d he did it; yes, he did! The clock struck nine . No Bob. A quarter past. No Bob. He was
his pen, as if he were trying to overtake nine o'clock. "Hallo!" growled Scrooge, in his a
kindly mention now, for instance, what nine times ninepen shilling
footed inmate of a menagerie. Towards nine o'clock he smoothed his ruffled aspect, an
-looking. Encamped at a quarter before nine , in good time to touch his three-cornered
t, and he is sought--how many months? nine , ten, eleven?" "No matter, the number," sa
about forty years; height, about five feet nine ; black hair; complexion dark; generally, rat

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ive days, six days, seven days, eight days, nine days. With a hope ever darkening, and wit
voice, asked, "Of how long duration?" " nine days and nights." "How did it show itself?
membering what he had seen in the last nine days, he knew that he must face it. "The o
ne thousand seven hundred and eighty - nine , Mr. Lorry came in late, from Tellson's, an
, two, three, four, five, six, seven, eight, nine , ten, eleven, twelve. Hush!' "This lasted tw
night, the last night of the year, towards nine o'clock, a man in a black dress rang at my
ne hour or two. If I go to Mr. Lorry's at nine , shall I hear what you have done, either fro
re to go. "At Tellson's banking-house at nine ," he said, with a musing face. "Shall I do w
the numbers he would never hear again. nine gone for ever, ten gone for ever, eleven go
e of all the packages and baskets: 'eight, nine , ten - where's eleven? Oh! my basket's elev
n give him a warm mash tonight. Eight, nine , ten. Why, where's eleven? Oh! forgot, it's
d she was listening. I had come down at nine o'clock as I always did to read the Bible to
ling the poor soul that it was half - past nine , did more for us in the way of bringing ou

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f), is the child who contributed two and nine -pence to the Great National Smithers Tes
ne and six, being the entire allowance of nine weeks; Oswald, one and a penny halfpenn
at half-past one and supper at half-past nine . Mr. Snagsby was about to descend into th
n on the Thursday morning at half after nine ." The tail of Mr. Snagsby's eye becomes co

Token: A Journal of English Linguistics

Volume 9

JAN KOCHANOWSKI UNIVERSITY OF KIELCE

Token: A Journal of English Linguistics

Volume 9
Special issue on
exploring healthcare communication and health literacy:
Cognitive and social community action in an online world

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Marina Dossena
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Introduction

Marina Bondi and Franca Poppi
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The issue of health literacy has become central in the debate on healthcare communication, particularly when dealing with chronic conditions. In the definition of the World Health Organization, health literacy is identified as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health"[1]. Chronic conditions require constant communication and a variety of communicative channels that might provide support for the patients and caregivers, as well as favour adherence to the recommended healthcare practices. While there has been a considerable body of research into doctor-patient discourse, the majority of the studies have focused on oral interaction and on unmediated consultation, exploring the interaction between patient and doctor. The relative scarcity of linguistic studies on other communicative situations highlights the need for further research on the whole range of communicative practices and situations, such as communication with and through caregivers, communication between patients/caregivers themselves, use of print materials or web-mediated genres. The literature on the quality of written communication, in particular, is largely based on statistical estimates of readability of patient information leaflets, rather than on a functional analysis of recontextualizing procedures which serve the purpose of making information relevant to the specific reader. This becomes central when addressing communication with caregivers, who need to be able to mediate health practices. Indeed, the links between literacy and health are undoubtedly worth investigating, as limited health literacy among patients/caregivers may result in poorer clinical outcomes and poorer patients' life quality due to lack of adherence

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[1] https://www.who.int/healthpromotion/conferences/7gchp/track2/en/

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to the recommended treatment (Sørensen et al. 2015; Rowlands et al. 2017; Dray – Papen 2007; Filippone et al. 2013). The effects of such poor health literacy have already been studied in diverse chronic conditions such as asthma (Mancuso – Rincon 2006), HIV/AIDS (Kalichman et al. 2000), diabetes (Collins – Lewis 2013; Bigi – Rossi 2015; Turnbull 2015).

The present special issue plans to provide a wider, encompassing overview of present research on health communication and literacy, by looking at it from a multiplicity of perspectives, which range from studying websites and online articles to examining Information Satisfaction Questionnaires; from exploring online forums to analysing nurse-patient face-to-face consultations.

The Internet and web applications in general have lately been playing a significant role in health knowledge dissemination, both as sources of information and communication channels (Eng et al. 1998). This has paved the way for more participatory medicine, as health professionals are no longer the sole providers of information and patients join discussions themselves. This kind of dynamic online communication was defined by Greene et al. (2010: 287) as "Health 2.0". It "offers patients an opportunity to […] learn about their illness and to gain support from others with similar experiences". In this way patients are "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" (Bondi et al. 2015: 14).

However, alongside the expression of personal experience and the understanding of illness shared among a virtual community, also more traditional forms of communication, like nurse-patient face-to-face interactions, can still provide useful insights and even serve as benchmarks for evaluating the communicative effectiveness of medical consultations, thus empowering medical and healthcare professionals in communicating with their patients and contributing to an improved quality of life for any groups of patients.

The first four papers of this special issue focus on the same context, consisting of the communication dealing with paediatric neurological syndromes. The opening paper by Diani investigates the webpages jointly created by medical experts and parents whose children are affected by neurological disorders resulting in epilepsy. By exposing how the writers of these webpages establish a relationship with their readers by means of metadiscursive devices, the paper highlights the participative, dialogic and inclusive way of exchanging adopted.

Lazzeretti and Poppi's contribution analyses the degree of accuracy, alteration or bias of a corpus of selected web texts appearing in websites dealing with autism, Dravet syndrome, Angelman syndrome and others. Special attention is given to the range of expressions used to identify patients and in particular to the use of person-first vs. identity-first language, with a view to assessing their relevance and evaluating whether the person-first language issue is indeed crucial in the process of online dissemination of medical knowledge.

Sezzi and Bondi's paper examines the popularizing strategies employed in the websites of the Matthew's Friends Foundation (UK) and the Charlie Foundation (US), which promote information on the Ketogenic Diet (KD), a dietary treatment for intractable epilepsy. In particular, the analysis makes use of discourse and corpus tools to show that, despite focusing on similar aspects and using similar techniques, the two foundations differ in the frequency of use of explanations and question-answer sequences, as well as in the way they interpret their roles as mediators of knowledge.

Caregiver informative materials are the subject of Cavalieri et al.'s contribution, focusing on KD materials distributed in Italy. By combining an ethnographic and a textual perspective, i.e. textual ethnography (Swales 1998), the authors look at the perceptions of caregivers on the current communicative situation and analyse the overall structure of the texts, the technicality of the vocabulary, the number of content words per clause ('lexical density'), and the clarity of the role relationship between author and reader. The results of the analysis confirm the relevance of key linguistic features in enhancing the quality of informational texts for caregivers.

The next three papers study social networks and forum discussions. Patients participating on a peer-to-peer basis are shown not only to seek information and guidance but also consolation, comfort and encouragement. Maci's paper, for instance, looks at support groups on healthtalk.org with a view to detecting how information and knowledge (and empathy) are conveyed to other people in a similar situation, with the aim of filling a cognitive and emotional gap. The analysis unveils the highly emotional connotation of the most frequently used verb, *know*, used to look for the listener's agreement, to show the parents' awareness of their child's medical condition, or to refer to when they were in turmoil due to shock and did not know it, and had no control over matters.

Similarly, Zabielska deals with lay medical language (Kokkinakis – Toporowska-Gronostaj 2006). By focusing on the main features of the patients' language used in the increasingly popular (Dosani et al. 2014; Neda et al. 2017) English Facebook ear nose and throat forums about cochlear implants, the study shows that among many other features, the lay language employed seems particularly emotional when explaining specialist issues, which may also prove to be useful for the doctor's perspective, the co-communicator in the doctor-patient dyad (Brown et al. 1997; Dobson 2003; Shoaib et al. 2016).

Online forums are the subject of Mansfield's paper, too. In fact, the author analyses a popular website Diabetes.co.uk as an instance of a virtual community of practice. The dataset includes news about diabetes and about people with diabetes, with posts published by Diabetes.co.uk staff and users who share their experiences with the disease. Findings show how the discussion forum posts frame diabetics as patients seeking to achieve empowerment and self-management from their peers who transmit experiential knowledge of their chronic condition. Moreover, the discursive strategies identified fall into two categories: a popularised medical news genre providing knowledge produced by the website staff, and an emotionally-charged informal written-to-be-spoken discourse shared by users joining the discussion forum.

By using SketchEngine software tools, Mattiello's study investigates the figures of speech that are used to disseminate health information to non-experts in online articles related to the topic of the obesity epidemic. While a quantitative analysis of the key words collocating with the lemma *obesity* shows its relevance to health problems and diseases such as diabetes, heart disorders, or depression, a qualitative analysis of figurative language in the corpus demonstrates that reporters privilege the use of metaphor, simile, metonymy, and hyperbole to increase individuals' health literacy and to help people make appropriate decisions related to nutrition, healthy eating, and physical exercise.

Turnbull investigates how health information and advice is communicated to the elderly on the Internet. Since recent studies have shown that there is a worryingly low level of health literacy among the elderly, the quality of health information made available to the public is of the utmost importance. By focusing on the strategies adopted to explain 'technical' information to the reader, and those aiming to establish a relationship of trust between the addresser and addressee, the study takes into account both the cognitive and communicative dimensions of knowledge transfer, and shows how some websites mainly focus on imparting specialized knowledge, while others take a much broader view of the issues under consideration focusing on the well-being and quality of life of the person, which are, in any case, fundamental aspects of health.

Finally, Cheng's paper examines the genre of nurse-elderly resident consultations in Hong Kong, focusing on how the closings of their interactions are structured. The author aims to ascertain the extent to which the patterns of closings conform to the canonical closing, or archetype closing, identified in telephone calls and conversations in American English, how the nurse and the elderly resident compare in initiating different patterns of closings, and the contextual and interactional reasons for any suspension or delay of a closing in the consultations. Findings show that the closing structure is genre-specific, dependent on such factors as institutional roles and communicative goals, conversational contexts, and relationships of the speakers.

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* * *

Dedication

While this issue was in preparation in September 2018, we received the sad news that Prof. Lavinia Barbaresi Merlini had passed away. We would like to dedicate this issue of *Token* to her memory. Lavinia was a pioneer in English Linguistics in Italy and a source of inspiration for many of us, who had the privilege to meet her and appreciate her scientific insight, as well as her modesty and unfailing generosity.

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Metadiscourse in web-mediated health communication

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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,

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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?

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[1] "Exploring Health Literacy. Communicative genres in liaising with caregivers: the case of the ketogenic diet". P.I. of the project: Prof. Marina Bondi, Dept. of Studies on Language and Culture – University of Modena and Reggio Emilia. Responsible for the Dept. of Biomedical, Metabolic and Neural Sciences: Prof. Giuseppe Biagini.

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

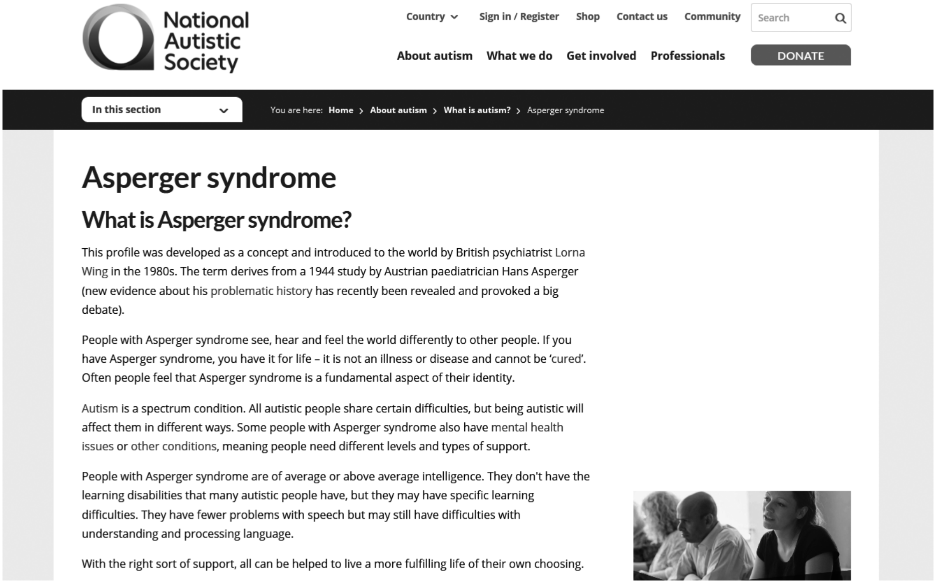
The corpus analyzed in the present study has been compiled by Silvia Cavalieri (see Cavalieri – Diani 2019). It consists of webpages gathered from the websites of the major foundations dealing with paediatric neurological syndromes for a total of 226,069 words. Table 1 shows a list of the 26 syndromes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

Table 1. List of paediatric neurological disorders in the corpus

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

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.



Asperger syndrome

What is Asperger syndrome?

This profile was developed as a concept and introduced to the world by British psychiatrist Lorna Wing in the 1980s. The term derives from a 1944 study by Austrian paediatrician Hans Asperger (new evidence about his problematic history has recently been revealed and provoked a big debate).

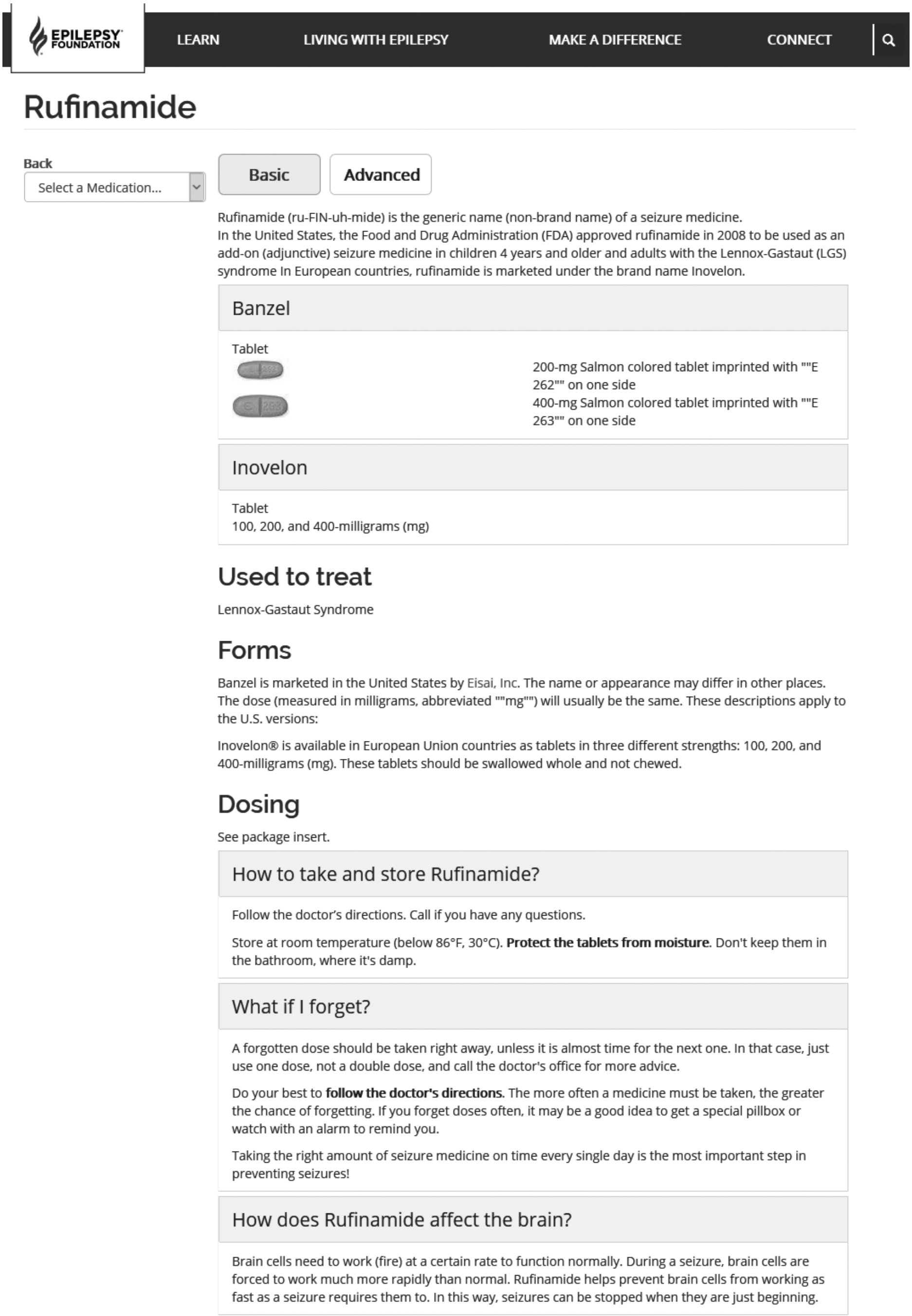
People with Asperger syndrome see, hear and feel the world differently to other people. If you have Asperger syndrome, you have it for life – it is not an illness or disease and cannot be ‘cured’. Often people feel that Asperger syndrome is a fundamental aspect of their identity.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some people with Asperger syndrome also have mental health issues or other conditions, meaning people need different levels and types of support.

