Metadiscourse in web-mediated health communication

Giuliana Diani
University of Modena and Reggio Emilia

ABSTRACT

This paper investigates web-based health communication used for liaising with caregivers of paediatric patients in the specific context of a chronic disease, i.e. neurological disorders resulting in epilepsy. The study focuses on webpages created by parents whose children suffered neurological diseases and written in collaboration with medical experts. The aim of this paper is to explore how the writers of these webpages establish a relationship with their readers by means of metadiscursive devices. The overall findings reveal that writers place more emphasis on the readership than on the manifestation of their identity, showing a participative, dialogic and inclusive way of exchanging specialized information.

Keywords: metadiscourse, self-mentions, engagement markers, online health communication.

1. Introduction

The spread of digital technologies and Web 2.0 has played a significant role in health knowledge dissemination (the so-called e-health) due to the larger footprint of social media (Dynel 2014). As Hawn (2009: 361) argues, “web-based social media like weblogs, instant messaging platforms, video chat, and social networks are reengineering the way doctors and patients interact”. This idea reinforces Bondi et al.’s (2015: 14) view that “the increasing accessibility to health information is leading towards peer-to-peer healthcare and more participatory medicine, with patients increasingly conceptualized as unique and active health consumers and, importantly, as having a right – and a social responsibility – to empowerment, that is,
to make informed decisions about their health and health care”. This view also supports Turnbull’s (2015: 291) claim that “patients take an active role not only in the management of their own illness, but also in knowledge dissemination through Web 2.0, which allows user-generated content to be uploaded in a virtual community, a blog or on social networks”. In her study on knowledge dissemination in the context of the communication of health information on the Internet, Turnbull shows that lay knowledge, defined as the expression of personal experience and understanding of illness, plays an increasingly important role within the patient-centred approach.

As research has shown, healthcare discourse addressed to the lay public (i.e. expert/non-expert to non-expert) has a marked informative function. According to Sala et al. (2015: 13-14), this function can be divided into two main parts on the basis of the type of interest accorded by the recipient to the domain-specific content at issue:

On the one hand, the recipient may be seeking information to know what decisions to make, or what are the best decisions in practical health-related contexts (this type of audience is targeted by public information material, self-medication websites, etc.). On the other hand, recipients may be willing to extend their competence on a given subject for purely speculative reasons, for their own interest out of curiosity (this being the case of the audience of scientific publications meant to disseminate specialized knowledge to the wider public).

As Sala et al. rightly observe (2015: 14), discursive realizations are influenced by popularization strategies, aiming not only at adjusting and adapting the communication of given contents to the linguistic competence and cognitive ability of the audience, but also at persuading them as to the reliability and validity of such meanings.

In this regard, popularized texts involve “the transformation of specialized knowledge into ‘everyday’ or ‘lay’ knowledge” (Calsamiglia – van Dijk 2004: 370). According to Calsamiglia and van Dijk, popularization involves not only a reformulation of specialized knowledge, but also a “recontextualization” of scientific knowledge originally produced in specific contexts to which the lay public has limited access. This view supports Gotti’s (2014) claim that popularized discourse is the transformation of expert knowledge for consumption by non-specialists, in terms of both information-giving and argumentative as well as promotional purposes. Health discourse is thus referred to as a case in point, in which factual information about
novel treatments and therapies from the scientific research community is adapted and disseminated to the lay public (Gotti 2014: 23).

Recently, there has been a growing interest in the study of web-mediated health communication in the context of knowledge dissemination. For example, Herrando-Rodrigo (2010) investigated the use of engagement markers and self-mentions in medical popularizations published online (Med-E-Pops), as a new electronic genre mainly addressing lay people (with no advanced medical knowledge) to facilitate the understanding of medical information on the Internet. She found that E-Pops writers constantly address their readers since their main concern is to make them feel part of the writer-text interaction. Moreover, they tend to adopt their voice as if they were finding themselves in the same medical situation. On the other hand, Luzón (2015) analyzed how the scientific research reported in academic journals is recontextualized in medical blogs. She observed that medical research-commenting posts provide personalized information for readers, but also arouse the readers’ interest in health research, bring it closer to the readers’ daily life and help them make informed decisions. Similarly, Turnbull (2015) investigated three websites about diabetes and identified the strategies adopted to recontextualize specialized knowledge as appropriate to the lay audience. She showed how lay knowledge is incorporated and exploited to overcome the gap between expert and layman. The online health-seeking behavior of diabetics as a discursive practice was also explored by Mansfield (2019), who examined the discursive strategies of seeking and giving information as well as emotional support in online forums for diabetics. The importance assumed by online health forums as a form of doctor-patient communication was further discussed by Anesa and Fage-Butler (2015), who illustrated how these forums may popularize biomedical knowledge. Their study also explored what explanatory tools (such as definitions, analogies, exemplifications, and generalizations) are used by experts to present complex or technical information.

