groups/176991415675866>, accessed February 2019

*Hearing Loss Community*

[https://m.facebook.com/profile.php?id=1574574379500364&ref=content\\_filter](https://m.facebook.com/profile.php?id=1574574379500364&ref=content_filter), accessed February 2019

**Special studies**

## Alessi, C. – A. Snowden – K. Schnarr

2014 “‘It’s all about me’: How to personalise healthcare”, <https://www.hs-j.co.uk/comment/its-all-about-me-how-to-personalise-healthcare/5069017.article>, accessed March 2019

## Borkan, J. – S. Reis – J.H. Medalie

2001 “Narratives in family medicine: Tales of transformation, points of breakthrough for family physicians”, *Families, Systems & Health* 19 (2), 121-134.

## Braithwaite, D.O. – V.R. Waldron – J. Finn

1999 “Communication of social support in computer-mediated groups for people with disabilities”, *Health Communication* 11 (2), 123-151.

## Brown, P.J.B. – C. Price – Y. Cox

1997 “Patient language – evaluating its relationship to a clinical thesaurus”, *AMIA Annual Symposium Proceedings Archive*, 917, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2233384/>, accessed March 2019

## Burlison, B.

2003 “What counts as an effective emotional support? Explorations of individual and situational differences”. In: M.T. Motley (ed.) *Applied Interpersonal Communication*. Mahwah: Lawrence Erlbaum, 207-228.

## Christensson, P.

2011 “Web forum definition”, [http://techterms.com/definition/web\\_forum](http://techterms.com/definition/web_forum), accessed March 2019

## Coulson, N.S.

2005 “Receiving social support online: An analysis of a computer mediated support group for individuals living with irritable bowel syndrome”, *CyberPsychology & Behavior* 8 (6), 580-584.

- Dobson, R.  
2003 "Patients prefer 'medical labels' to lay language, study finds", *BMJ: British Medical Journal* 326 (7399), 1105.
- Donnelly, W.J.  
1988 "Righting the medical record: Transforming chronicle into story", *Journal of the American Medical Association* 260 (60), 823-826.
- Donnelly, J.  
1997 "The language of medical case histories", *Annals of Internal Medicine* 127 (11), 1045-1048.
- Dosani, S. – C. Harding – S. Wilson  
2014 "Online groups and patient forums", *Current Psychiatry Reports* 16 (507), 1-6.
- Eng, T. et al.  
1998 "Access to health information support: A public highway or private road?", *Journal of the American Medical Association* 280 (15), 1371-1375.
- Eysenbach, G.  
2008 "Medicine 2.0: Social networking, collaboration, participation, apomediation, and openness", *Journal of Medical Internet Research* 10 (3), e22, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2626430/>, accessed March 2019
- Fleischman, S.  
2001 "Language and medicine". In: D. Schiffrin – D. Tannen – H.E. Hamilton (eds.) *The Handbook of Discourse Analysis*. Oxford: Blackwell, 470-502.
- Frank, A.  
1995 *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: The University of Chicago Press.
- Giles, D.C. – J. Newbold  
2013 "'Is this normal?': The role of category predicates in constructing mental illness online", *Journal of Computer-mediated Communication* 18 (4), 476-490.
- Gotti, M.  
2008 *Investigating Specialised Discourse*. Bern: Peter Lang.
- Gustafson, D.H. et al.  
1998 "Computer support for elderly women with breast cancer", *Journal of the American Medical Association* 280 (15), 1305.
- Haidet, P. – D. Paterniti  
2003 "Building a history rather than taking one. A perspective on information sharing during the medical interview", *Archives of Internal Medicine* 163 (10), 1134-1140.
- Harvey, K.  
2013 *Investigating Adolescent Health Communication: A Corpus Linguistics Approach*. London: Bloomsbury.

- Harvey, K. – N. Koteyko  
 2013 *Exploring Health Communication. Language in Action*. London: Routledge.
- Herring, S.C.  
 2001 “Computer-mediated discourse”. In: D. Schiffrin – D. Tannen – H.E. Hamilton (eds.) *The Handbook of Discourse Analysis*. Oxford: Blackwell, 612-634.  
 2004a “Computer-mediated discourse analysis: An approach to researching online behavior”. In: S. Barab – R. Kling – J.H. Gray (eds.) *Designing for Virtual Communities in the Service of Learning*. New York: Cambridge University Press, 338-376.  
 2004b “Slouching toward the ordinary: Current trends in computer-mediated communication”, *New Media Society* 6 (1), 26-36.
- Hunt, D. – K. Harvey  
 2015 “Health communication and corpus linguistics: Using corpus tools to analyse eating disorder discourse online”. In: A. McEnery – P. Baker (eds.) *Corpora and Discourse Studies: Integrating Discourse and Corpora*. London: Palgrave Macmillan, 134-154.
- Janicki, K.  
 2010 “Lay people’s language problems”, *International Journal of Applied Linguistics* 20 (1), 73-94.
- Jodlowski, D. et al.  
 2007 “‘Screwed for life’: Examining identification and division in addiction narratives”, *Communication & Medicine* 4 (1), 15-26.
- Karimi, S. – S.N. Kim – L. Cavedon  
 2011 “Drug side-effects: What do patients forum reveal?”, *Proceedings of the 2<sup>nd</sup> International Workshop on Web Science and Information Exchange in the Medical Web*, Glasgow, 14-15.
- Kiesler, S. – J. Siegel – T.W. McGuire  
 1984 “Social psychological aspects of computer-mediated communication”, *American Psychologist* 39 (10), 1123-1134.
- Kokkinakis, D. – M. Toporowska-Gronostaj  
 2006 “Lay language versus professional language within cardiovascular subdomain – a contrastive study”, *Proceedings of the 2006 WSEAS International Conference on Cellular & Molecular Biology, Biophysics & Bioengineering*, 1-7.
- Kruk, B.  
 2015 “I can’t bear the thought that he might not recognise me”, *Communication & Medicine* 12 (2-3), 273-286.
- Lasker, J.N. – E.D. Sogolow – R.R. Sharim  
 2005 “The role of an online community for people with a rare disease: Content analysis of messages posted on a primary biliary cirrhosis mailing list”, *Journal of Medical Internet Research* 7 (1), e10, <https://www.jmir.org/2005/1/e10/>, accessed March 2019