People with Asperger syndrome are of average or above average intelligence. They don't have the learning disabilities that many autistic people have, but they may have specific learning difficulties. They have fewer problems with speech but may still have difficulties with understanding and processing language.

With the right sort of support, all can be helped to live a more fulfilling life of their own choosing.

Figure 1. Example of webpage of the SYNDROMES sub-corpus



Rufinamide

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 Eisai, 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

Everything you need to know

Communicating

How to communicate with autistic people, support communication development, and find available support systems.

Children

Autistic children may face communication and social interaction challenges. Find resources and get ideas for how to help.

Sex education

How to talk about puberty, sex, sexuality and relationships, with links to useful resources.

Social isolation

Help for autistic people experiencing social isolation and information for adults about making friends and socialising.

Figure 3. Example of webpage of the GUIDELINES FOR FAMILIES 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

Interactional metadiscourse markers	Raw freq.	Freq. per 1,000 words (ptw)
self-mentions	193	0.85
engagement markers	1,795	7.94

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

Interactional metadiscourse markers	Syndromes Raw freq. /ptw	Medications& Treatments Raw freq. /ptw	Guidelines for families Raw freq. /ptw
self-mentions	32/0.14	52/0.23	109/0.48
engagement markers	275/1.22	722/3.19	798/3.53

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

Exclusive pronouns as self-mentions	Syndromes Raw freq. /ptw	Medications& Treatments Raw freq. /ptw	Guidelines for families Raw freq. /ptw
I	2/0.00	8/0.04	14/0.06
my	1/0.00	0	0
we	12/0.05	21/0.09	42/0.19
our	14/0.06	23/0.10	45/ 0.20
us	3/0.01	0	8/0.04

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

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

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.

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Children with autism or autistic children? Indexicality in the websites for parents of children with neurological conditions[1]

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ABSTRACT

Online resources have a great potential for families of children affected by different kinds of disorders. In fact, acquiring knowledge on a child's disease is essential for parents and carers so that they may understand and adjust to an initially distressful condition, and also increase their participation in clinical decisions. The present study explores the degree of accuracy, alteration or bias of a corpus of selected web texts appearing in websites dealing with autism, Dravet syndrome, Angelman syndrome and others, which were set up with the aim to provide useful information and support. Special attention is given to the range of expressions used to identify patients and in particular to the use of person-first vs. identity-first language, with a view to assessing their relevance and evaluating whether the person-first language issue is indeed crucial in the process of online dissemination of medical knowledge.

Keywords: health information, indexicality, neurological conditions, qualitative analysis, quantitative analysis.

1. Introduction

Nowadays health consumers have access to a wide range of online resources. As a consequence, both patients and their carers often turn to the Web in search of medical information. Previous studies on the use of the Internet

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for seeking and sharing health information show that online resources have a great potential for families of children affected by different kinds of disorders. According to Gundersen (2011), acquiring knowledge on a child's disease is essential for parents so that they may understand and adjust to an initially distressful condition. Therefore, Internet resources can play a part in helping a person to re-establish a sense of coherence after experiencing what Antonovsky (1987: 29) defined as a "major stress or life event", namely parenting a child suffering from a condition that will impair his/her quality of life. Moreover, effective and meaningful communication can improve the quality of care and increase patients' and carers' participation in clinical decisions (Eysenbach 2008).

An online survey carried out among Italian families of patients with rare diseases demonstrated that parents are very active Internet users, strongly engaged in information searches and in online communities (Tozzi et al. 2013). Conversely, at a broader level, there is large dissatisfaction with the information received from health personnel (Case 2000; Graungaard – Skov 2007; Hedov et al. 2002; McLaughlin 2005; Skotko 2005).

Even though this is still a little-researched topic, a recent study (Oprescu et al. 2013) has underlined the importance of offering user-friendly online resources addressed to parents of patients with rare diseases, as well as the necessity of adopting a meaningful and respectful communication towards this very sensitive category of users. This entails the use of plain language, free from obscure medical terms and technicalities that may inhibit comprehension – a still underestimated aspect of online healthcare documents (Peters et al. 2016). At the same time, in order to establish a positive relation with users and achieve a sense of proximity it is necessary to adopt an inclusive language, which can foster acceptance and empathy.

The present study explores the lexical quality of the information available in web resources for parents of patients affected by neurological disorders. In particular, the dataset consists of a corpus of selected web texts appearing in thematic websites dealing with autism, Dravet syndrome, Angelman syndrome and others. These websites were set up with the aim to provide useful information and support to families of children with a dysfunction in part of the brain or nervous system, resulting in physical and/or psychological symptoms. It may therefore be expected that language is a matter of utmost importance in these websites and that linguistic choices have been pondered deeply in order to reduce asymmetry and distance between physicians, experts and/or volunteers working on healthcare platforms on the one side, and communities of users, on the other.

Drawing upon a combined methodology, based on both qualitative discourse analysis and quantitative corpus methodologies, the analysis focuses on aspects of discursive indexicality (i.e. on the range of expressions used to identify patients and index different aspects of positive vs. negative representation). Special attention is given in particular to the use of person-first vs. identity-first language, with the aim of assessing their relevance in the overall communication and evaluate whether the person-first language issue is indeed perceived as crucial in the process of online dissemination of medical knowledge to a sensitive audience, or is rather considered as a semantic argument that can be relegated to 'political correctness' and therefore neglected. The study also has the objective of pinpointing which elements are used to improve the comprehension of health information by the relevant community of users, as well as the degree of accuracy, alteration or bias of the content provided.

2. Discursive indexicality

Indexicality, which refers to the pervasive context-dependency of natural language utterances, includes a wide range of phenomena like regional accent, indicators of verbal etiquette (marking deference or demeanour), the referential use of pronouns, demonstratives, deictic adverbs and tense (Hanks 1999). However, despite its broad scope, indexicality is most frequently mentioned in connection with pronouns and deictics.

Yet any linguistic sign in its contexts of use accomplishes functions other than pure reference, since only part of its meaning is semantic (Silverstein 1976). Accordingly, in the attempt to capture the total meaning of a linguistic sign in terms of all of its communicative functions, it is important to bear in mind that a sign is often associated with specific locally or contextually significant social characteristics (Dyer 2007: 102). We can say, therefore, that a linguistic form can become an index of a speaker's social identity (Milroy 2000). This is, for instance, most obvious in code-switching. In such contexts, the speaker may at times become the victim of other-imposed identities, if the listener ascribes social characteristics that he/she is not aware of or does not recognize.

At the same time, a linguistic form can also become an index of a speaker's attitude towards the signified, as each lexical choice one makes inevitably brings along specific locally or contextually significant features.

2.1 Indexicality and identity

When talking about identity we are inevitably confronted with the "who am I?" question, as it refers to a sense of who we are and how we relate to the social world (Norton 2010). Identity has been investigated in a myriad of fields including anthropology, psychology, education, sociology, literature, politics, etc. Labov's (1966) study on language and identity and subsequent replications (e.g. Trudgill 1974) were founded on a correlational approach. In this way sociolinguistic researchers in the early days of the discipline assigned identity as if it were a social category membership (Mendoza-Denton 2008), not so differently from social class, age, sex and ethnicity. This kind of research was important, however, because it not only revealed the range of variation in a community, but also highlighted which types of people used particular variants. Unfortunately, as claimed by Mendoza-Denton, this early variationist research did not provide much explanation at all, as it simply consisted of "statistically motivated observation-cum-speculative description" (2008: 475). Yet this 'essentialist' attitude describes how identity was generally perceived at the time. Social psychologists such as Tajfel followed this view, defining social identity as: "the part of an individual's self concept which derives from his [sic] knowledge of his membership of a social group (or groups) together with the emotional significance attached to that membership" (1974: 69).

Individuals were therefore viewed as "occupying particular social identities throughout their lives by virtue of their position in the social structure" (Bucholtz 1999: 209). Speakers were therefore also largely considered agentless, viewed as the products of a particular social structure, which they in turn would reproduce through their language. However, it is definitely more productive to look at identity not as something fixed, deriving from certain social factors, but rather as a dynamic and complex entity, which is lived, negotiated, on-going, and changing constantly across time and space. It may be in part intentional, in part habitual and less than fully conscious, in part an outcome of interactional negotiation, in part a construct of others' perceptions and representations, and in part an outcome of larger ideological processes and structures. Identity is the product of linguistic and other semiotic practices and can therefore be indexed through labels, implicatures, stances, styles, or linguistic structures and systems (Bucholtz – Hall 2005).

The present study focuses on the lexical quality of the information available in selected web resources for parents and patients affected by neurological disorders. Bearing in mind that the language of these websites should be structured in such a way as to establish a meaningful and respectful communication towards this very sensitive category of users, it was decided to focus on the range of expressions used to identify patients, with a view to establishing whether the terms adopted were meant to index different aspects of positive vs. negative representation.

3. The debate around person-first vs. identity-first language

The lexical choice of adopting person-first and/or identity-first language can be regarded as a means for indexicalisation, on the grounds of its ability to suggest different representations of disability and to influence the general semantic prosody of its co-text.

Person-first language (from now on PF language) is identified by the structural form in which a noun referring to a person or persons (e.g. person, adults, or children) precedes a phrase referring to a disability (e.g. persons with a disability, children with autism). As such, person-first language contrasts with identity-first language (from now on, IF language), where the term for the disability, serving as an adjective, precedes the personhood-noun (e.g. disabled persons, autistic children).

PF language draws on the philosophy of linguistic relativity that states that language shapes perceptions of the world and significantly influences cognitive processes (Wolff – Holmes 2011). In other words, the labels and language we use to describe persons with illnesses or disabilities shape not only how they perceive and treat themselves, but also how others perceive and treat them. The American Psychological Association advocates for the use of person-first language in order to reduce stigma towards people with disabilities or diseases (Dunn – Andrews 2015). In particular, the Manual of the American Psychological Association (APA 2010: 76) states that:

> the overall principle for "nonhandicapping" language is to maintain the integrity (worth) of all individuals as human beings. Avoid language that objectifies a person by her or his condition […] that uses excessive and negative labels […] or that can be regarded as a slur. Use people-first language, and do not focus on the individual's disabling or chronic condition.

However, the effects of using person-first language are under debate among scholars:

> Person-first language is used more frequently to refer to children with disabilities than to refer to children without disabilities; person-first

> language is more frequently used to refer to children with disabilities than adults with disabilities; and person-first language is most frequently used to refer to children with the most stigmatized disabilities. Therefore, the use of person-first language in scholarly writing may actually accentuate stigma rather than attenuate it (Gernsbacher 2017: 4).

Also Granello and Gibbs (2016), for instance, contend that it is time to find out whether the use of postmodified nouns is worth defending or whether the use of these labels is, in fact, simply a semantic argument with little or no relationship to levels of stigma and tolerance. Common criticism is based on the idea that PF language reflects an overload of political correctness or points to the hypocrisy of hiding the names of diseases in clever words, actually contributing to the stigma rather than preventing it. To such an extent Collier (2012a) adds that the grammar of PF language forces long, awkward, clunky sentences.

Rinn (2018) has highlighted the paradox by which, among those who criticise PF language, we can find directly involved parties, such as the National Federation for the Blind in the United States and autistic communities, which are split over the issue. Parents whose children have autism often differ from those with autism themselves, the latter preferring to call themselves autistic rather than "a person with autism" (Collier 2012b). Some prefer the 'identify first' option to stress that disability is nothing to be ashamed of and that disability expresses a cultural and lived identity (Ladau 2015). An ideal way out, be it not always feasible, could be to ask the persons in question how they identify themselves and find a solution respectful to their own language use.

A preliminary exploration of the corpus collected for this study shows occurrences of "disabled children", as well as of "children with disabilities"; of "autistic people" as well as of "children with autism" and "children on the autistic spectrum"; of "birth defect", "handicap", "handicapped children", as well as of "normal child". It is therefore worth analysing more in-depth the writing protocols of online resources for parents of children with neurological disorders and the discursive practices adopted in addressing patients.

4. Materials and methods

The list of neurological disorders affecting child brain development and behaviour is unfortunately very long. These paediatric neurological conditions are a terrible burden for the families of the affected children, and, according to what emerged from the Berlaymont conference[2] in 2012, they also represent a high and increasing paediatric disease burden in countries where these disease trends have been observed.

The present study explores selected web communication on neurological disorders, taken from six websites of non-profit organizations and charities involved in research, advocacy and family support: 1) www.autism.org.uk; 2) www.epilepsy.com; 3) https://www.rettsyndrome.org; 4) www.angelman.org, 5) www.childneurologyfoundation.org; 6) https://ulf.org.

www.autism.org.uk is the web interface of the National Autistic Society, a charity founded in 1962 in the UK to improve the lives of individuals of all ages with autism and to support families and carers. The website provides a wide range of useful information for approaches, therapies and interventions available for children and adults on the autism spectrum. It also hosts a discussion forum for people on the autism spectrum, their carers and relatives, and professionals working in the field of autism, who can meet online and share their thoughts and experiences.

epilepsy.com is the online voice of the Epilepsy Foundation, also known as the Epilepsy Foundation of America (EFA): a non-profit national foundation dedicated to the welfare of people with epilepsy and seizure disorders. The organization was established in 1968 and works to ensure that people with seizures are able to participate in all life experiences and to prevent, control and cure epilepsy through research, education, advocacy and services.

rettsyndrome.org mirrors the International Rett Syndrome Foundation (IRSF), a non-profit, voluntary organization dedicated to research, advocacy and family support related to the Rett syndrome, a rare genetic neurological disorder that primarily affects females, characterized by normal early development in the first year of life followed by a regression, which leads to severe handicaps by the age of three years. The foundation's mission includes supporting and promoting research into the prevention, control, and cure of the disorder; increasing public awareness; and providing emotional support for affected families.

Behind *angelman.org* is the Angelman Syndrome Foundation (ASF), a non-profit organization which works to advance the awareness and treatment of Angelman syndrome through education and information, research, and support for individuals with Angelman syndrome, their families, and other concerned parties. Angelman syndrome is a rare genetic disorder characterized by mental and motor retardation, absence of speech, muscular abnormalities, unprovoked laughter, and characteristic facial abnormalities.