Other research that has focused on the contribution of online platforms to knowledge dissemination is that of Mattiello (2019) who, in a study of TED Talks pertaining to the medical area, investigated the explanation strategies used by experts to disseminate scientific knowledge addressed to both experts and laypersons. Parallel to popularizing practices, attention was also paid to web-mediated health communication from a multimodal discourse analysis approach. Tessuto (2015) presented a multimodal discourse analytic description of online self-care communication as a medium for engaging people in their health.
As research has shown, the web plays a fundamental role in popularizing health information. Following this research strand, this study contributes to ongoing research into health literacy focusing on recontextualizing procedures involved in written communication with caregivers of paediatric patients, who need to mediate health practices to them (FAR 2015 project financed by the University of Modena and Reggio)\(^1\). The context for this analysis is provided by a previous study (Cavalieri – Diani 2019), which investigated web-based health communication used for liaising with caregivers of paediatric patients in the specific context of a chronic disease, i.e. neurological disorders resulting in epilepsy. The analysis focused on webpages of foundations dealing with paediatric neurological syndromes. Attention was paid to the popularizing practices used to bridge the knowledge asymmetry between expert/semi-expert and layman, in the dissemination of specialized information. The aim of this paper is to explore how the writers of these webpages establish a relationship with their readers (i.e. potential parents of children affected by neurological diseases) by means of metadiscursive devices.

As defined by Hyland (2005a: 37), metadiscourse is “the cover term for the self-reflective expressions used to negotiate interactional meanings in a text, assisting the writer (or speaker) to express a viewpoint and engage with readers as members of a part community”. Referring to oneself by means of a person marker may contribute to shaping the writer-reader/speaker-listener relationship and it can also help writers/speakers indicate what their own contribution and ideas are. In that sense, person markers can be considered to play an important role in the construction of the writer or speaker’s stance.

The present study focuses on the use of two specific features of metadiscourse: self-mentions and engagement markers. Drawing on the research strands outlined so far, the paper intends to answer the following questions:

1) How do writers project their voices in online health communication?

2) How do writers engage with their readers by means of metadiscursive devices?

The next section provides a description of the corpus used for the study as well as the methodology adopted. The results will be reported in Section 3, followed by some concluding remarks in Section 4.

2. Materials and methods

The corpus analyzed in the present study has been compiled by Silvia Cavalieri (see Cavalieri – Diani 2019). It consists of webpages gathered from the websites of the major foundations dealing with paediatric neurological syndromes for a total of 226,069 words. Table 1 shows a list of the 26 syndromes included in the corpus.

Table 1. List of paediatric neurological disorders in the corpus

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Disseminated Encephalomyelitis (ADEM)</td>
<td>Krabbe disease</td>
</tr>
<tr>
<td>Alexander Disease</td>
<td>Emery-Dreifuss Muscular Dystrophy (EDMD)</td>
</tr>
<tr>
<td>Alternating Hemiplegia of Childhood (AHC)</td>
<td>Canavan disease</td>
</tr>
<tr>
<td>Amyotrophic Lateral Sclerosis (ALS)</td>
<td>Lennox-Gastaut Syndrome (LGS)</td>
</tr>
<tr>
<td>Angelman Syndrome</td>
<td>Leukodystrophy</td>
</tr>
<tr>
<td>Asperger Syndrome</td>
<td>Mitochondrial Diseases</td>
</tr>
<tr>
<td>Ataxia-telangiectasia (A-T)</td>
<td>Metabolic Myopathies</td>
</tr>
<tr>
<td>Autism</td>
<td>Peroxisomal Disorders</td>
</tr>
<tr>
<td>Charcot-Marie-Tooth Disease</td>
<td>Pitt Hopkins Syndrome (PTHS)</td>
</tr>
<tr>
<td>Congenital Muscular Dystrophy (CMD)</td>
<td>Sanfilippo Syndrome</td>
</tr>
<tr>
<td>Dravet syndrome</td>
<td>Traumatic Brain Injury on Paediatric Brain</td>
</tr>
<tr>
<td>Duchenne Muscular Dystrophy (DMD)</td>
<td>Tourette Syndrome</td>
</tr>
<tr>
<td>Endocrine Myopathies</td>
<td>Tuberous Sclerosis Complex (TSC)</td>
</tr>
</tbody>
</table>