- Lave, J. – E. Wenger  
1991 *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.
- Lopez, J.J.  
2007 “Notes on metaphors, notes as metaphors: The genome as musical spectacle”, *Science Communication* 29 (1), 7-34.
- Morrow, P.  
2006 “Telling about problems and giving advice in an Internet discussion forum: Some discourse features”, *Discourse Studies* 8 (4), 531-548.
- Mullany, L. et al.  
2015 “‘Am I anorexic?’ Weight, eating and discourses of the body in online adolescent health communication”, *Communication & Medicine* 12 (2-3), 211-223.
- Neda, Z. – L. Varga – T.S. Biró  
2017 “Science and Facebook: The same popularity law!”, *PLoS ONE* 12 (7): e0179656, <https://doi.org/10.1371/journal.pone.0179656>, accessed March 2019
- Ownby R.L.  
2005 “Influence of vocabulary and sentence complexity and passive voice on the readability of consumer-oriented mental health information on the Internet”, *AMIA Annual Symposium Proceedings Archive*, 585-588, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1560876/>, accessed March 2019
- Pawelczyk, J.  
2011 *Talk as Therapy. Psychotherapy in a Linguistic Perspective*. Berlin: Mouton de Gruyter.
- Plastina, A.F.  
2015 “Discourse of comforting: The case of online health support groups”, *Token: A Journal of English Linguistics* 4, 37-56.
- Radin, P.  
2006 “‘To me, it’s my life’: Medical communication, trust, and activism in cyberspace”, *Social Science & Medicine* 62, 591-601.
- Ryberg, I.  
2013 “Does newspapers’ political alignment influence the emotional language in British newspapers? An analysis of headlines about the nuclear accident in Fukushima on 11 March 2011”, Halmstad University, <http://www.diva-portal.se/smash/get/diva2:626240/FULLTEXT01.pdf>, accessed March 2019
- Sharf, B.F.  
1997 “Communicating breast cancer on-line: Support and empowerment on the Internet”, *Women & Health* 26 (1), 65-84.
- Sharf, B.F. – M.L. Vanderford  
2003 “Illness narratives and the social construction of health”. In: T.L. Thompson et al. (eds.) *The Routledge Handbook of Health Communication*. Mahwah NJ: Lawrence Erlbaum Associates, 9-34.

- Shoaib, M. et al.  
 2016 "Doctor-patient language barrier – compromising on quality care", *Journal of Ayub Medical College Abbottabad-Pakistan* 28 (2), 426.
- Sinclair, J.  
 2001 "Preface". In: M. Ghadessy – A. Henry – R.L. Roseberry (eds.) *Small Corpus Studies and ELT: Theory and Practice*. Amsterdam: John Benjamins, vii-xv.
- Stommel, W.  
 2008 "Conversation analysis and community of practice: An approach to studying online community". In: J. Androutsopoulos – M. Beißwenger (eds.) *Data and Methods in Computer-mediated Discourse Analysis*, *Language@internet* 5, <https://www.languageatinternet.org/articles/2008/1537>, accessed March 2019
- Stommel, W.  
 2009 *Entering an Online Support Group on Eating Disorders: A Discourse Analysis*. Amsterdam: Rodopi.
- Stommel, W. – T. Koole  
 2010 "The online support group as a community: A micro-analysis of the interaction with a new member", *Discourse Studies* 12 (3), 357-378.
- Stommel, W. – J. Lamerichs  
 2014 "Communication in online support groups: Advice and beyond". In: H. Hamilton – S. Wen-Ying Chou (eds.) *Handbook of Language and Health Communication*. New York: Routledge, 198-211.
- Tse T. – D. Soergel  
 2003 "Exploring medical expressions used by consumers and the media: An emerging view of consumer health vocabularies", *AMIA Annual Symposium Proceedings Archive*, 674-678, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1479921/>, accessed March 2019
- Ungerer, F.  
 1997 "Emotions and emotional language in English and German news stories". In: S. Niemeier – R. Dirven (eds.) *The Language of Emotions: Conceptualisation, Expression, and Theoretical Foundation*. Amsterdam: John Benjamins, 307-328.
- Vayreda, A. – C. Antaki  
 2009 "Social support and unsolicited advice in a bipolar disorder online forum", *Qualitative Health Research* 19 (7), 931-942.
- Weisgerber, C.  
 2004 "Turning to the Internet for help on sensitive medical problems: A qualitative study of the construction of a sleep disorder through online interaction", *Information, Communication & Society* 7 (4), 554-574.
- Zabielska M. – M. Żelazowska  
 2017 "From breathing difficulty to dyspnea: A translation process from the patient's story to the doctor's report in interactive medical case reports", *Communication & Medicine* 14 (1), 69-81.



Zabielska M. – M. Żelazowska

In press “Fakty i doświadczenie pacjenta, mialgia i ból mięśni – spójność interaktywnej odmiany medycznego opisu przypadku”.  
In: M. Górnicz – M. Kornacka (eds.) *Spójność tekstu specjalistycznego* (3).  
Warszawa: Wydawnictwo Naukowe Instytutu Komunikacji  
Specjalistycznej i Interkulturowej Uniwersytet Warszawski.

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