The Child Neurology Foundation (CNF), represented online by the website *childneurologyfoundation.org*, is a voluntary organization that gathers together 1,300 child neurologists of North America. Its mission is to advocate for children with neurologic disorders; to promote the career of child neurology with medical students; to fund child neurology research; and to provide vetted educational materials for the health community and parents.

Finally, *ulf.org* is the official website of the United Leukodystrophy Foundation (ULF): a non-profit, voluntary health organization based in the United States, and dedicated to providing patients and their families with information about their disease and assistance in identifying sources of medical care, social services, and genetic counseling. The ULF works to establish a communication network among families as well as to increase public awareness.

Web texts collected from these six websites can be divided into three main typologies: 1) guidelines for families, 2) medications and treatments, and 3) description of syndromes. Table 1 below shows how these three different typologies of text are distributed in the dataset. Quantitatively speaking, texts describing syndromes are the most relevant component of the corpus, covering more than 50% of the whole dataset.

Table 1. Description of the corpus

Text typology	Number of collected texts	Number of running words
guidelines for families	28	46,028
medications and treatments	18	44,457
description of syndromes	42	148,652
TOTAL	88	239,137

Since identity is a dynamic phenomenon, Hansen and Liu (1997) contend that it should be studied with a methodology that is dynamic both in philosophy and in practice. Therefore, the research design appropriate for studies exploring identity should be qualitative in nature. Qualitative research is offered here in order to better investigate indexicality and establish whether or not at times the adopted signifier might actually connote the signified in a negative way. However, in order to ascertain what kind of imposed/

attributed identity emerges from the corpus, it was considered necessary to integrate the qualitative analysis with quantitative data.

The data processing consisted therefore of different stages, including both computer-based and manual scrutiny of the texts. The first step involved an extensive analysis of the corpus. Then corpus linguistics was used to explore the data in more detail. In particular, the study followed the principles of corpus-assisted discourse studies (CADS), as carried out by, among others, Partington et al. (2013), and Baker (2006). At first Keyword lists were used as a basis for the analysis (see e.g. Gabrielatos 2018). This stage was followed by concordance searches and collocational analyses of words conducted to elicit contextual information that might explain their typical patterns of usage. Items under scrutiny were examined in more detail by deriving frequency lists for clusters of words and sorting concordances. The collocates were calculated using the −3 to +3 span.

5. Discussion of findings

As a preliminary step, texts were manually inspected in order to identify the quality of the information provided, as well as the lexical and interpersonal features deployed by the authors to position themselves with respect to the readership.

5.1. Extensive analysis of the three sub-corpora

Texts belonging to the first category – guidelines for families – are those where practical advice is provided and critical situations that might occur with children affected by neurological disorders are described, in order to prepare parents and enable them to react adequately. Users are directly addressed, by means of second person deixis (see examples 1 and 2) and plain language is adopted. To be noted is an effort to try to positively "engage" users (examples 3 and 4), involving them in the treatments and making them feel as part of a community (examples 5 and 6, where inclusive "we" is employed), which can provide support and help (example 7). The tone adopted is friendly and writers tend to highlight positive solutions that parents might adopt rather than indulging in the negative aspects (see example 8).

(1) Managing sleep issues is an important aspect in the care of *your* child

(2) Counselling can help *you* with things like coping strategies, relaxation techniques and relationship issues

(3) 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

(4) *There are a number of things you can do to try to manage and improve* your child's gait

(5) When *we* burn fat, we produce ketones. It is being in this ketotic state that, for some reason, can have a positive effect on seizure control and quality of life. The reasons why are still unclear; researchers are continuing to investigate this.

(6) *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. Nocturnal seizures are no different as they significantly reduce the time spent in deep sleep and can be dangerous for children whose parents are unable to monitor them throughout the night.

(7) We have *provided some protocol examples* as appendices at the back of the book. Having emergency protocols that are readily available and accessible can make treating your child in an emergency situation a lot easier

(8) *The positive news is* that, with good treatment, children with ADHD can manage their symptoms.

Conversely, texts belonging to the second category – medications and treatments – tend to be more impersonal and provide information in very instructional terms, reminding, in a way, of patient information leaflets (see examples 11, 12 and 13). Users are, however, directly addressed (examples 14, 15 and 16) as if to mitigate the distancing effect generally created by the instructional nature of the texts and also in order to keep them involved in the treatment all the same. This is for instance the case in example 15, where we can see exclamation marks and the use of capitals to add emphasis, and example 16, with its rhetorical question and related answer, which simulate an imaginary dialogue between the writer of the text and the reader(s):

(9) Clobazam tablets should be swallowed whole, followed by at least a half a glass of water.

(10) Dietary therapy is an approach to help control seizures, usually in conjunction with seizure medications.

(11) People who are not able to swallow for some reason may be given a form that can be given under the tongue (sublingual), between the cheek and gum (buccally), or sprayed into a nostril (nasal spray). People who are not able to take an oral form can use the rectal form of diazepam. This is most often prescribed for children.

(12) When *you* read about valproic acid, you will also see the word valproate (val-PRO-ate). This is the name of valproic acid after it has changed into the form that actually works in the body.

(13) And of course, practice makes perfect! *You* want to know ahead of time how to give the medicine quickly when you really need it. Learn more about lorazepam or diazepam by mouth. […] Le AccuDia! GET THE NEWS!

(14) How can I learn more about these? Glad *you* asked! Everyone who is given a prescription for a rescue treatment should receive training on what to do, when and how often.

(15) *You* should meet regularly with your Key Worker or SENCO to discuss your child's progress and if your child is not making enough progress through the Early Years Action programme, they may be able to receive additional support.

(16) The assessment will be based on conversations between the local authority and a number of people including *you* and *your* child, their school or nursery, doctor and an educational psychologist.

Descriptions of syndromes, the third and largest component in the corpus, are overly technical texts of symptoms and prognoses, often written by pediatricians and physicians, offering detailed explanations of the factors which produce or predispose children toward a certain disease. Direct address towards readers is still employed, even if the occurrences of *you* are definitely fewer than in the sub-corpus of "guidelines for families" (0.032% vs. 1.23 %). The tone is generally characterized by a distant attitude, as the texts seem aimed only at informing, rather than engaging the readers. In fact, as highlighted by Cavalieri (2019) and Sezzi and Bondi (2019), web-users are often addressed directly by using questions (Cavalieri 2019), which are very similar to the ones they might ask themselves. This is a strategy used by writers to anticipate and turn aside possible criticism from their readers (Hyland 2004).

The overall impersonal character of these texts is further confirmed by the anaphoric repetition of "the child" (rather than "your child") when addressing patients (see example 17), without any possible emotional involvement on the writer's part.

(17) It is not possible to outgrow a peroxisomal disorder. Children with these disorders will require full care and multiple therapies. The child will not be able to perform independent activities of daily living (hygiene, dressing, eating). The ability to learn and grow will be very limited by these disorders. The child's life will be majorly impacted by these disorders. The child may not survive beyond a few years after diagnosis. The child may not achieve typical milestones or may lose milestones already achieved.

5.2 Quantitative analysis

The qualitative impression provided by the manual inspection of texts is confirmed by a quantitative analysis of keyness applied to the three sub-sections of the corpus. By means of the corpus linguistics software Wordsmith Tools 6 (Scott 2012), three wordlists – one for each relevant component of the corpus – were derived. Each of them was then compared in turn to the overall wordlist to gain an insight into the specificity of each single category of texts with respect to the whole corpus.

5.2.1 Wordlist analysis

The list of keywords belonging to the first sub-section, "guidelines for families", is characterised by the presence of many personal pronouns (*you*, *I*, *we*) and of the possessive adjective *your*, implying that communication is more personalised, directly addressing readers through second-person deixis and aimed at establishing reciprocal rapport and sense of community (support) also through the use of the inclusive pronoun "we".

Table 2. Guidelines for families

N	Key word	Freq.	%	Keyness	P
1	YOU	568	1.23	448.24	0.00
2	YOUR	410	0.89	327.94	0.00
3	SMA	259	0.56	307.46	0.00
4	DRAVET	191	0.41	192.98	0.00
5	SUPPORT	219	0.48	185.86	0.00
6	CARE	214	0.46	164.12	0.00
7	I	147	0.32	120.38	0.00
8	TO	1.504	3.27	114.54	0.00
9	WE	130	0.28	113.89	0.00
10	UK	88	0.19	88.59	0.00

The "medications and treatments" sub-section is confirmed to be characterised by pharmacological terminology, with words specifically referring to dosage (*mg*, *dose*) and drugs (*valproic acid*, *lamictal*, *medicines*).

Table 3. Medications and treatments

N	Key word	Freq.	%	Keyness	P
1	MG	246	0.55	344.51	0.00
2	DOSE	217	0.48	267.29	0.00
3	TAKING	231	0.51	262.62	0.00
4	EFFECTS	256	0.57	240.86	0.00
5	ACID	216	0.48	238.33	0.00
6	VALPROIC	195	0.43	236.5	0.00
7	MEDICINES	179	0.4	221.36	0.00
8	SIDE	234	0.52	209.81	0.00
9	LAMICTAL	160	0.36	203.61	0.00
10	DOCTOR	182	0.4	203	0.00

Keywords related to the third sub-section, "syndromes" – already appearing as the most impersonal after a first qualitative inspection- point to an intense degree of specification (prominent use of the preposition *of*) when describing syndromes; moreover, the description is associated with an overly negative semantic prosody as suggested by the presence of *dis*-words: disorders, disorder, disease.

Table 4. Syndromes

N	Key word	Freq.	%	Keyness	P
1	BRAIN	739	0.5	59.48	0.00
2	OF	5,397	3.63	52.27	0.00
3	DISORDERS	475	0.32	40.91	0.00
4	DISORDER	418	0.28	37.86	0.00
5	DISEASE	433	0.29	33.89	0.00
6	SYMPTOMS	434	0.29	29.8	0.00
7	VERTIGO	259	0.17	29.04	0.00
8	MOVEMENT	260	0.17	28.73	0.00
9	DRUG	38	0.03	-28.66	0.00
10	WHAT	161	0.11	-29.37	0.00

5.2.2 Frequency and collocations

In order to achieve a more refined view of lexical choices, a further quantitative stage of the analysis focused on frequency and collocation of items. First a list of the most frequent lexical words and terms (e.g. the nouns, verbs, adjectives and lexical adverbs) was derived in order to identify the "aboutness" of the corpus:

Table 5. The ten most frequent lexical words

N	word	Freq.	%
1	CHILDREN	1,289	0.54
2	CHILD	1,057	0.44
3	BRAIN	801	0.33
4	SEIZURES	758	0.32
5	SYNDROME	624	0.26
6	EPILEPSY	607	0.25
7	PATIENTS	558	0.23
8	DISORDERS	507	0.21
9	SYMPTOMS	486	0.2
10	DISEASE	472	0.2

As expected, the main focus of the corpus is on “children” and “child”, secondly on “diseases that typically affect the brain”, “related symptoms” and “treatments”. But how are children described in the corpus? To address that, frequency lists for clusters of the words “children” and “child” have been derived.

Table 6. The most frequent three-word clusters around ‘children’

N	Cluster	Freq.	%
1	IN CHILDREN WITH	104	0.04
2	OF CHILDREN WITH	73	0.03
3	CHILDREN WITH EPILEPSY	49	0.02
4	FOR CHILDREN WITH	37	0.015
5	CHILDREN AND ADULTS	33	0.013
6	CHILDREN WITH ADHD	31	0.012
7	CHILDREN WITH ASD	30	0.012
8	CHILDREN AND ADOLESCENTS	23	0.009
9	IN CHILDREN AND	23	0.009
10	CHILDREN S HOSPITAL	21	0.008

Table 7. The most frequent three-word clusters around ‘child’

N	Cluster	Freq.	%
1	THE CHILD’S	88	0.036
2	YOUR CHILD’S	71	0.029
3	THE CHILD NEUROLOGY	48	0.020
4	OF THE CHILD	41	0.017
5	A CHILD WITH	41	0.017
6	A CHILD’S	41	0.017
7	THE CHILD IS	37	0.015
8	TO THE CHILD	34	0.014
9	YOUR CHILD IS	29	0.012
10	FOR THE CHILD	28	0.012

Table 6 showing the most frequent three-word clusters around the noun “children”, points to a preference towards the construction “children with” + [name of the syndrome], that is PF language, while table 7, showing the most frequent three-word clusters around “child”, apparently suggests that impersonal reference to patients- "the child"- is preferred to the personalised form ("your child"). Most occurrences of the form "your child" belong to the first category of collected texts (guidelines for families) which have been already shown to be more user-directed than the other two.

In the light of this premise, PF language – namely the linguistic structure where a personhood noun is followed by a phrase referring to illness or disability – appears as the main option in the corpus. Confirming this evidence are quantitative findings related to the frequency of adjectives such as "autistic" and "disabled", which, instead, are typical of IF language: the corpus offers only 6 occurrences of the locution "autistic children" (see Table 8), 8 of "disabled children", 2 of "autistic child", 2 of "disabled child", along with single occurrences of "Dravet children", "severely handicapped children", and "Canavan child". IF language is also applied in the negative form: "non-epileptic children" and in "normal child or adult".

With respect to the overall cases, expressions belonging to IF language are therefore a minority within the corpus.

Table 8. Concordances of autistic children

1	on strategies and approaches for dealing with young *autistic children*. Both programmes work on understanding autism, building con
2	ut audio-visual cues. Non-verbal communication Some *autistic children* are delayed in their use of language and some autistic adult
3	ort programme to help promote good mental health in *autistic children*. The National Autistic Society EarlyBird Centre is based in S
4	rome, often do not 'look' disabled. Some parents of *autistic children* say that other people simply think their child is naughty, w
5	nds sessions, we will look strategies that can help *autistic children* to: build self-esteem increase confidence reduce anxiety d
6	evidence which indicated that a high percentage of *autistic children* are at risk of experiencing mental health problems in adoles

In one case, PF and IF language are used interchangeably:

(18) The EarlyBird Healthy Minds programme is a six-session parent support programme to help promote good mental health in *children with autism* (including Asperger syndrome).

(19) The EarlyBird Healthy Minds programme is a six-session parent support programme to help promote good mental health in *autistic children.*

In other cases, however, if we have a close look at the co-text, we can notice that the instances of IF language seem to be surrounded by terms which evoke a negative scenario:

(20) A 2016 study found that neurotypical people often quickly develop a *negative bias* towards autistic people in face to face social situations. However, these biases were not present when the conversation took place without audio-visual cues. Non-verbal communication. Some autistic children *are delayed* in their use of language and some autistic adults *don't use speech*. In those cases, *other methods* of communication need to be established.

(21) Healthy Minds has been developed in response to recent evidence which indicated that a *high percentage* of autistic children *are at risk of experiencing mental health problems* in adolescence and adulthood.

(22) Autistic people can find *any kind of change difficult*, but there are many things you can do to support them.

Conversely, occurrences of the form "children with" + name of the syndrome or disease amount to almost 200 in the corpus: "children with epilepsy" (48), "children with ADHD" (29 instances), "children with ASD (30), "children with NF1" (13), "children with Dravet Syndrome" (13), "children with autism" (12), "children with DLD" (10), "Children with Lennox-Gastaut syndrome" (7)/ Children with LGS" (6), "children with TS/TSC" (8). It is also worth noticing that the structure "children with" + [name of the disease] is not used most often in the case of autism: the predominant form is children/child/adults/people + "on the autism spectrum", with 36 overall cases. Also belonging to the syntax of PF language, and already highlighted as prevalent, is the locution "children who have"+ [name of the disease], which occurs 8 times here.

Syndromes are often identified by means of acronyms: a choice to be interpreted in terms of simplification, since one of the common criticisms against PF language is that it forces language into long and clunky stretches of words (Collier 2012a). However, the use of acronyms can also be read as a way to mitigate stigma surrounding diseases, by means of implicitness. Abbreviations make communication more rapid and smoother, and indeed can contribute to building community- in the present case, they can create a sense of belonging among parents of children with rare diseases, who can easily read these acronyms and do not need glosses – but they can also keep at a distance those who are not familiar with this technical "jargon" and, more or less intentionally, are excluded from communication.