The choice of these syndromes was based upon a complete list of neurological disorders in children found on Wikipedia (https://en.wikipedia.org/wiki/Category:Neurological_disorders_in_children). Only those resulting in epilepsy, which is the chronic condition under investigation in the FAR 2015 project, were selected. These webpages were created by parents whose children suffered neurological diseases for parents of children affected by
one of the above-mentioned syndromes and written in collaboration with medical experts. Thus, these texts can be considered as an instance of semi-expert to lay communication. This idea is further reinforced by the fact that these pages are said to be just informative and always present a warning formula in which parents are advised to refer to doctors for professional medical diagnosis, treatment and care (“The information provided on this web site should NOT be used as a substitute for seeking professional medical diagnosis” [Pediatric Brain Foundation]; “Never rely on the information in this booklet in place of seeking professional medical advice. You should never delay seeking medical advice, disregard medical advice, or discontinue medical treatment because of information in this booklet” [Dravet Foundation]).

The corpus consists of three sub-corpora each of which includes webpages about a specific aspect concerning the life of caregivers of paediatric patients affected by neurological disorders, namely: 1) syndromes (i.e. webpages describing the different types of diseases causing epilepsy); 2) medications and treatments (i.e. webpages detailing the drugs, surgical operations and treatments and explaining their results and side effects); 3) guidelines for families (i.e. webpages providing parents with strategies to cope with their children’s disease). Figures 1, 2 and 3 provide an example of webpages taken from each sub-corpus.

Figure 1. Example of webpage of the SYNDROMES sub-corpus
Rufinamide (ru-FIN-uh-mide) is the generic name (non-brand name) of a seizure medicine. In the United States, the Food and Drug Administration (FDA) approved rufinamide in 2008 to be used as an add-on (adjunctive) seizure medicine in children 4 years and older and adults with the Lennox-Gastaut (LGS) syndrome in European countries. Rufinamide is marketed under the brand name Inovelon.

**Banzel**

Tablet

200 mg Salmon colored tablet imprinted with "E 262" on one side
400 mg Salmon colored tablet imprinted with "E 263" on one side

**Inovelon**

Tablet

100, 200, and 400 milligrams (mg)

**Used to treat**

Lennox-Gastaut Syndrome

**Forms**

Banzel is marketed in the United States by Elcsai, Inc. The name or appearance may differ in other places. The dose (measured in milligrams, abbreviated "mg") will usually be the same. These descriptions apply to the U.S. versions:

Inovelon® is available in European Union countries as tablets in three different strengths: 100, 200, and 400 milligrams (mg). These tablets should be swallowed whole and not chewed.

**Dosing**

See package insert.

**How to take and store Rufinamide?**

Follow the doctor's directions. Call if you have any questions.

Store at room temperature (below 86°F, 30°C). Protect the tablets from moisture. Don't keep them in the bathroom, where it's damp.

**What if I forget?**

A forgotten dose should be taken right away, unless it is almost time for the next one. In that case, just use one dose, not a double dose, and call the doctor's office for more advice.

Do your best to follow the doctor's directions. The more often a medicine must be taken, the greater the chance of forgetting. If you forget doses often, it may be a good idea to get a special pillbox or watch with an alarm to remind you.

Taking the right amount of seizure medicine on time every single day is the most important step in preventing seizures.

**How does Rufinamide affect the brain?**

Brain cells need to work (fire) at a certain rate to function normally. During a seizure, brain cells are forced to work much more rapidly than normal. Rufinamide helps prevent brain cells from working as fast as a seizure requires them to. In this way, seizures can be stopped when they are just beginning.

---

**Figure 2. Example of webpage of the MEDICATIONS&TREATMENTS sub-corpus**
From a methodological point of view, the analysis combines text and corpus perspectives. Text analysis contributes to the study of textual/discursive features, whereas corpus linguistics offers ways of looking at language: in particular, the use of WordSmith 6 (Scott 2012) enables us to obtain wordlists and concordances on which to base our findings.

In analyzing the two specific features of metadiscourse, self-mentions and engagement markers, I will refer to Hyland’s (2005b) model of interaction in academic writing, where self-mentions and engagement are presented as discursive features for writer-reader interactions. The following realizations of self-mentions and engagement markers will be taken into consideration:

- exclusive first-person pronouns and possessive adjectives as forms of self-mentions (I, my, we, our, us)
- reader pronouns (you, your), inclusive we and our, directives, and questions as engagement markers.
3. Results and discussion

3.1 Interactional metadiscourse markers in web-based health communication: A quantitative overview

A quantitative investigation of the presence of interactional metadiscourse markers in the corpus analyzed provides the results summarized in Table 2. All frequency data reported in the table are presented as raw figures, followed by the normalized figure of the number of occurrences per 1,000 words.