6. Conclusions

The objective of the present study was to explore the lexical quality of the information available in web resources for parents of patients affected by neurological disorders. Starting from the assumption that it is of paramount importance to adopt a meaningful and respectful communication towards this very sensitive category of users, the analysis focused on aspects of discursive indexicality, that is on the range of expressions used to identify patients and index different aspects of positive vs. negative representation. Special attention was given to the use of person-first vs. identity-first language, with the aim to assess their relevance in the overall communication.

The results of the analysis show in the first place a decreasing degree of personalisation across the three categories of collected texts: from very user-oriented and engaging communication in guidelines for families to the "detached" perspective of clinical descriptions of syndromes. This is possibly an aspect which may be related to difference in authorship: attentive and engaged authorship (carers, health counsellors) vs. detached and impersonal authorship (paediatricians). Moreover, the keywords related to the third sub-corpus point to an intense degree of specification and are also often associated with a negative semantic prosody, as attested by the presence of words charged with an unfavourable connotation, like *disorder*, *disorders* and *disease*.

As expected, the main focus of the corpus is on "children" and "child", and secondly on diseases that affect the brain, related symptoms and treatments. Children are mainly referred to by means of PF language, which can be said to reflect a respectful attitude towards what is considered a sensitive readership. This is further confirmed by the use of acronyms, used to simplify the syntax of PF language, but also to possibly mitigate the stigma surrounding the diseases and indeed contribute to building a community of people sharing their own jargon.

Finally, concerning the degree of accuracy, alteration or bias of the content provided, we can say that while engagement strategies are deployed in the "guidelines for families" to improve the quality of the information provided and increase the readers' involvement, a more detached attitude is displayed in the other two sub-corpora, and especially when the symptoms of the various disorders are dealt with. Moreover, in this latter part of the corpus, the detached attitude that characterises its texts is reinforced by the presence of 5 out of the 6 occurrences of IF language connected with autism. The noun group "autistic children" is often found in the near proximity of words with a somewhat negative connotation. However, this does not mean that it is used to emphasise the stigma towards the people affected by this disability. On the basis of the evidence collected thanks to the present analysis, it is in fact possible to claim that it simply reflects a rather impersonal attitude, which, as such, cannot but dwell also on the negative sides associated with disorders, and bears no traces of the empathy characterising other texts.

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"I am going on a ketogenic diet". Communicating dietary requirements for pediatric patients

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ABSTRACT

The aim of this paper is to examine the popularizing strategies adopted in the websites of the *Matthew's Friends Foundation* (UK) and the *Charlie Foundation* (US), which promote information on the ketogenic diet (KD), a dietary treatment for intractable epilepsy. The study is part of a wider project meant to explore how knowledge is mediated to patients and their caregivers. The analysis uses discourse and corpus tools to explore the main differences between the two foundations in the use of knowledge dissemination strategies and in the construction of the relationship with the caregivers through the use of multiple textual voices (representing experts and the readers themselves). While focusing on similar aspects and using similar techniques, the two foundations differ in the frequency of use of explanations and question-answer sequences, as well as in the way they interpret their role as mediators of knowledge.

Keywords: ketogenic diet, medical discourse, popularizing strategies, discourse analysis, corpus analysis.

1. Introduction

The Internet has had a major impact on the way specialized knowledge is disseminated among non-experts (see, for example, Garzone 2007; Caliendo 2014; Scotto di Carlo 2014; Bondi 2015). This can also be observed in medical communication for lay people. Indeed, nowadays, health information can be easily obtained from the Internet and mass media (Gotti 2015: 14). The advent of Web 2.0 has redefined the transmission of medical knowledge (called *e-health*) (Dynel 2014), with the social media further reshaping the interaction between specialists and patients (Hawn 2009).

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As a matter of fact, the general availability of information has underpinned a paradigm change: it entails that patients are no longer passive recipients but "informed and activated consumer[s]" (Wolf et al. 2008: 98), thereby modifying the relationship between doctors and patients as well as marking a shift from cure to prevention and health enhancement, but also to self-care (Anderson – Rainey - Eysenbach 2003). In this regard, health popularisation is inherently different from science popularisation. Health communication implies more than a simple knowledge transmission (Harvey – Koteyko 2013). As Turnbull observes: "healthcare information will give practical and pragmatic advice to empower a person, enabling him to understand better his illness in order to manage his condition and even take a more active part in medical decisions" (2015a: 248).

Against this background, health education and health literacy have been brought to the fore: currently, patients' education and their subsequent ability to access and understand concepts related to their health are central. The consequence has been an increase in the "demand for texts that facilitate the transfer of medical knowledge to a wide, non-specialized, heterogeneous audience" (Muñoz-Miquel 2012: 187). As already mentioned, this need is largely met by digital genres.

Alongside discourse-analytic research focused on well-established genres, such as patient information leaflets – PILs – (Van Berkel – Gerritsen 2012; Cacchiani 2013, 2016; Frade 2015; Maglie 2015), consumer medical information leaflets – CMIs – (Clerehan – Hirsch – Buchbinder 2009), pharmaceutical brochures (Coupland – Williams 2002), popular media texts and magazines (Candlin – Candlin 2003; Coupland – Williams 2002), as well as newspapers (Lupton 1992; Seale 2001; Clarke 2006), medical knowledge dissemination has been thence investigated also in digital media, from websites to weblogs, e-brochures, and TED talks (Vicentini 2012; Luzón 2015; Anesa – Fage-Butler 2015; Turnbull 2015a, 2015b; Mattiello 2017; Maglie 2017). Yet, as Cavalieri (2019) points out, there is still a need for empirical research dealing with the intersection of knowledge dissemination and health literacy (Muñoz-Miquel 2012; Briones 2015). The strict connection between inadequate health literacy and patients' low quality of life is now acknowledged, particularly in cases of chronic diseases such as diabetes, HIV/AIDS, or epilepsy (Dray – Papen 2004; Bautista et al. 2009; Turnbull 2015b; Kalichman et al. 2000).

The present paper is part of a wider study of the case of communicating the ketogenic diet to caregivers of pediatric patients. We look at the web-based communicative practices of two major foundations active in the field of the ketogenic diet and compare their knowledge dissemination strategies. This issue becomes central when addressing communication with caregivers, who need to be able to mediate health practices to pediatric patients.

2. Popularisation, epilepsy, and the ketogenic diet

The scarcity of studies on knowledge dissemination and epilepsy is noticeable, if we consider the disabling nature of epilepsy and the fact it is the fourth most common brain disorder. Characterized by continued seizures, epilepsy can be controlled by anticonvulsant medications. However, 30% of patients have refractory epilepsy. If some of them can be treated with surgery, others need viable alternative treatments such as palliative surgery, or the ketogenic diet. The Keto-Diet, from now on KD, "is a high-fat, low-carbohydrate, adequate-protein diet […]" (Stratform – Rho 2004: XV) that dates back to the beginning of the twentieth century. Today, it is widespread especially in the UK and in the USA. As Wheless underlines, when tracing its rich history in the United States: "[I]ts use has increased the last 10 yr, and now it is available at all major children's hospitals (Wheless 2004: 47). As its benefits are still under debate, many stakeholders, including health institutions, foundations, and the press, offer information and guidelines to the parents who want their children to undertake this regimen, and to the adults who need it.

Knowledge of the Keto-Diet is scanty in Italy. That is why the University of Modena and Reggio Emilia developed the *FAR 2015 Project: Exploring Health Literacy in Liaising with Caregivers: The Case of the Ketogenic Diet1* with the aim of investigating the linguistic strategies that can be the most appropriate in informative materials both for the patients and for their caregivers.

The preliminary results are discussed in three papers. Mazzi (2018) analyses two small comparable corpora of web-based materials from significant stakeholders in the debate on the KD, that is, health institutions, charities and the press, subdivided into two sub-corpora: the UK and the Irish websites. The quantitative analysis of phraseology shows that the definition of the diet and its mechanisms are relevant in both corpora. The qualitative study of patterns of argumentative discourse proves that the Irish discourse on the KD is more multifaceted than the UK discourse since

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[1] P.I. of the project: Prof. Marina Bondi, Dept. of Studies on Languages and Cultures – University of Modena and Reggio Emilia. Co- Investigator for the Dept. of Biomedical, Metabolic and Neural Sciences: Prof. Giuseppe Biagini.

citations from influential figures do not simply support the diet but assume different argumentative positions, for instance on the use of diet for cancer patients.

Cavalieri (in press) investigates 38 YouTube videos on KD gathered from the YouTube Channel of *The Charlie Foundation*, a foundation with the aim of providing information on KD. By adopting corpus and discourse analytical tools, the analysis indicates that the experts and specialists rely on "concretization" strategies of knowledge transmission such as scenarios, hypothetical question-answer sequences and exemplifications. In so doing, abstract medical notions are inserted into hypothetical situations that the caregiver might have experienced so as to make them more comprehensible. On the other hand, medical terminology and the associated acronyms are used, hence identifying the caregiver as a semi-expert. The specialists in the videos then use both the singular and plural first person pronouns. They do discursively present themselves as part of a team of either doctors implementing the treatment or researchers reflecting on the mechanisms of the diet. When looking at markers of reader engagement, i.e. the ways writers explicitly orient to their readers (Hyland 2004: 10), it can be noticed that *you* may refer both to the general audience and also to fellow researchers or caregivers interested in the ketogenic diet.

These results on the popularising and engagement strategies are confirmed in another study by Cavalieri (2019), based on a corpus of web-based informative materials, called the *Keto-Corp*. They are taken from the websites of the two major foundations providing information on the ketogenic diet: the *Matthew's Friends Foundation* for the UK and the *Charlie Foundation* for the US. The analysis corroborates the tendencies identified in the previous study: the use of concretization strategies, of technical language, and of *you*. Both charities also use the pronoun *we* for self-reference as an inclusive strategy suggesting empathy with caregivers, and thus facilitating knowledge dissemination. Impersonal forms typical of research papers (*it* constructions) are also sometimes employed in order to scientifically support the information provided to caregivers.

The present paper is part of this strand of research. Starting from Cavalieri's cross-sectional study of the web-based materials of the two foundations, we aim to address the following questions: What are the main differences in the use of the strategies of knowledge dissemination between the two foundations? Is there any difference in their relationship with the caregivers? In particular, how do they use explanation strategies and textual voices (in particular, citations and question-answer sequences)?

The rest of the paper is structured as follows. In Section 3, the materials and the methodological framework are described. The findings of the analysis are discussed in Sections 4 and 5, then followed by some preliminary conclusions.

3. Materials and methodology

3.1 Corpus

The corpus is composed of web-materials found in the websites of the two most relevant UK and US foundations devoted to the diffusion of information and guidelines on the ketogenic diet, respectively *Matthew's Friends* (https://www.matthewsfriends.org) and *Charlie Foundation* (https://charliefoundation.org*)*.

Matthew's Friends is a registered charity founded in 2004 by Emma Watson, who insisted for years to have her son Matthew treated with the KD but whose doctors always denied its positive effects. As expressly stated in its homepage, the aim of the charity is "to support patients, families and professionals by providing information, training, research and grants to develop ketogenic services and support systems for drug resistant (refractory) epilepsy as well as other neurological and metabolic disorders and emerging cancer types".

The story behind *The Charlie Foundation for Ketogenic Therapies* is analogous. It was founded in 1994 inspired by the story of Charlie Abrahams, whose parents decided to treat him with the KD. Its goal is similar to that of the UK charity.

The *Keto-Corp* was collected in June 2017. It consists of 44,030 tokens and is divided into three sub-corpora. The first one is named *Dietary Treatment* and it includes all the webpages presenting the different types of ketogenic diets (the classic ketogenic diet, the Modified Atkins, and the MCT – medium chain triglyceride C – diet). The second is termed *Guidelines* and it offers caregivers a description of the different steps to follow and to adhere to the diet, especially in the case of children. The third, *Syndromes*, deals with neurological diseases and syndromes that can cause refractory epilepsy and that can be treated with the ketogenic diets.

As recognized by Cavalieri (2019), from a quantitative point of view the corpus might be seen as too small according to the thorny principle "the larger the better" (Sinclair 1991), but it includes a large proportion of the data on the issue existing at the moment. Additionally, as argued by Vaughan and Clancy (2013), small domain-specific corpora are a rich resource for establishing the range and frequency of certain linguistic items but also for observing their use in different contexts.

Since the aim of the paper is to compare knowledge dissemination in the two Foundations, the analysis was carried out considering the two sub-corpora constituted by the materials of the two distinct websites, more specifically, *Matthew's Friends* (36,626 tokens) and *Charlie's Foundation* (7,404 tokens). Quantitatively, the considerable disparity in size between them is overcome by the fact that data can be normalized, and are in fact normalized, i.e frequencies are calculated per 1,000 words, for statistical comparison.

3.2 Methodology

The methodology is grounded on different approaches to popularising strategies. The first one is Calsamiglia and van Dijk's classification of six "types of explanation" (2004: 372):

a. *Denomination* or *Designation* so that new terms are introduced indicating their specialized denominations (2004: 381);
b. *Definition*, linked to denomination, involves the explanation of unfamiliar words by describing properties or components of the thing being referred to (2004: 375);
c. *Reformulation* or *paraphrase,* often signalled by appositions, parentheses, dashes, quotes and metalinguistic expressions, underline, "establish a link between old and new knowledge, where usually a new notion is introduced first, followed by an explanatory reformulation or paraphrase" (2004: 383);
d. *Exemplification* involves specific examples of general phenomena "such as mentioning Alzheimer's as one of the diseases that might be better understood now that the human genome has been sequenced" (2004: 383);
e. G*eneralization* in which general conclusions are drawn from specific examples (2004: 383);
f. *Analogy* or *Association* (2004: 376), namely, comparisons with objects cognitively familiar to the layman or easily understandable, such similes or metaphors.

A further focus of the analysis lies in the multiplicity of textual voices involved in knowledge dissemination and how these are used as strategies of dissemination. An element of interest – facilitating understanding and potentially involving these several voices – is provided by the use of questions as engagement markers (Hyland 2002, 2004: 21, 2005). Web-users are often addressed directly by using questions (Cavalieri 2019), but these often turn out to be their own potential questions. Engagement is seen here more in terms of positioning the reader than just emphasizing a connection between the reader and the writer: "Positioning the audience involves predicting and responding to readers' possible objections and alternative viewpoints. By anticipating their readers' questions and objections, writers can predict and head off criticism as they lead them through an argument" (Hyland 2004: 17). The present analysis, therefore, includes *wh*-questions and *yes/no* questions as engagement markers and looks at their structure and functions. While keeping in mind that *wh*-questions often express "an imbalance of knowledge between participants, [they help] to construct readers as learners, and learning as a one-way transfer of knowledge" (Hyland 2002: 535) from expert to non-expert, it is important to consider how these questions contribute to constructing the audience in terms of knowledge, interests, personal experience, needs etc.

The use of citations, or reported discourse in general, can also be seen as a relevant feature (see also Mazzi 2018), as it contributes to guiding the audience into an understanding of the relevance and credibility of the information provided. The present study focuses on citation styles and on the types of voices involved in the citations.