Table 2. Overall frequencies of self-mentions and engagement markers in the corpus

<table>
<thead>
<tr>
<th>Interactional metadiscourse markers</th>
<th>Raw freq.</th>
<th>Freq. per 1,000 words (ptw)</th>
</tr>
</thead>
<tbody>
<tr>
<td>self-mentions</td>
<td>193</td>
<td>0.85</td>
</tr>
<tr>
<td>engagement markers</td>
<td>1,795</td>
<td>7.94</td>
</tr>
</tbody>
</table>

If we take an overview of the distribution of the markers used in the corpus, undoubtedly the most striking feature is the heavy concentration of engagement markers (1,795 occurrences/7.94 ptw) as compared to the low frequency of self-mentions (193 occurrences/0.85 ptw). This finding is not surprising because the aim of the webpages under scrutiny is to build a relationship with parents as caregivers who face the difficulties of coping with their children’s disease for the first time. It is therefore expected that these webpages will display a high frequency of engagement markers, as caregivers are directly addressed and included as discourse participants. The results here echo those of Herrando-Rodrigo (2010), who found that the use of engagement markers is a characteristic feature of medical electronic popularizations.

Although the analysis reveals a tendency towards the use of engagement markers as opposed to self-mentions, a significant difference exists in their frequency distribution across the three sub-corpora.

As shown in Table 3 below, there is a much larger frequency gap between engagement markers occurring in the Syndromes corpus (275 occurrences/1.22 ptw) than those occurring in the Medications&Treatments and Guidelines for families corpora (722 occurrences/3.19 ptw and 798 occurrences/3.53 ptw respectively). A possible explanation derives from the fact that the Syndromes webpages consist of descriptions of the
different types of diseases causing epilepsy in which scientific evidence is presented to caregivers and thus a less direct relationship with them is established. On the contrary, in the two sub-corpora (Guidelines for families and Medications&Treatments), there is a more balanced proportion of engagement markers, accounting for 798 occurrences in the Guidelines for families corpus and 722 instances in the Medications&Treatments corpus. Again, these figures respond to the finalities of these two sets of webpages: to build a relationship with caregivers by giving suggestions for dealing with their children’s medical treatments or aspects concerning their everyday life.

Table 3. Frequency distribution of self-mentions and engagement markers across the three sub-corpora

<table>
<thead>
<tr>
<th>Interactional metadiscourse markers</th>
<th>Syndromes Raw freq./ptw</th>
<th>Medications&amp;Treatments Raw freq./ptw</th>
<th>Guidelines for families Raw freq./ptw</th>
</tr>
</thead>
<tbody>
<tr>
<td>self-mentions</td>
<td>32/0.14</td>
<td>52/0.23</td>
<td>109/0.48</td>
</tr>
<tr>
<td>engagement markers</td>
<td>275/1.22</td>
<td>722/3.19</td>
<td>798/3.53</td>
</tr>
</tbody>
</table>

Likewise, the occurrences of self-mentions are differently distributed in the three sub-corpora with a prevalence in the Guidelines for families corpus (109 instances) and a small proportion in the Syndromes and Medications&Treatments corpora (32 and 52 instances respectively). This quantitative investigation leads us to conclude that these figures clearly respond to the different purposes of the webpages analyzed. They show how distinctive contexts influence the way writers project their voice and engage with their readers.

3.2 Self-mentions

Table 4 shows the results emerging from the comparative analysis of exclusive pronouns as self-mentions employed in the three sub-corpora under investigation.

As regards the use of the first person singular pronoun *I*, an interesting realization is found in the whole corpus. Of the 24 instances of *I* occurring in the data, 18 occurrences are shown in direct questions that, as Herrando-Rodrigo interestingly notes (2010: 266) in her study on the role of engagement markers in medical electronic popularizations, “readers may pose to themselves whose answers are provided by the writer”.

Table 4. Exclusive pronouns as self-mentions across the three sub-corpora

<table>
<thead>
<tr>
<th>Exclusive pronouns as self-mentions</th>
<th>Syndromes Raw freq./ptw</th>
<th>Medications&amp;Treatments Raw freq./ptw</th>
<th>Guidelines for families Raw freq./ptw</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>I</em></td>
<td>2/0.00</td>
<td>8/0.04</td>
<td>14/0.06</td>
</tr>
<tr>
<td><em>my</em></td>
<td>1/0.00</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><em>we</em></td>
<td>12/0.05</td>
<td>21/0.09</td>
<td>42/0.19</td>
</tr>
<tr>
<td><em>our</em></td>
<td>14/0.06</td>
<td>23/0.10</td>
<td>45/0.20</td>
</tr>
<tr>
<td><em>us</em></td>
<td>3/0.01</td>
<td>0</td>
<td>8/0.04</td>
</tr>
</tbody>
</table>

This is the case for the 2 occurrences found in the Syndromes corpus, 8 in the Medications&Treatments corpus and 8 in the Guidelines for families corpus, as shown in the extracts (1) to (3) where, by using *I*, the writer adopts the caregiver’s voice. This use is evidently intended to involve the reader as an active participant. In so doing, s/he models her/his identity as if s/he were experiencing the caregiver’s situation and recontextualizing it as reality.

(1) Are there organizations or support groups *I* can contact? (Syndromes)

(2) What if *I* forget? Ask the doctor or nurse what to do if you forget to take a dose. (Medications&Treatments)

(3) Disability Living Allowance or Personal Independence Payment. Carer’s Allowance. Employment and Support Allowance. Disabled Facilities grants. Am *I* entitled? PIP is paid at different rates depending on the level of help you need. You will need to complete an assessment to find out how much support you are entitled to. PIP is not means tested. If you already have an existing Disability Living Allowance (DLA) claim, you can use an online PIP checker (https://www.gov.uk/pip-checker) to find out how your DLA is affected by PIP. Note that other benefits you receive may increase if you start receiving a PIP. How do *I* apply? Call the Department for Work and Pensions (DWP) to make a new Personal Independence Payment (PIP) claim if you’re in Great Britain. (Guidelines for families)

Herrando-Rodrigo observes (2010: 266) that these questions function as a guideline to parents for helping them cope with their children’s disease. As she points out, this dialogic (parent-addressed) format is very frequent in
medical electronic popularizations, since “writers give priority to engaging with their readers rather than claiming authority”.

Although only 4 instances were found in the corpus, I is also exemplified in tips, as the following extracts illustrate. The purpose here is chiefly informative and provides practical advice (use their name at the beginning; make sure they are paying attention before you ask a question or give an instruction; say less and say it slowly).

(4) They don’t pay attention to what I’m saying.
Always use their name at the beginning so that they know you are talking to them. Make sure they are paying attention before you ask a question or give an instruction […] (Guidelines for families)

(5) They find it hard to process what I say
An autistic person can find it difficult to filter out the less important information. If there is too much information, it can lead to ‘overload’, where no further information can be processed. Say less and say it slowly. Use specific key words, repeating and stressing them […] (Guidelines for families)

There is only one instance in which my is used in the corpus. Again, this self-mention device is shown in a question (Can my child die from this condition?).

Let us consider the first person plural pronoun as exclusive we and the possessive adjective our. The Guidelines for families corpus tends to employ more instances of we and our, with a density of 0.19 ptw and 0.20 ptw respectively, compared to the Medications&Treatments and Syndromes corpora (we 0.09 ptw; our 0.10 ptw in the Medications&Treatments corpus; we 0.05 ptw; our 0.06 ptw in the Syndromes corpus). Differently from the use of I, the writers manifest their identity by using we and our when they announce the finality of the webpages, as in (6), (7) and (8) or “identify themselves with a particular argument and gain credit for an individual perspective” (Hyland 2005b: 181), as in (9).

(6) We are educating the public about autism through our Too Much Information campaign. (Syndromes)

(7) We hope this introduction and accompanying video provide all of those affected with a comprehensive overview into the many considerations of living with Dravet syndrome. You are not alone and
Dravet Syndrome UK and our community are here to support you every step of the way. (Syndromes)

(8) Our mission. The mission of the Epilepsy Foundation is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. (Medications&Treatments)

(9) In our discussion of treatment options it must be emphasized that ASD is a lifelong disability, with the needs of the child changing with different developmental stages. No single treatment offers a cure for ASD. However, these treatments, particularly in combination, can greatly improve a child’s function. (Syndromes)

The writer’s visibility is also realized through direct recommendations, as exemplified in (10):

(10) We again urge patients and families to contact their doctor before stopping an epilepsy medication because this may possibly lead to seizures and worsening of mood. (Medications&Treatments)

As regards exclusive us, only 11 instances were found in the whole corpus: 3 occurrences in the Syndromes corpus and 8 in the Guidelines for families corpus. Again, it represents the voice of the foundation, as highlighted in the following examples:

(11) Sign up to support our Too Much Information campaign donating so we can continue to give millions of people information and advice about support volunteering in one of our schools, care services or offices fundraising for us. (Syndromes)

(12) Our engagement with families told us that: Parents seek respite to provide them with essential breaks from coping with the complexities of the condition; and to ensure that the needs of the whole family are met, particularly those of siblings, for whom the impact can be enormous. (Guidelines for families)

The overall findings reveal that, although the presence of self-mentions is limited in the whole corpus, their use is representative of specific rhetorical devices, as exemplified in the extracts analyzed.
3.3 Engagement markers

As pointed out in 3.1., the frequency of engagement markers is very high in the whole corpus (7.94 ptw). Hyland (2005a: 53) observes that engagement markers are devices explicitly addressing readers, either to focus their attention or include them as discourse participants. In the webpages under investigation, writers engage with the reader by means of three linguistic manifestations: pronouns/possessive adjectives, directives and questions, as shown in Table 5.