The classification of citation types adopted here integrates Calsamiglia and López Ferrero (2003) with Semino and Short (2004). Calsamiglia and López Ferrero's classification of citation formulae is reported hereinafter verbatim (2003: 155):

a. Direct citation: There is a fracture between the syntax of D1 and D2[2] because it entails the maintenance of two different deictic centers (affecting tense, space and time adverbs and person-reference words), as a result of the two different enunciations being put in relation one to another; the two segments are connected through juxtaposition and they are signalled by graphic markers such as (:);
b. Indirect citation: There is only one discourse, D1, with a single deictic centre, a subordinate clause introduced by a conjunction, and the correspondent agreement of tenses;

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[2] As Calsamiglia and López Ferrero specify: "D1 refers to main discourse by writer 1 (W1); D2, to quoted discourse by writer 2 (W2)" (2003: 171).

c. Integrated citation: it has the form of indirect citation but with segments – of greater or lesser extension – signalled as being cited directly/literally with clear graphic or typographic marking, mainly with quotation marks marked fonts (boldface or italics);
d. Inserted citation: Words of W2 are brought into the main discourse by means of markers such as […] 'in the words of X', 'according to X' which have the function of assigning explicit words to a particular agent (literal or non-literal, depending on the use of graphic signs of quotation) without any communicative verb.

The only variation we introduced was that we considered an additional case, namely, the Narrator's Representation of Speech Act –NRSA(p) (Semino – Short 2004: 52). This is a special case of indirect citation, where there is a summary or report of the speech act without a separate reported clause (including both cases where the topic is specified and cases where it is not, as conventionally signalled by the letter p in brackets). This type of citation is characterized by a high degree of interpretation of the reported source on the part of the author of the reporting discourse.

When analyzing the reporting format, we also considered the types of voices presented, using an adapted version of Thompson's (1996) classification, which included:

a. Self (the voice of the foundation or of the web-community);
b. Specified others (patients/ caregivers/ official guidelines/ research studies);
c. Unspecified others (unspecified studies or impersonal sources, with *it* + passive form);
d. Community (folk-quotes) (1996: 509).

The corpus was annotated using the UAM corpus tool (O'Donnell 2008a, 2008b), a free software for the annotation of text corpora. It is a system for manual and semi-automatic annotation that enables users to tag segments of texts. Two types of annotation are supported: assigning features to texts as a whole and assigning features to segments within each text. Users can define their own multi-layered coding scheme, based on "project". As O'Donnell points out (2008b: 13): "To overcome the complexity of dealing with multiple source files annotated at multiple levels, the main window of the CorpusTool is thus a window for project management."

Therefore, the first step was to start our project, *Ketostrategies*, by uploading the text files to the project. Then, the corpus was annotated at a document-level by subdividing the individual texts firstly according to the different sections and then according to the websites.

Figure 1. Document-level annotation scheme

Afterwards, a segment-level annotation scheme was created with the popularizing strategies, the types of questions, and forms of speech and thought representation, with types of voices, so as to compare the popularizing strategies adopted and their recurrence. An annotation scheme was also created for the sources of citations. The texts of the *Keto-Corp* were then manually annotated thanks to a project window that allows annotators to underline the text segments and to assign tags to the selected segments. Multiple tags can be assigned to each segment. The corpus tool automatically performed a chi-square test for the comparisons and specified those strategies that are statistically significant.

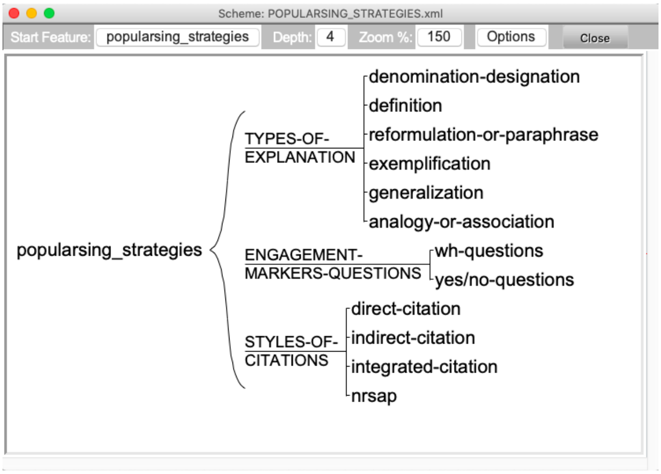
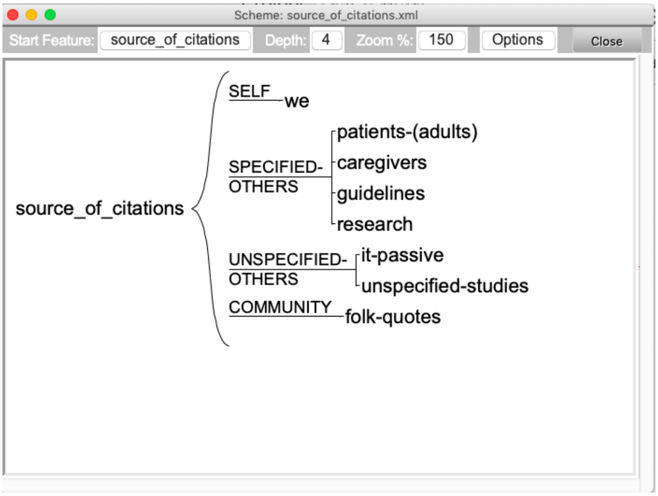


Figure 2. Segment-level annotation scheme



Scheme: source_of_citations.xml

Start Feature: source_of_citations

Depth: 4

Zoom %: 150

Figure 3. Source of citations annotation scheme

4. Findings: Types of explanations

Table 1 reports the frequencies of the explanatory strategies identified and the relative proportion of the different types.

Table 1. Types of explanations in the Keto-Corp

TYPES OF EXPLANATIONS	*Matthew's Friends*		*Charlie's Foundation*		Chi-Square	
	N=157		N=50			
Feature	N	Percent	N	Percent		
– denomination-designation	65	41.40%	23	45.10%	0.216	
– definition	22	14.01%	7	13.73%	0.003	
– reformulation or paraphrase	30	19.11%	8	15.69%	0.302	
– exemplification	39	24.84%	11	21.57%	0.226	
– generalization	0	0.00%	0	0.00%	0.000	
– analogy	1	0.64%	2	3.92%	2.922	+ weak significance (90%)
Frequency per thousands words (ptw)	**6.75**		**4.29**			

The analysis of the types of explanation used in the corpus validates previous studies (Cavalieri 2019), as strategies of denomination and exemplification prevail in both websites. The examples of denomination refer to technical vocabulary and acronyms associated with chemical mechanisms and diseases, correlated to the Keto-Diet. They are often found in complex, highly specialized sentences, as in (1) and (2).

(1) Doose syndrome, also known as myoclonic astatic epilepsy (MAE) or epilepsy with myoclonic-atonic seizures, is a rare type of generalised epilepsy that was first described in 1970. (*Matthew's Friends*)

(2) Amyotrophic lateral sclerosis (ALS) also known as Lou Gehrig's disease is a rapidly progressive disease caused by degeneration of neurons that control motor activity in the brain and spinal cord. (*Charlie Foundation*)

The technicality of these denominations is in contrast with the second most frequent strategy – exemplification – where tangible instances of food, medicines, or possible side effects are given, in a process that is rather one of concretization (Cavalieri 2019). Caregivers can more easily recognize and understand scientific elements and processes by linking them to something they are familiar with and the situations they have to face daily, as in examples (3) and (4):

(3) Fat is mainly from foods, such as cream, butter, oil and mayonnaise although products available on prescription can also be useful. (*Matthew's Friends*)

(4) A typical meal includes a carbohydrate source such as small amount of fruit or vegetable, and/ or low glycemic carbohydrate bread or pasta, a protein rich food such as meat, fish, poultry or cheese, and a source of fat such as heavy cream and butter or vegetable oil. (*Charlie Foundation*)

The two other most used strategies are definitions, present in examples (1) and (2) together with denomination, and reformulations, exemplified in (5) and (6).

(5) These names refer to the chemical structure of the fatty acid; both types are unsaturated, that is, they contain carbon-carbon double

bonds, the type is determined by the final double bond being either at the n-3 or n-6 position. (*Matthew's Friends*)

(6) MCT refers to the type of oil (medium-chain triglyceride), which produces ketones more easily than LCT (long-chain triglyceride) fat. This means that less total fat is needed, thus allowing more carbohydrate and protein to be included in the regimen. (*Charlie Foundation*)

Once again the strategies somehow oscillate between the necessity of giving caregivers scientifically precise information and the need to make this information comprehensible and applicable to their specific problems. In fact it should be noted that the reformulation in example (5) offers a more detailed and scientific explanation rather than a more understandable clarification of what *unsaturated* means. On the other hand, the specialized description in example (6) is reformulated in terms of implications and practical applications for the diet.

The quantitative data in Table 1 also show that the distribution of the types of strategies in the two websites is quite uniform. Variation is noticeable for the use of analogy, but the figures are so low as to prove hardly meaningful. The American website exploits analogy twice in the sections dealing with the syndromes the Keto-Diet can treat: the first time when explaining mithocondrial disorders paralleling mithocondria with a powerhouse, giving fuel to our body (7); the second time when paralleling the physical state generated by the diet to fasting (8). Conversely, *Matthew's Friends* used it once in a more generic way (9), referred to the ability of implementing the diet as a form of learning.

(7) Mitochondrial disorders Mitochondria are the powerhouse of providing energy in our cells. (*Charlie Foundation*)

(8) The ketogenic diet, because of its very restricted carbohydrates and limited proteins, forces the body to use fat rather than glucose as an energy source and thus produces a metabolic state similar to fasting. (*Charlie Foundation*)

(9) However, like learning any new skill, the whole process becomes very much easier in time and if symptoms start to improve, the sense of empowerment can be immense. (*Matthew's Friends*)

On the whole, then, the analysis of types of explanation strategies shows that convergences seem to be more interesting than divergences. In addressing the patients' caretakers, both websites make recourse to the strategies identified, with denomination and exemplification constituting the vast majority of the strategies, followed by reformulation and definition. They also show that the focus of the explanations is often the same: caregivers and patients have first to be convinced of the benefits of the diet and taught how to expertly implement it.

If we look at the normalized frequencies of these strategies, however, we notice that *Charlie's Foundation* uses them more forcefully, with a frequency of 6.75 per thousand words (ptw) as against a frequency of 4.29 for *Matthew's Friends*. The American foundation thus seems to pay more attention to the need to provide explanations than the British charity, thus possibly highlighting its own role as popularizer of knowledge about the diet.

5. Textual voices

5.1 Use of questions

The use of questions (both *wh-* and *yes/no* questions) is another recurrent popularising strategy. The quantitative data, reported in Table 2, show that once again there are no noticeable formal differences between the two websites: there is rather a remarkable similarity in the proportion of Wh- or yes/no questions.

Table 2. Questions in the Keto-Corp

QUESTIONS	*Matthew's Friends*		*Charlie's Foundation*		Chi-Squ
	N=28		N=46		
Feature	N	Percent	N	Percent	
– wh-questions	18	64.29%	28	60.87%	0.086
– yes/no questions	10	35.71%	18	39.13%	0.086
Frequency per thousand words (ptw)	**0.76**		**6.21**		

As already noted by Cavalieri (2019), the question-answer structure in the corpus evokes potential medical encounters in which caregivers ask a question then answered by a specialist, starting from the very fundamental notions at the basis of the KD. Questions can be found in the titles of the different sections.

(10) Who is ketogenic therapy suitable for? Ketogenic therapy should be considered as a treatment for epilepsy after two appropriate anticonvulsant medications have failed to be effective or produced unacceptable side effects. (*Matthew's Friends*)

(11) How long should I be in the ketogenic diet? We at the Charlie Foundation believe that a 3-month commitment to the diet is the minimum trial period necessary to understand if ketogenic therapy is right for the individual. (*Charlie Foundation*)

Questions creating the scenario of doctor-patient interactions are again a type of concretization, such as exemplification, that helps caregivers and patients recognize situations in which they might have found themselves and resolve their doubts. They are cases connected to concrete problems one might run into when implementing the diet, as in example (12) and (13).

(12) Is there increased risk of side effects when using ketogenic therapy in combination with certain AEDs? Kidney stones and metabolic acidosis are reported side effects of both ketogenic therapy and the carbonic anhydrase inhibitor AEDs topiramate and zonisamide; it has been suggested that concurrent use of these AEDs with ketogenic therapy could further increase risk. (*Matthew's Friends*)

(13) Will my child gain too much weight with this high fat diet? The ketogenic diet is calculated at a specific calorie level for children. (*Charlie Foundation*)

As can be seen from the examples above, questions are often explicitly presented as voicing the worries and doubts of both patients (*How long should I be on a ketogenic diet?*) and caregivers (*Will my child gain too much weight*). Even when they are not explicitly marked as such, they are often presented (even if not explicitly denominated) as FAQs, frequently asked questions, representing the interests of the audience.

In the website materials, the voice of the patient and the caregiver often overlap and cannot be easily distinguished, whereas the voice of the patient becomes prominent only in specific leaflets produced for the children themselves. These are diffused through the web, but they are presented as

PDF leaflets to be used by parents. *Matthew's Friends*, for example, produces and publishes a booklet called "I am going on a ketogenic diet", which is all a Question & Answer sequence more explicitly addressed to children, articulated around a series of questions: *What is a ketogenic diet? How does a ketogenic diet work? How soon will I know if my ketogenic diet is working? How will I feel on my ketogenic diet? Will I feel hungry? Do I have to go into Hospital* etc.

The question and answer sequences in the website pages are rather didactic questions, guiding the reader through the explanations, offering support in understanding the nature of the diet and providing counterarguments for the potential doubts that caregivers might have. Yet, they also allow the Foundation to package more persuasive input in the supposed response, to present itself as being able to help patients and their families, to find new solutions or even just to encourage further exploration of the site.

Both formally and functionally, then, the two websites seem to follow very similar patterns. In terms of frequency, however, the difference between the two websites is marked, and significantly so: 46 occurrences of questions in 7.404 tokens represent a normalized frequency of 6.21 ptw for *Charlie's Foundation*, whereas 28 occurrences in 36,626 tokens represent a normalized frequency of 0.76 ptw for *Matthew's Friends*. The difference is striking, but the data can be interpreted in different ways, of course: on the one hand, the American website can be seen to be much richer in dialogic question and answer sequences; on the other, it can also be seen to be more directive in guiding the reader's interpretation of the information provided through this insistent pattern.

5.2 Other textual voices

Both websites are characterized by the use of citations whereby different textual voices can be heard. From an argumentative point of view, this plurality of voices invariably ends up supporting the use of the Diet as an effective therapy. This can be noted also in the sections referring to brain tumor, unlike what happens with the Irish informative materials studied by Mazzi (2018), in which the relation between the ketogenic diet and brain cancer is controversial. Given the non-dialectical nature of their argumentation, these voices orchestrate what could be called a symphonic (Bondi – Yu 2018) rather than a polyphonic "layering of voices" (Güthner 1999), in that all these voices are aligned and take the same stance.

The data in Table 3 show that this time there is no marked difference in the frequency of citations: the frequency is 5.60 ptw for *Matthew's Friends* and 4.46 for *Charlie's Foundation*. The difference lies rather in the preferred format.

Table 3. Styles of citations in the Keto-Corp

STYLES OF CITATIONS	*Matthew's Friends*		*Charlie's Foundation*		Chi-Square	
	N=205		N=33			
Feature	N	Percent	N	Percent		
– direct citation	14	6.83%	2	6.06%	0.027	
– indirect citation	70	34.15%	14	42.42%	0.853	
– integrated citation	1	0.49%	2	6.06%	7.093	+++ High Significance (98%)
– inserted citation	1	0.49%	5	15.15%	24.871	+++
– NRSA(p)	119	58.05%	10	30.30%	8.815	+++
Frequency per thousand words (ptw)	**5.60**		**4.46**			

The comparison between the two websites shows that if both websites do use direct and indirect citations (14 and 15), *Charlie's Foundation* significantly also includes forms of inserted citation (16) and integrated citation (17).