Table 5. Engagement markers across the three sub-corpora

<table>
<thead>
<tr>
<th>Engagement markers</th>
<th>Syndromes Raw freq./ptw</th>
<th>Medications &amp; Treatments Raw freq./ptw</th>
<th>Guidelines for families Raw freq./ptw</th>
</tr>
</thead>
<tbody>
<tr>
<td>you</td>
<td>82/0.36</td>
<td>227/1.00</td>
<td>247/1.10</td>
</tr>
<tr>
<td>your</td>
<td>86/0.38</td>
<td>128/0.57</td>
<td>292/1.29</td>
</tr>
<tr>
<td>inclusive we</td>
<td>10/0.04</td>
<td>0</td>
<td>9/0.04</td>
</tr>
<tr>
<td>inclusive our</td>
<td>7/0.03</td>
<td>0</td>
<td>7/0.03</td>
</tr>
<tr>
<td>questions</td>
<td>90/0.40</td>
<td>115/0.51</td>
<td>39/0.17</td>
</tr>
<tr>
<td>directives</td>
<td>0</td>
<td>252/1.12</td>
<td>204/0.90</td>
</tr>
</tbody>
</table>

Second person pronoun you and possessive adjective your are the most frequent engagement markers in the whole corpus (2.46 ptw and 2.24 ptw respectively). You refers to the parents as caregivers and your to their children suffering neurological syndromes. Your child occurred 199 times out of 506 instances of your in the corpus. Here are some examples taken from the three sub-corpora:

(13) Lack of sleep as a cause of seizures: Lack of sleep is often cited as a key trigger for seizures and can cause a vicious cycle, in which a child that becomes sleep deprived has more seizures, and the increase of seizure activity causes a child to become even more sleep deprived. It is therefore vital that you try to ensure your child sticks to a healthy sleeping pattern, where possible. Sleep disturbance could be a phase that your child will come out of once their bodies are used to the medication they are taking. (Syndromes)

(14) It’s OK to take clobazam either with food or without food. To give it to small children or others who cannot swallow tablets, you can
crush it and mix it with a spoonful of soft food such as applesauce, yogurt, or ice cream. Do NOT stop taking this drug suddenly. (Medications&Treatments)

(15) In this section Communicating Here we give you some quick tips for communicating with an autistic person, help with understanding an autistic person’s communication, information about the different stages of communication, ideas on how you can support communication development and use communication supports, and information about communication in school. (Guidelines for families)

In agreement with Tessuto (2015: 220), the extracts show how directly addressing the readers with you not only simulates a relationship of intimacy and solidarity in a correspondingly conversational relationship, but also identifies them in their different roles of individuals, parents or caregivers.

It is worth noticing that the possessive adjective your also refers to doctors (77 occurrences in the whole corpus), as exemplified in the following extracts taken from the Medications&Treatments corpus, where the collocate is frequently attested (49 occurrences). This finding should not be surprising because these webpages are said to be merely informative and parents are advised to refer to doctors for professional medical diagnosis, treatment and care.

(16) The potential for serious side effects in nursing infants is unknown. If you want to breastfeed your baby, check with your doctor about what seizure medicine would be best for you. (Medications&Treatments)

(17) As with all medications, it is very important to comply with all the instructions provided when administering medications to your child, especially dosing and course completion. It is suggested you speak to your child’s doctor if you have any concerns over their medication – it is better to seek guidance than to alter their medication yourself. (Medications&Treatments)

While the engagement functioning role of you and your was the most common choice made by the foundations managing the webpages under investigation, only a few instances of the inclusive pronoun we and possessive adjective our were found in the whole corpus (19 and 14 occurrences respectively). Here are some examples, in which their rhetorical effect is to make the reader feel part of a community, i.e. parents with children affected by diseases.
As a consequence, by using *we* and *our*, the writers express empathy with caregivers, facilitating the transfer of information that is perceived as more familiar (Cavalieri 2019).

(18) *We* all have different ways of dealing with stress and difficult periods in *our* lives. Your child may see food as a source of comfort, or they may be under eating as a way of dealing with stress. (Guidelines for families)

(19) *We* all know that not getting a good night’s sleep can affect how *we* function during the day, leading to fatigue and an inability to function. (Guidelines for families)

(20) Myoclonus is another type of generalized seizure – a sudden jerk of part or most of the body. This resembles what *we* all experience occasionally as *we* fall asleep. (Guidelines for families)

Emphatic support is further emphasized by the use of the word *all* that conveys the idea of inclusiveness and creates a rhetorical effect of involvement.

The second most frequent engagement markers are directives (456 occurrences/2.02 ptw in the whole corpus). They represent one of the most direct ways of addressing the reader/caregiver, and are used for advice and suggestions where there is a supposed benefit to caregivers. Their heavy concentration in the Medications&Treatments and Guidelines for families corpora (252 and 204 instances respectively) is a clear attempt to instruct or give readers advice on aspects concerning their children’s disease, as shown in the following examples:

(21) Fever management is key to managing Dravet Syndrome as a fever often triggers a seizure. *Keep* a close eye on your child and *manage* the symptoms of a fever quickly. It may be necessary to use rectal fever treatments if your child is ill. Your child may be reluctant to take oral medication when unwell, or perhaps they are vomiting or have a stomach bug. In cases such as these it can be easier to use rectal paracetamol suppositories. (Medications&Treatments)

(22) As parent or carer, you have to be proactive in finding out what is involved in a specific change. For example, you might know that a teacher is leaving your child’s school, but might not have been given
any further information about new staff or new timetables. *Find out* when exactly changes are going to take place and what is involved. *Describe* the change. *Mark* the day of the change on a calendar and *encourage* the person to count down to that day. *Use* clear language when describing the change, giving the person time to process what you say, and *limit* your use of gestures and facial expressions. *Use* visual supports. (Guidelines for families)

Although less frequent (244 occurrences/1.08 ptw), *what-* and *how-*questions were used as engagement devices. Through these questions, the writers position the reader as having relevant knowledge of the syndromes (*What is Asperger syndrome? How common is Asperger syndrome? How do people with Asperger syndrome see the world?*) or of medications and treatments (*What are the most common side effects of Clonazepam? What are the most serious side effects of Clonazepam? Why ventilate? What happens when your child is ventilated?*):

(23) *What is Asperger syndrome?* Like other autism profiles, Asperger syndrome is a lifelong developmental disability that affects how people perceive the world and interact with others. […] *How common is Asperger syndrome?* Autism, including Asperger syndrome, is much more common than most people think. […] *How do people with Asperger syndrome see the world?* Some people with Asperger syndrome say the world feels overwhelming and this can cause them considerable anxiety. In particular, understanding and relating to other people, and taking part in everyday family, school, work and social life, can be harder. (Syndromes)

(24) *What are the most common side effects of Clonazepam?* Clonazepam belongs to a class of medications called benzodiazepines. Benzodiazepines are tranquilizers (sedatives) that prevent or stop seizures by slowing down the central nervous system. This makes abnormal electrical activity less likely. As a result, common symptoms include: tiredness dizziness unsteadiness impaired attention and memory irritability hyperactivity (in children) drooling (in children) depression (usually in adults) nausea loss of appetite. […] *What are the most serious side effects of Clonazepam?* Most people who take clonazepam have no side effects or mild side effects that go away with no lasting harm. But a few people have serious reactions. Here’s a list of symptoms that may be the start of one of these problems. (Medications&Treatments)
(25) *Why ventilate?* There are two main reasons why your child may need to be ventilated, either because they are unable to breathe effectively for themselves or because they are unconscious and are unable to protect their airway sufficiently [...] *What happens when your child is ventilated?* Your child will be given some medication to help them relax; even if they appear unconscious. An endotracheal tube will be placed into the mouth and fed down the trachea (wind pipe) under direct vision. [...] (Medications&Treatments)

As it may be expected, the occurrences of *what*- and *how*-questions are mainly found in the Medications&Treatments and Syndromes corpora (115 and 90 occurrences respectively). Again, this may find an explanation in the finalities of those webpages: in Medications&Treatments writers seem to simulate a medical consultation where readers as caregivers ask questions about drugs and treatments and receive the information requested from the expert (see ex. 24 and 25). On the other hand, in Syndromes questions are used to introduce the definitions and explanations as characteristic of this sub-corpus (see ex. 23).

4. Concluding remarks

The paper testifies to the growing level of attention to communicative issues within the context of online health communication targeting parents whose children suffer chronic neurological diseases. This study is a continuation of previous research on the popularizing practices of web-based health communication aimed at making information cognitively accessible for parents/caregivers. As the present work demonstrates, the webpages of the foundations under investigation respond to this intent.

The overall findings reveal that writers place more emphasis on the readership than on the manifestation of their identity, confirming Herrando-Rodrigo’s (2010) claim that engaging with the reader and making the text accessible is a priority for writers of online medical popularization. As a result, in spite of the varying nature of the webpages analyzed – the Syndromes are merely informative, while the Medications&Treatments and Guidelines for families are more advisory – they nevertheless highlight a participative, dialogic and inclusive way of exchanging health information.