(14) Their research and others suggests a possible mechanism by which the glucose transporter deficiency may lead to neurodegeneration. (*Charlie Foundation*)

(15) "Together, these behaviors represent the complement of core symptoms used to diagnose autism, and all were reversed by the ketogenic diet (http://www.plosone.org/article/info:doi/10.1371/journal.pone.0065021)," said Masino. (*Charlie Foundation*)

(16) Similarly, the current federal dietary guidelines for American adults recommends "fruits, vegetables, whole grains, fat-free and low-fat dairy products, and seafood" and discourages "solid fats." (*Charlie Foundation*)

(17) According to the Physicians Committee for Responsible Medicine, avoiding saturated fats and eating a diet rich in carbohydrate from vegetables, legumes, whole grains and fruit are key recommendations to prevent Alzheimer's disease. (*Charlie Foundation*)

A major difference between the two sub-corpora lies also in the fact that *Matthew's Friends* depends more than *Charlie's Foundation* on the highly interpretative Narrator's Representation of Speech Act, as Table 3 suggests. This higher frequency, however, should be seen in the light of the types of the sources quoted. In both websites voices are always *specified* (Thompson 1996: 508), as the citations are summaries of studies of research groups or guidelines mentioned within the text. Yet, they are different. Interestingly enough, in the ten examples of NRSA(p) in the *Charlie's Foundation* website, all the references are links to webpages or online PDFs in brackets so that caregivers and patients can easily have direct access to primary sources, as in example (18):

(18) In 2007 the University Hospital of Wuerzburg in Germany (http://www.biomedcentral.com/con - tent/pdf/1743-7075-8-54.pdf) published the first 16-patient pilot study looking at the effects of a ketogenic diet on patients with advanced metastatic brain tumors. (*Charlie Foundation*)

The accessibility of primary information seems to be a major concern of the American foundation. It also concerns ensuring full comprehension by everyone, independently from his or her familiarity with the ketogenic diet. As a matter of fact, the website does not seem to be addressed only to semi-expert caregivers and patients but to neophytes too, as the references to Wikipedia attest (19):

(19) This theory has been tested on a case-by-case basis with the first publication in 1995 (http://www.sciencedirect.com/science/article/pii/S0002822395001891) of two young patients receiving an MCT (medium-chain triglyceride) (http://en.wikipedia.org/wiki/Medium-chain_triglyceride) based ketogenic diet therapy. Both patients had high-grade brain tumors (astrocytomas), unresponsive to standard treatments, and were expected to succumb to these tumors. (*Charlie Foundation*)

Sources of NRSA(p) citations in the website of *Matthew's Friends*, on the other hand, have a more academic format. The source is either indicated with the author-date system (20) or indicated by a number (21) with the list of references at the end of the webpage. The reader is not directed to the source text or supported in understanding it:

(20) Children on a ketogenic diet will have regular blood monitoring to check nutritional status. This should include fat-soluble vitamins due to the risk of high levels of vitamins A and e (Christodoulides et al, 2011). (*Matthew's Friends*)

(21) Raised blood lipids may trend back to normal with time on treatment (17) and dietary modifications can also help to achieve healthy levels (18). (*Matthew's Friends*)

When considering the types of voices, it soon becomes apparent that the sources are predominantly research studies in both websites, as shown in Table 4.

Table 4. Sources of citations in the Keto-Corp

SOURCES OF CITATIONS	Matthew's Friends		Charlie's Foundation		Chi-Squ	
	N=205		N=33			
Feature	N	Percent	N	Percent		
– Self (we)	5	2.44%	0	0.00%	0.822	
– Specified others (patients)	2	0.98%	0	0.00%	0.325	
– Unspecified others (it-passive)	4	1.95%	0	0.00%	0.655	
– Community (folk quotes)	15	7.32%	0	0.00%	2.577	
– Specified others (caregivers)	3	1.46%	3	9.09%	6.729	+++ High Significance (98%)
– Specified others (guidelines)	8	3.90%	1	3.03%	0.059	
– Specified others (research)	161	78.54%	23	69.70%	1.266	
– Unspecified others (studies)	7	3.41%	6	18.18%	12.004	+++

Only a minority of the textual voices included are *unspecified research* (Thompson 1996: 510) in *Matthew's Friends*. Indeed, some of the indirect citations in the UK website are based on impersonal passive constructions, which are also characteristic of research papers:

(22) […] it is recommended that the following biochemical indices are checked: Full blood count, renal function, liver function, ammonia, bicarbonate, lactate, beta-hydroxybutyrate, urinalysis, capillary blood gases. (*Matthew's Friends*)

(23) However it is suggested that brain cancer cells may not adapt so readily and could be impaired by this shift. (*Matthew's Friends*)

On the other hand, *Charlie's Foundation* is sometimes more inclined to give medical information indicating a general collective source (unspecified studies), so as to make the addressees understand that it is something commonly agreed (24) or so as to suggest that the results of the research are considered more important than the reference to the precise source, which can be somehow irrelevant for the lay audience (25).

(24) Doctors agree that physical exercise, social and mental activity and a healthy diet maximize brain health in the face of Alzheimer's disease. (*Charlie Foundation*)

(25) A small clinical study of seven volunteers with Parkinson's agreed to maintain a ketogenic diet for one month. (*Charlie Foundation*)

Charlie's Foundation also gives more significant voice to caregivers, as can be seen in the proportion of the sources they represent (over 9%). The number of examples, however, is limited: there is only one caregiver's evidence of her experience in an integrated citation (26), whilst the other reference to caregivers and the one to families are inserted in descriptions of studies (27, 28). The three general references to families in *Matthew's Friends* (29, 30, 31) represent a much smaller proportion of their citations:

(26) After two weeks on ketogenic therapy his wife reported "his night terrors and freezing have greatly abated". (*Charlie Foundation*)

(27) In this study, 90% of their caregivers reported improvement in one or more areas including memory, cognition, social interaction, speech, resumption of lost activities, sleep, appetite and vision. (*Charlie Foundation*)

(28) Although the LGIT is less restrictive than the ketogenic diet, about 1⁄4 of families who have used this treatment report that it is too difficult to follow long-term. (*Charlie Foundation*)

(29) […] some families have reported their children not being able to tolerate the very strong varieties – so it may be advisable to use a milder formation. (*Matthew's Friends*)

(30) Electric vaporisers have been recommended by some families. (*Matthew's Friends*)

(31) Some children with seizures cannot tolerate these types of medication and increases in seizures have been reported from some families. (*Matthew's Friends*)

Matthew's Friends, on the other hand, is noticeable for a wider range of voices represented. It is the only one of the two websites that refers to adult patients (32, 33).

(32) Adults also readily report an increase in alertness and energy as positive 'side effects' of the therapy, leading to an enhanced sense of wellbeing and control over day to day life. (*Matthew's Friends*)

(33) However, it is not just a change in the frequency, intensity and recovery from seizures that adults report; many also notice a marked improvement in their alertness, energy levels and wellbeing despite there being no changes in anticonvulsant doses. (*Matthew's Friends*)

It is also characterized by thirteen direct citations that are in fact titles indicating the negative stereotypes surrounding KD for children. These provide substantial examples of the *community* type of source (Thompson 1996: 509), which are dutifully challenged by the text that follows:

(34) "It is unpalatable"
ALL forms of these dietary therapies are high fat, adequate protein and low in carbohydrate and in the early days of the diet the above was true – cups of oil had to be drunk and spoonfuls of butter needed to be eaten – that is NOT the case anymore. (*Matthew's Friends*)

In *Matthew's Friends*, there are also five indirect citations using the plural *we*, mostly used as a form of self-mention, as in the instances of indirect speech in which the charity gives recommendations and suggestions (35):

(35) […] we recommend that you eliminate every other possible cause of increased seizures/lowered ketones before worrying about sun cream, skin cream or shampoo's. (*Matthew's Friends*)

On the whole, considering the styles of reporting and textual voices included, the analysis suggests that the symphony of voices in the two websites produces different emphases. The interplay of different types of voices in the UK website highlights the voice of the foundation itself (contributing directly to the debate, interpreting scientific studies and refuting folk beliefs): the foundation appears particularly concerned with supporting its own scientificity, while evidently addressing a semi-expert audience. The textual voices of the American website, on the other hand, seem to pay greater attention to giving readers direct access to the sources (including research and other caregivers), as well as to catering for the needs of a more diversified audience, whose expertise is not taken for granted.

6. Conclusions

The analysis has shown great similarity, both formal and functional, between the two foundations in terms of the choices of types of explanation and forms of involvement of textual voices. In addressing patients and caretakers, both websites find it important to make recourse to the same types of explanation, with denomination and exemplification constituting the vast majority, followed by definition and reformulation. The need to mediate specialized knowledge also revolves around the same topics: the benefits of the diet and ways of implementing it.

The patterns and function of question-answer sequences are also similar: questions are often explicitly presented as voicing the worries and doubts of both patients and caregivers, whose voices often overlap and cannot be easily distinguished. The questions act as website FAQs (frequently asked questions), guiding the reader through the explanations, offering support in understanding the nature of the diet and providing counterarguments for the potential doubts, while at the same time allowing the foundation to present itself in a positive light and encouraging the reader to explore the site further.

The main differences lie in the frequency of explanation strategies and question-answer sequences in the two websites. The American website shows a much higher frequency of both explanations and questions.

As for citations, there is no significant difference in frequency, but interestingly diverging formal choices, with the American foundation paying greater attention to providing direct access to sources and the British website, on the other hand, highlighting the authoritative, scientific voice of the foundation itself. On the whole, the American foundation thus seems to pay more attention to highlighting its own role as popularizer of knowledge about the diet, mostly guiding the reader's interpretation of the information provided, whereas the British foundation appears more interested in substantiating its claims scientifically and highlighting its direct role in the debate.

The comparison, however, confirms the relevance of these metadiscursive and intertextual elements in the discourse of health communication. The need to mediate knowledge is quite central to the discourse of both websites and the strategies very similar and well-established. Discourse choices show an awareness of the need to engage a multiplicity of addressees, but also of the centrality of caregivers in mediating the information to pediatric patients. They also show awareness of various current opinions on the diet and its efficacy. These differences, however, are not reflected in a dialectical representation of different position, but rather as potential doubts in the mind of the audience, to be dispelled by the text, whereas external voices quoted seem to converge around the procedures advocated.

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Assessing caregiver informative materials on the ketogenic diet in Italy: A textual ethnographic approach

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ABSTRACT

Caregiver informative materials are an important complement to verbal interaction in medical encounters enhancing caregivers' health literacy and this is particularly true when dealing with treatments that are still little known, as is the ketogenic diet (KD) for pediatric refractory epilepsy in Italy. Their value is dependent upon whether they contain useful information from the viewpoint of the caregiver and are easily understood. The present study analyses informative booklets on the KD found in the Italian context, combining an ethnographic and a textual perspective, i.e. textual ethnography (Swales 1998) for assessing the quality of written caregiver information on the KD in Italy. We based our analysis on a two-fold methodology involving an Information Satisfaction Questionnaire (ISQ) and the application of a framework theory created by Clerehan et al. (2005), i.e. the Evaluative Linguistic Framework (ELF). Results show that together with the ethnographic assessment of informative materials obtained through the questionnaire, the analysis of key linguistic features gave important evidence to improve the quality of informational texts for caregivers.

Keywords: Caregivers, informative materials, health literacy, questionnaire, Evaluative Linguistic Framework

1. Introduction

Health literacy is defined as ''the degree to which individuals can obtain, process, and understand basic health information and services needed to make appropriate health decisions'' (Elliot et al. 2007: 525).

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In recent years, the links between literacy and health have received much attention by researchers and policy-makers, since limited health literacy among patients/caregivers has often been associated with poorer clinical outcomes, poorer quality of life of patients due to lack of adherence to the proposed treatment (Dray – Papen 2004; Elliot – Shneker 2008; Bautista et al. 2009, 2015; Filippone et al. 2013) and with higher healthcare costs. The effects of scarce health literacy have already been studied in diverse chronic conditions, such as asthma (Mancuso – Rincon 2006), Acquired Immuno Deficiency Syndrome (AIDS) (Kalichman et al. 2000), and diabetes (Schillinger et al. 2002; Bigi – Rossi 2015; Turnbull 2015).

Few researchers have examined the role of health literacy among epilepsy patients (Elliott et al. 2007; Bautista et al. 2009), although epilepsy is a major neurological problem, diffused in the general population as diabetes mellitus type I (Heinemann et al. 2006). Epilepsy is a chronic brain disorder resulting in an extremely low quality of life. 70% of patients can be treated with antiseizure drugs, but those with refractory epilepsy need alternative cures, such as surgery, or the ketogenic diet (KD). The KD is a high-fat, low carbohydrates nutritional treatment especially used in pediatric patients with intractable epilepsy that has spread in the UK and in the US thanks to the activity of two major foundations: *Matthew's FriendsFoundation* and *The Charlie Foundation*. Since the putative benefits of the KD are still the subject of much debate, these foundations provide clear and exhaustive information to parents considering this therapy on the diverse syndromes that can be treated with the diet. They also give the guidelines to be followed in the implementation of the treatment in order to help parents in making the right choice for their children.

In Italy, knowledge of the KD is still scarce and parents often cannot find adequate information. From these premises, we developed the FAR 2015 – UNIMORE project 'Exploring Health Literacy in Liaising with Caregivers: The Case of the Ketogenic Diet'. The FAR 2015 project was conceived at the University of Modena and Reggio Emilia as collaboration between doctors (neurologists/dieticians in this case) of the Department of Biomedical, Metabolic and Neural Sciences and linguists of the Department of Studies on Languages and Cultures[1], and addressed the recontextualizing procedures involved in written communication with caregivers, who need

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[1] PI of the project: Prof. Marina Bondi, Dept. of Studies on Languages and Cultures – University of Modena and Reggio Emilia. Responsible for the Dept. of Biomedical, Metabolic and Neural Sciences: Prof. Giuseppe Biagini.

to be able to mediate health practices with pediatric patients. The aim of the project was thus to develop a linguistic framework for assessing best practices in informative materials for chronic pediatric patients and their caregivers. The project was based on a case study of the communication of the KD in the UK and US by the two major foundations, i.e. *Matthew's Friends* and *The Charlie Foundation*. Using a multi-layered methodology, the study envisaged 4 main phases: a) investigating the role of genre theories in developing a framework to critically appraise doctor-caregivers written communication; b) exploring best practices in UK-US informative materials by analysing the textual genres (both traditional and computer-mediated genres) and the discursive strategies used; c) analysing the Italian context and the reception of already existing materials by caregivers[2]; d) adapting UK-US communicative best practices to the Italian context to create new materials in collaboration with the dieticians of the Department of Biomedical, Metabolic and Neural Sciences (e.g. a booklet, the website, the YouTube channel, the app).

A body of discourse-analytic research has examined health information materials (Wall 2001; Finlay – Sarangi 2006; Sarangi 2007), i.e. pharmaceutical brochures (Coupland – Williams 2002) and leaflets on specific treatments (Clerehan et al. 2005, 2009). Other studies have focused on media texts, such as newspapers (Lupton 1992, 1999; Seale 2001) and magazines (Candlin 2000a/b; Coupland – Williams 2002). According to Dixon-Woods (2001), there have been two main trends in the literature: 1) "patient education", assuming patient incompetence, 2) "patient empowerment", assessing the extent to which printed information facilitates patients' participation to a shared decision-making. When looking at patients'/caregivers' use of (and reactions to) such texts, many recent studies (Molina 2001; Nicholas et al. 2001; Smart – Burling 2001; Eysenbach – Kohler 2002) have taken a cognitive approach focusing only on statistical estimates of readability (Payne et al. 2000) and paying little attention to contextual and institutional aspects of health literacy. Readability formulas tend to assume a direct relationship between average sentence length, number of words and the ability to act upon information received (Dray – Papen 2004: 313), but do not take into account the overall organization of the text, readers' prior knowledge, author-reader relationships, cultural differences (Bruce – Rubin 1988) and

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[2] This phase involved the participation of medical units implementing the KD protocol in their hospitals, i.e. the Policlinico Hospital (Modena), the Meyer Hospital (Florence), the Bellaria Hospital (Bologna), and the "Bambino Gesù" Hospital (Rome).

visual elements. While these factors are key to understanding written texts, there is still need for an analysis of best practices in doctor-caregiver written communication.

Moreover, studies have shown that patients/caregivers have priorities different from those of doctors about the information they wish to receive (Grime et al. 2007; Raynor et al. 2007). Doctors generally ask for written information that helps them save time during consultations. Patients/caregivers, on the other hand, wish for information that is easy to understand, straightforward and with non-technical language, but at the same time with sufficient detail to meet their needs. As a consequence, to enhance the value of written information for caregivers, obtaining patients/caregivers' feedback is fundamental.

To this purpose, in the FAR 2015 project, we decided to take a social approach to both literacy and language and we proposed a research methodology that combines an ethnographic perspective (Green – Bloome 1997) with textual analysis as developed in the field of Systemic Functional Linguistics (SFL) to take account of the relevant textual elements. While there has been a considerable body of SFL-influenced research into medical discourse, among these studies the majority has focused on oral discourse analysis (see for example Candlin – Candlin 2003). The aim of the current study is to present the results of our reader-focused assessment of the quality of Italian written caregiver information about the KD, which combines the investigation of contextual factors (through the administration of a questionnaire) and the detailed analysis of informative texts (booklets). Thanks to this analysis, some areas of improvement were identified and have been used to create new and more suitable informative materials for caregivers.

The paper is organized as follows: section 2 describes the data analysed and the methodologies adopted; in section 3, results of the analysis are presented; finally, in section 4 some conclusive remarks are offered.

2. Methods and materials

Our approach to the study of caregivers' health literacy can be described as a 'textography' (Alexander 2000) or a 'textual ethnography' (Swales 1998) of health literacy events. By 'textual ethnography' we mean an ethnography that concerns the mediating role of (written) texts in social events, such as healthcare encounters. What makes our approach different from more conventional ethnographies of literacy is that we rely not only on the observation of the social context in which a linguistic event takes place, but also on the analysis of the texts involved in a healthcare encounter in order to gain a complete understanding of it. To reach this goal, our investigation consisted of two main steps: 1) the administration of a questionnaire assessing the perception of caregivers on the current communicative situation and the informativeness of written materials on the KD (Oppenheim 1992) aimed at highlighting strengths and weaknesses of the communicative practices adopted by the health institution in the implementation of the treatment; 2) an analysis of the KD informative materials provided by the centers and indicated by caregivers involved in the administration of the questionnaire. The analysis was performed adopting the Evaluative Linguistic Framework (ELF) (Cleheran et al. 2005).

2.1 The questionnaire

The questionnaire (see Appendix 1) followed the structure of the Information Satisfaction Questionnaire (ISQ) (Loblaw et al. 1999) and aimed at evaluating the quality of the information under examination considering comprehensiveness, accuracy, credibility, relevance, and suitability. It was administered during three months in 2016 (January-March) with the help of the medical centre's implementation of the KD for pediatric patients with refractory epilepsy, so as to provide a picture of the state of the art of KD informative materials at the beginning of our project. Caregivers could decide to participate in the survey on a voluntary basis and the questionnaire was anonymous. The questionnaire was written using simple language, as was suggested in the guidelines provided by the working group for health literacy of the health section of Emilia Romagna.[3]

The questionnaire was structured into four sections with the following titles: 1) General information; 2) Where did you find preliminary information about the ketogenic diet? 3) Can you evaluate the informative materials on the ketogenic diet given by the centre that follows your child? 4) Suggestions to improve the information for families[4].

In the first section caregivers were asked through multiple choice questions about their gender, age, state of origin (if not Italian they had to indicate how long they had been living in Italy), number of children in the

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[3] http://salute.regione.emilia-romagna.it/news/newsletter/2013/health-literacy-capirsi-fa-bene-alla-salute

[4] All the translations into English are provided by the authors.

family, age of the child on the KD, name of the hospital tracking the child, duration of the treatment and who the person in charge of implementing the diet at home is/was.

Also, the second section contained multiple choice questions and concerned the sources where caregivers had found preliminary information about this diet and about the hospitals offering the KD protocol before contacting a specialized centre. The last question of the second section (directly) asked caregivers about the kind of informative materials provided by the hospital in which their children were/are under treatment (i.e. paper-based materials produced by the hospital; paper-based materials produced by pharmaceutical companies; website\app\YouTube videos of the hospital). This last question could be considered a "bridge" to the third part of the questionnaire where caregivers were requested to directly evaluate the informative materials they were presented.

The third section, in fact, was further sub-divided according to the channel of communication through which informants had received information about the diet (namely, sub-section 1: booklets/leaflets; sub-section 2: website; sub-section 3: app; sub-section 4: YouTube videos). Parents were asked to complete only the sub-section dealing with the informative materials they were provided. Questions in this section were developed on a 5-point Likert scale that ranged from 1= strongly disagree to 5= strongly agree, and were aimed at investigating the quality of the information considering readability, comprehensiveness, accuracy, credibility, relevance, and convenience of use (Pollock et al. 2011). Specifically, caregivers had to give their opinion about the level of informativeness of the materials in terms of preliminary data to help choose (the) treatment, management of the diet, benefits and side effects, when and how to call specialists in case of need, usefulness of the informative materials in motivating families to choose the diet and in increasing confidence in its beneficial effects. The third section ended with a summative part in which caregivers were asked about their overall judgment on the following aspects: information about the KD and about the questions with their overall satisfaction; whether they had had a change in their attitude on the treatment after reading the informative materials; whether they had become more aware regarding the management of the diet; whether the informative materials had stimulated them to continue with the diet; whether the information received had helped them to explain the KD to their children/other people involved in the management of the diet; and whether they would use the informative materials to help another family chose the KD.

The fourth section was developed to gather comments and possible suggestions to improve written information about the dietary treatment, and it included four open questions. Caregivers were asked what they would have improved in the materials they had received, what extra information they would have liked, what was the most and the least useful thing in the informative texts they were given, and lastly what medium of communication they considered the most valuable among those cited in the questionnaire.

2.2 ELF assessment

The second part of our analysis involved the assessment of the materials indicated by caregivers in the questionnaire adopting the ELF developed by Clerehan et al. (2005, 2009). This framework is based upon the theoretical scaffolding of systemic functional linguistics (Halliday 1994) and considers language as a pattern of interlocking systems, from those of the smaller units (e.g. words, phrases) up to those of the larger units (e.g. paragraphs, longer stretches of text). Moreover, to gain a complete understanding of texts, the context should be taken into account. Halliday identifies two types of contexts, namely the context of culture, which deals with the knowledge, set of values and practices of society having an impact on the language used in texts, and the context of situation. The latter consists of the shape of the text in terms of: 1) genre (Swales 1990), that is the macro-structure of the communicative event, 2) tenor, the participants in the communicative event, 3) field, what is being talked about in the text, and 4) mode, the channel of communication. All these elements "knitted together" (Clerehan et al. 2005: 336) are fundamental to interpreting whether a given text is understandable to a reader.

Upon these theoretical premises, Clerehan et al. (2005) developed a framework for evaluating healthcare texts (2005: 337) as shown in the following table:

Table 1. Framework for evaluating healthcare text based upon systemic functional linguistics (Cleheran et al. 2005: 337)

Item	Description	Assessment
Overall organization or generic structure of the text	Series of sections or move in a text (e.g. background, instructions, side-effects)	What identifiable sections of text (moves) are present? Are all essential moves included? What is the sequence of moves and is this appropriate?

Rhetorical elements	The function of each move in relation to the reader (e.g. to define, instruct, inform)	What is the function of each move in relation to the reader? Are these clearly identified and appropriate? Is there a clear guidance about what to do with the presented information?
Metadiscourse	Description of the purpose/structure of the text	Is there a clear description of the purpose of the text?
Headings	Signposts in the text	Are headings present? If present, are they appropriate?
Factual content of texts	Facts included in the text	Is the factual information correct and up-to-date? Is the source of information provided? Is the quality and strength of the evidence discussed?
Technicality of vocabulary	The technicality of the medical terminology/ other vocabulary that is used	How technical is the vocabulary that is used in the text? Is this appropriate?
Lexical density	Density of the content words in the text	What is the average content density of the text (content-bearing words per clause)? Is this appropriate? (e.g. below 3-4 if possible)?
Relationship between the writer and reader	What is the relationship between the writer and the reader (e.g. medical expert to layperson; doctor to his/her patient)?	Is it clear who the writer and intended audience is? Is the relationship between writer and reader clear and consistent? Is the person who is expected to take responsibility for any actions clear?
Format	Visual aspects such as layout, font size, style, use of visual materials etc.	What are the length, layout, font size and visual aspect of the document?

2.2.1 Organization or structure of the text (generic structure)

As for the organization or structure of the text, Clerehan et al. (2005: 336), adopting Swales's approach (1990), argue that different kinds of text generally have a specific genre consisting of a series of sections or 'moves' with a communicative purpose, which can be recognized by the members of a particular audience in a given situation. As a consequence, according to Clerehan et al. (2005: 336) the comprehensibility of a piece of text will also be affected by expectations of which 'moves' are likely to be included, as well as how these are going to be organized, i.e. their order or sequence. For the purpose of provision of written patient/caregiver information about a treatment, there may be some 'moves' that are considered essential and some that are considered useful, but non-essential.

For each informative document about the KD cited in the answers to the questionnaires by caregivers we identified the 'moves' that were present as well as the order in which they occurred.

2.2.2 Function of each 'move' in relation to the reader (rhetorical elements)

As regards the functions of each 'move' in relation to the reader (e.g. to define, inform or instruct the reader), they are called rhetorical elements and their purpose is to influence the behaviour of the reader (Clerehan et al. 2005: 336). In informative materials the rhetorical elements need to be clear in every step of the text, otherwise the reader might be confused and not know what to do or how to interpret the information that is presented. For each informative document about the KD cited in the questionnaire, we distinguished the rhetorical elements in each of the identified moves.

2.2.3 Technicality of vocabulary used in the text

According to Clerehan et al. (2005: 336), the 'technicality' of the vocabulary used in the text refers to the degree of complexity of the medical terminology and/or other vocabulary used. Vocabulary items are generally selected by making assumptions about the intended readers' levels of understanding and their familiarity with particular terms.

2.2.4 Purpose of the text (metadiscourse)

'Metadiscourse' is an umbrella term for words used by a writer or speaker to mark the direction and purpose of a text. It is defined as the language about the text itself and, according to Hyland (2005), metadiscourse reveals the writer's awareness of the reader and his or her need for elaboration, clarification, guidance and interaction. As a consequence, it can support the reader's interpretation of the text. This is particularly important for health informative materials in which the reader needs to be carefully guided to understand the salient parts of the text.

2.2.5 Role relationships expressed in the text

As reported by Clerehan et al. (2005: 337), there are language features in texts that could represent the author's assumptions about the relative status of writer and reader (e.g. expert or lay person). Indeed, texts may be written in different ways to be assertive, directive, conciliatory and/or collaborative, as well as use either less personal (e.g. *the doctor, patients*) or more personal (e.g. *I, you*) language.

2.2.6 The use of headings

The use of headings is a feature that is to be considered important in any assessment of text quality and may be particularly important for patient/caregiver informative materials. Studies of headings show that readers using texts to make informed decisions do not usually read in a linear manner, but skip from one section to another looking for answers to their questions (Wright 1999).

2.2.7 Density of information in the text (lexical density)

A language is made up of what may be called 'content' words (e.g. ketogenic diet, epilepsy, fasting) and 'non-content' words (e.g. with, and, if). The density of information in a portion of text, or 'lexical density', refers to the average number of content words per clause. In general, written language is denser than spoken language, i.e. it has more content words (Halliday, 1985). According to Halliday, the average lexical density for spoken English is between 1.5 and 2 compared with between 3 and 6 for written English, depending on the level of formality of the written text. Unfortunately, few studies have been conducted on this parameter for the Italian language and their results have shown that lexical density values for Italian can be considered similar to those for English (Voghera 2001: 88). A lexical density analysis was performed on each of the KD informative documents cited by caregivers in the questionnaire, and more specifically, only considering the parts explaining the mechanisms of the diet.

2.2.8 Validity of factual content

As argued by Clerehan et al. (2005: 338), the validity of factual content is not an issue of linguistic concern; however, it should be accurate and up-to-date, with a strong evidence base. Hence, reported facts may need to be acknowledged and the source of information identified.

2.2.9 Visual aspects of text

Although not strictly related to the linguistic analysis of documents, the visual aspect of the presentation also needs to be considered in the assessment of the quality of the texts, adopting a multimodal approach (Hartley 1994, Sanson-Fisher et al. 1997, Schriver 1997). This includes the length, format, layout and graphical aspects of the information being outlined (Clerehan et al. 2005: 338).

2.3 Textual materials for the analysis

All caregivers from the centres involved in the investigation were exposed to paper-based information (booklets) about the KD, whereas only the Modena group was also given access to the draft of a/the website and app, as well as to some videos of Keto-recipes created by the dieticians. In order to carry out a homogenous analysis, we decided to take into account only paper-based informative materials and to leave web-based ones to future research. To this end, the centres (see footnote 2) were asked to provide the booklets that health operators give to caregivers during doctor-caregiver encounters and we gathered the three samples in figure 1:

NUTRICIA
Advanced Medical Nutrition

La Dieta Chetogenica
MANUALE INFORMATIVO PER LE FAMIGLIE

AZIENDA U.S.L.
CITTA' DI BOLOGNA
PRESIDIO OSPEDALIERO BELLARIA - MAGGIORE
SERVIZIO DI DIETOLOGIA E NUTRIZIONE CLINICA

LA
DIETA
CHETOGENICA

MANUALE DI AIUTO ALLE FAMIGLIE

SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA
Azienda Ospedaliero-Universitaria di Modena
Policlinico

Trattamento dietetico
dell'epilessia

La dieta chetogenica

Manuale informativo

Realizzato da Dr.sa Dietista Maddalena Marchiò

Figure 1. Paper-based informative materials on the KD offered by the centres participating in the research

As is possible to see in the pictures, the first booklet starting from the left was produced by the medical nutrition company "Nutricia", which offers specialized products (food and therapeutic preparations) for the management of the diet, whereas the second and the third were written by the dieticians of the Bellaria Hospital (Bologna) and the Policlinico Hospital (Modena). In general, the booklets consist of an average of 30 pages and all present a combination of text and images that range from pictures of food, scales and other instruments to tables with data.

In the next sections results from the analysis will be presented. The first part will be devoted to the discussion of the outcomes of the questionnaires, while the second will focus on the analysis of the informative materials.

3. Results

3.1 Results of the questionnaires

A total of 40 families participated in the survey and completed the questionnaire. Specifically, we gathered 25 questionnaires in Modena, 8 in Bologna, 5 in Florence and 2 in Rome. The limited number of the caregivers involved in the study is mainly due to the fact that this treatment is still not widespread in Italy and few people know about it, as mentioned in the introduction; as a consequence, there are still few families who have decided to adopt it for their children. However, it is interesting to trace a profile of the caregivers involved in the survey. They are all parents, most of them mothers (60%) of Italian nationality (77.5%). Only 9 caregivers (22.5%) originate from other countries, namely the Philippines, India, Bangladesh and Maghreb, but they claim to have lived in Italy for more than 10 years. The average age of caregivers ranges from 30 to 40 (60%), but we also find a large percentage of respondents (35%) whose average age is between 40 and 50. According to the survey, their level of education is mixed, with 40% of caregivers who left school after graduating from junior high school, 32% of them with a Master’s degree, and 20% who hold a high school degree. As for the children on the KD, we find that they are mainly girls (65%) and their average age ranges from 4-6 (42.5%) with a consistent portion ranging from 7-9 (32.5%). At the time of the questionnaire, the majority of the children were still treated with the KD (62.5%) and they had been following the treatment plan for 2 years on average, whereas 47.5% had already been weaned and had thus returned to a normal diet. Mothers seem to be the ones most involved in the management of the KD (i.e., cooking meals), but in some families (17.5%) grandparents or nannies were also in charge of respecting the strict dietary rules of this treatment, thus confirming the need for clear informative materials for caregivers other than parents.