As the data show, readers – parents/caregivers – are very closely engaged by means of personal markers (second person pronouns) that involve them in the discourse. The strategy of addressing them directly
foregrounds the highly dialogic and reader-oriented nature of the websites analyzed, whose main purpose is to involve their readership and create a rhetorical effect of closeness and involvement.

Interestingly, the dialogic interaction between writer and reader is also evident in the question-answer pattern that characterizes the two sets of webpages: Syndromes and Medications&Treatments. The writer anticipates the reader’s questions. It seems that s/he implicitly uses a FAQ strategy: s/he explicitly asks the question and immediately gives the answer/explanation.

Our results corroborate the general picture emerging from other studies on popularized medical texts that providing empathic support to patients is one of the main aims of online health communities (see Morrow 2006, Fage-Butler – Nisbeth Jensen 2013 and Mansfield 2019). This is evident in our data, as exemplified in a case study reported in the Guidelines for families sub-corpus, where a parent/caregiver says that the Dravet Syndrome UK website:

has opened a new world to us. It is full of amazing people, all knowing exactly how you feel and what our children go through. It is such a nice relief to have other people to talk to about Dravet Syndrome [...] (Guidelines for families)

This view is also explicitly mentioned by the Dravet Syndrome Foundation when saying that “it’s lovely to be able to offer support to parents and it really is like one big extended family”. As the following extract shows, it is the mission of the foundation to make the parents feel not alone on their “journey”:

This section aims to provide a more ‘hands on, personal’ approach to how the family survives the ups and downs of living with a Dravet Syndrome diagnosis. Having a family member with Dravet Syndrome does affect the entire family and can have a huge impact on many areas of life that most families take for granted. This section will provide you with some tips, ideas and hopefully help you realise you are not alone on your journey. (Guidelines for families)

It is worth noting that the language used by the foundation involves metaphors (the writers identify themselves and caregivers as “one big extended family”, and the caregiver’s condition is interpreted as that of “journey”). In terms of discursive strategies, through the use of metaphors, they present
their mission by choosing a context that belongs to the caregiver’s everyday experience.

Empathic support is also manifest in the corpus where, by using the inclusive we and our, the writers identify or place themselves on the same footing as the parents who are suffering their children’s neurological conditions (We all have different ways of dealing with stress and difficult periods in our lives; We all know that not getting a good night’s sleep can affect how we function during the day).

In conclusion, the study highlights that the writers of the webpages analyzed tend to engage with parents/caregivers of paediatric patients, while informing and providing advice and suggestions. They do this by adopting their voice and aligning with them to show solidarity and offer support. In all, they enhance caregiver health literacy and achieve the goal of caregiver “empowerment” (Askehave – Zethsen 2010), giving her/him greater control over decisions affecting her/his child’s health.

REFERENCES

Sources

Dravet Syndrome Foundation
https://www.dravetfoundation.org/, accessed April 2019

Epilepsy Foundation
https://www.epilepsy.com/, accessed April 2019

National Autistic Society
https://www.autism.org.uk/, accessed April 2019

Neurological disorders in children

Pediatric Brain Foundation
https://www.pediatricbrainfoundation.org/, accessed March 2019

Special studies

Anesa, P. – A. Fage-Butler
2015 “Popularizing biomedical information on an online health forum”, Iberica 29, 105-128.

Askehave, I. – K.K. Zethsen
2010 “‘Check it out’: The construction of patient empowerment in health promotional leaflets”. In: M.F. Ruiz-Garrido – J.C. Palmer-Silveira –

**Bondi, M. – S. Cacchiani – D. Mazzi**


**Calsamiglia, H. – T.A. van Dijk**


**Cavalieri, S.**


**Cavalieri, S. – G. Diani**


**Dynel, M.**


**Fage-Butler, A.M. – M. Nisbeth Jensen**


**Gotti, M.**

2014 “Reformulation and recontextualization in popularization discourse”, *Ibérica* 27, 15-34.

**Hawn, C.**

2009 “‘Take two aspirin and tweet me in the morning’: How Twitter, Facebook, and other social media are reshaping health care”, *Health Affairs* 28 (2), 361-368.

**Herrando-Rodrigo, I.**


**Hyland, K.**


Luzón, M.J.

Mansfield, G.

Mattiello, E.

Morrow, P.R.

Sala, M. – S. Maci – M. Gotti

Scott, M.

Tessuto, G.

Turnbull, J.

Address: GIULIANA DIANI, Department of Studies on Language and Culture, University of Modena and Reggio Emilia, Largo Sant’Eufemia 19, 41121 Modena, Italy.
ORCID code: orcid.org/0000-0001-7044-9039.