Since one of the major goals of the FAR 2015 project was the creation of web-based information on the KD, in the second section of the questionnaire we asked whether caregivers had frequent access to the Internet; the trend recorded by the questionnaire was that 90% of them get online on a regular basis (58.3% every day). However, when caregivers had to tell where they had found the preliminary information about the KD and the centers offering the treatment, we discover that only 15% of them had gathered it from websites or social media. The majority of caregivers, in fact, came to know about the KD either from health institutions they had been in contact with or from word of mouth (52.1% and 21% respectively). As to the last question of the second section of the survey, we asked caregivers about the kind of informative materials provided by the hospital in which their children were/are under treatment (i.e. paper-based materials produced by the hospital; paper-based materials produced by medical nutrition companies; website\app\YouTube videos by the hospital;). The totality of caregivers had been exposed to booklets (either (written) by the company "Nutricia", or by the center itself). Only those belonging to the Policlinico Hospital in Modena were also given videos, and a draft of an app with Keto-recipes produced by the dieticians. In general, the booklets were considered readable (65% of 4 = I agree) and the facts in them understandable (60% 4 = I agree). Nevertheless, these informative materials were perceived by caregivers as containing insufficient preliminary information to allow them to decide whether to choose the KD (70% of 2 = I disagree) as treatment for their children. Moreover, they also indicated a scarcity of instructions on the management of the diet as well as on its benefits and side effects (55% of 2 = I disagree). The overall opinion was that this kind of paper-based informative material was neither satisfactory nor adequate to allow caregivers to make an informed choice (62.5% of 2 = I disagree), since they do not enhance awareness of the various aspects of the treatment and they are not an incentive to follow it (72.5% of 2 = I disagree). Moreover, the booklets were not seen as a valid medium which could explain the KD to other people who might be interested in it (57.5% of 2 = I disagree, and 25% of 1 = I strongly disagree).

On the other hand, the questionnaire pointed out that caregivers of the Modena Policlinico Hospital appreciated the videos with the Keto-recipes and the draft of the app produced by the dieticians (55% of 4=I agree) because they were considered more useful since they give practical help in the management of the diet. Moreover, looking carefully at the results obtained on the booklet distributed by the center of Modena we discovered that caregivers are more satisfied about it (80% of 4 = I like). This booklet was considered particularly useful for explaining the KD to other people involved in the life of the child under treatment.

Moving on to the free comments, they generally showed a need for more information with easy, ready-made facts concerning the everyday aspects of managing the KD (e.g. management of ketosis, what to do in case of…, management of crisis and of side effects, how to explain the KD to teachers in school, recipes). Some caregivers also highlighted that information should be written in plain language suitable for anybody who is considering the treatment for the first time. Furthermore, some parents mentioned that the format and layout of the paper-based documents should be more reader-friendly. Among the informative materials requested, we found that the website would be appreciated because it is perceived as a way to always have updated information and it would cover a wider range of topics than the booklet. Finally, foreign caregivers asked for translated, or at least simplified, versions of informative materials, and for ethnic recipes respecting cultural differences in the use of food.

3.2 Results of the ELF assessment

3.2.1 Organization or structure of the text

The three booklets are 30 pages in length on average, with a combination of text and images. The one produced by the Policlinico Hospital (Modena) has more images than the other two, and also uses symbolic pictures, such as smiles to indicate which type of food is good/allowed in the KD as well as images depicting scenes of everyday life.

The following thirteen possible sections or ‘generic moves’ were identified: ‘introduction to the KD’, ‘general description of the KD, ‘allowed/prohibited food’, ‘how to choose food’, ‘how to measure ketosis’, ‘protocol followed by the centre’, ‘everyday life and the KD’, ‘recipes’, ‘monitoring side-effects’, ‘interaction with drugs’, ‘contacts’ and ‘glossary’. In general, these moves could be identified as discrete segments in the structure of the documents. Table 2 shows the moves identified with their rhetorical function, their presence in the three booklets[5] and provides some examples.

There was a large degree of variability among booklets with respect to the incidence and sequence of the moves. None of the leaflets contained all thirteen moves. The only ‘obligatory’ moves appeared to be ‘general

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[5] MO = Modena, BO = Bologna, PH = Nutricia.

description of the KD, 'allowed/prohibited food', and 'how to measure ketosis'. Only two booklets provided an offer of clinical contact.

Ordering of information was often consistent among the documents.

Table 2. Generic structure of the KD booklets

Moves	Number	Rhetor-icalele-ments	Examples
Introduction to the KD	BO	inform	Le prime applicazioni della dieta chetogenica nelle epilessie infantili hanno avuto luogo negli Stati Uniti, Paese in cui sono ne state concepite le basi teoriche (= the KD was born in the US where its theoretical bases were conceived)
General description of the KD	MO, BO, PH	inform/ describe	La dieta chetogenica è un regime calcolato matematicamente , caratterizzato da elevate quantità di lipidi e ridotto introito di carboidrati. (= the KD is a high-fat, low-carbdiet)
Allowed/ prohibited-food	MO, BO, PH	instruct	Cibi proibiti: carboidrati - pasta, pane e prodotti simili ecc. (= prohibited food: carbohydrates – pasta, bread and similar products)
How to choosefood	MO	instruct	La prima "spesa chetogenica" deve contenere cibi come mascarpone, yoghurt greco ecc. per la preparazione di mousse salate o dolci … (= the first KD shopping must contain food as mascarpone, Greek yoghurt that will be used to prepare savoury or sweet mousse)
How to measureke-tosis	MO, BO, PH	instruct	Il livello di chetosi cioè la quantità di corpi chetonici in circolo può essere misurata direttamente nel sangue (chetonemia) o nelle urine (chetonuria). (= the level of ketosis can be measured in the blood (ketonemia) or in the urine (ketonuria))

Protocolfollowed by the centre	MO, BO	inform/ describe	Come si procede: giorno 1… (= How to start the KD: day 1 …)
Everydaylife and the KD	MO, BO	describe/ instruct	Quando c' è la babysitter, in viaggio, buon compleanno (= with the babysitter, travelling, happy birthday)
Recipes	BO, PH	instruct	Pizza – ingredienti: albume d'uovo, pomodoro, mozzarella di bufala ecc. (= pizza – ingredients: eggwhite, tomatoes, buffalo mozzarella, etc.)
Monitoring side-effects	MO, BO	describe	Stipsi: se la dieta non contiene un adeguato apporto di fibre, la stipsi è un problema frequente. Per evitarla bisogna somministrare liquidi, aumentare l'attività fisica ecc. (= constipation: it is a frequent side-effect if the diet does not contain enough fibers. To avoid it, drink water and increase physical activity, etc.)
FAQ	PH	inform	Se il bambino mangia per sbaglio una caramella che fare? (= what if the child eats a candy?)
Clinicalcontactsavailable	MO, BO	offer	Medico neurologo – tel…, email… (= neurologist – tel…, email…)
Glossary	BO	define/ instruct	Calorie: così si definisce l'energia prodotta in seguito all'ingestione di alimenti … (= calories: it is the energy produced after food ingestion…)

3.2.2 Function of each move in relation to the reader (rhetorical elements)

The function of some rhetorical elements within the moves was uniform among the documents (e.g. *instructing* caregivers about allowed and prohibited food). Some documents included more than one rhetorical element for the same move.

At some points the booklets contained instructions where responsibilities were not clear, such as 'The diet should be stopped after two years at the most' without specifying who would be responsible for making the decision to stop it.

3.2.3 Technicality of the vocabulary

The booklets sometimes contained statements which lacked awareness of the level of understanding of a lay person (cf. Askehave – Zethsen 2003). Such terms included: "organizzazione citoarchitettonica (= cytoarchitectural organization)" "glucogenesi endogena (= endogenous glycogenesis)" and "deficienza di GLUT1 e di piruvato deidrogenasi (= GLUT1 and pyruvate dehydrogenase deficiency)". Also found was semi-technical vocabulary such as "mechanism of action", "dietotherapy" and "use of a concomitant drug", which, while not involving technical terminology, is based on assumptions regarding readers' knowledge or familiarity with specific terms.

3.2.4 Purpose of the text (metadiscourse)

Only one booklet (BO) included explicit information about the booklet's purpose, although it seems to use semi-technical language not easily understandable for lay-people. It began with: "Questo manuale, di lettura comprensibile anche ai non addetti ai lavori per il suo taglio espositivo-pragmatico, […] si cala nelle difficoltà che il bambino e i suoi genitori devono affrontare nella quotidianità […] (= This manual, which can be understood even by those who are not medical professionals because of its expositive-pragmatic approach, […], has the aim of providing solutions to the difficulties faced by children and their parents in everyday life)".

3.2.5 Role relationships expressed in the text

Two documents (PH, MO) used a question–answer format, which shows that the authors had considered the relationship between writer and reader. The question/answer format is commonly used to disseminate knowledge; on the one hand, it facilitates the finding of information, and on the other it provides a framework for the questions to be asked.

All the three booklets, however, tend to use an impersonal style ("si consiglia di…" = 'it is suggested'), or refer to the patient ("il paziente può assumere 4 grammi di lipidi" = 'the patient can take 4 gr of lipids') or to children ("i bambini seguono la dieta 4:1 per circa due anni" = 'the children follow the diet 4:1 for about two years'). It is interesting to notice that, although these documents are expressly addressed to caregivers, the latter are never directly mentioned in the text.

3.2.6 The use of headings

All the three booklets used headings to focus the reader's attention upon the content. Headings were generally considered adequate and appropriate, since they mostly used plain language and avoided technicalities or unclear phrasing. Some of them, however, turned out to be ambiguous, such as "Apporto di energia" (= energy intake) or "Carenze, eccessi e integrazioni" (= Deficiences, excesses and integrations). The formatting of headings was clearly distinguishable from the highlighted words in the body of the text even though both headings and highlighted words within the text were underlined and in upper case.

3.2.7 Density of information in the text (lexical density)

The lexical density (average number of content words per clause) was extremely varied among the three booklets. The PH booklet contained the densest sentences (8-12 content words per sentence); on the other hand, the MO and BO ones had an average of 5-6 content words. The following extract provides an example of high lexical density (lexical items, or vocabulary, are in italics):

> Per il *mantenimento* della *chetosi* è *essenziale* un *basso apporto* di *zuccheri* che viene *monitorato* nel *tempo* tramite la *misurazione* della *chetonuria* (*livelli* di *chetoni* nelle *urine*) e, quando *possibile*, della *chetonemia* (*livelli* di *chetoni* nel *sangue*)" (= For the maintenance of ketosis a low intake of sugars is essential, which is monitored over time by measuring ketonuria (levels of ketones in the urine) and, when possible, ketonemia (levels of ketones in the blood)).

3.2.8 Factual content

One of the documents (BO) specified the sources of information or gave a sense as to the quality and/or strength of evidence to support the information that was provided by adding a reference list at the end.

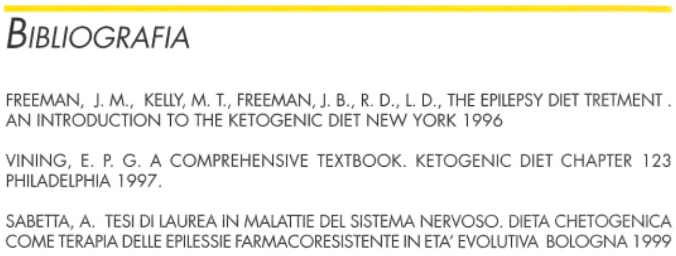

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Figure 2. Reference list in the BO booklet

3.2.9 Visual aspects of text

The three booklets combined different textual styles, including both parts in prose with long paragraphs (seven or more lines) and sections using bullet points, numbers, and dashes. On the other hand, five leaflets used enumeration. They all used the same type of font, i.e. where the order of information was unimportant. Four used a font equal or bigger than 12-point and the formatting was consistent with the presentation of the topics, using bold types or underlined for emphasis. In the BO and PH booklets, titles of different sections featured a bigger font or upper-case lettering. All documents included visual material, with some images as part of the explanation and others simply as decoration (See figure 3 for examples from each booklet.).

1

PIRAMIDE ALIMENTARE DIETA NORMALE

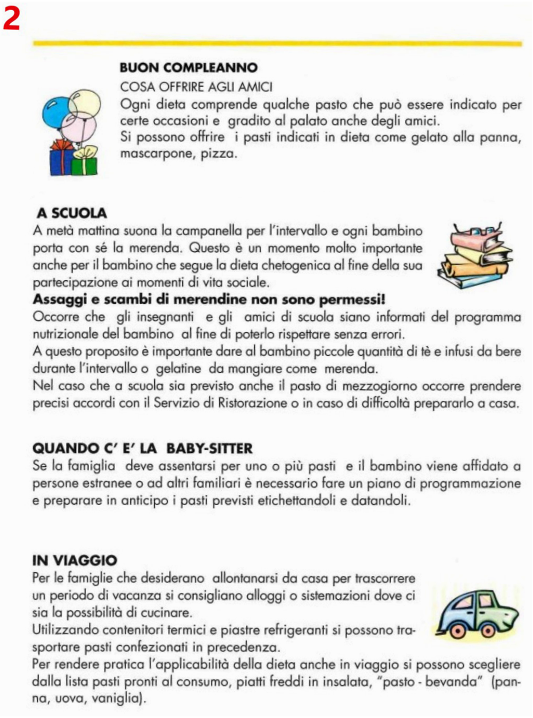
FIGURA 1

La **dieta chetogenica** è una dieta **terapeutica** e pertanto non valgono le regole su cui si basa la dieta equilibrata che segue il modello alimentare mediterraneo. Nella **dieta chetogenica** i grassi rappresentano l'87-90 % delle calorie e gli zuccheri meno del 5% per cui il contenuto è ridotto fino ad un minimo di 10 grammi al giorno. Questo non deve in alcun modo spaventare perché l'organismo si può adattare ad un a dieta povera di carboidrati **(BOX 1)** ma occorre tenere presente che la dieta va sempre impostata e controllata dalla dietista e dal medico specialista in Scienza dell'Alimentazione.

7

Figure 3.1 Example of image in the booklet 1 – PH respectively

2



BUON COMPLEANNO

COSA OFFRIRE AGLI AMICI

Ogni dieta comprende qualche pasto che può essere indicato per certe occasioni e gradito al palato anche degli amici.
Si possono offrire i pasti indicati in dieta come gelato alla panna, mascarpone, pizza.

A SCUOLA

A metà mattina suona la campanella per l'intervallo e ogni bambino porta con sé la merenda. Questo è un momento molto importante anche per il bambino che segue la dieta chetogenica al fine della sua partecipazione ai momenti di vita sociale.

Assaggi e scambi di merendine non sono permessi!

Occorre che gli insegnanti e gli amici di scuola siano informati del programma nutrizionale del bambino al fine di poterlo rispettare senza errori.
A questo proposito è importante dare al bambino piccole quantità di tè e infusi da bere durante l'intervallo o gelatine da mangiare come merenda.
Nel caso che a scuola sia previsto anche il pasto di mezzogiorno occorre prendere precisi accordi con il Servizio di Ristorazione o in caso di difficoltà prepararlo a casa.

QUANDO C' E' LA BABY-SITTER

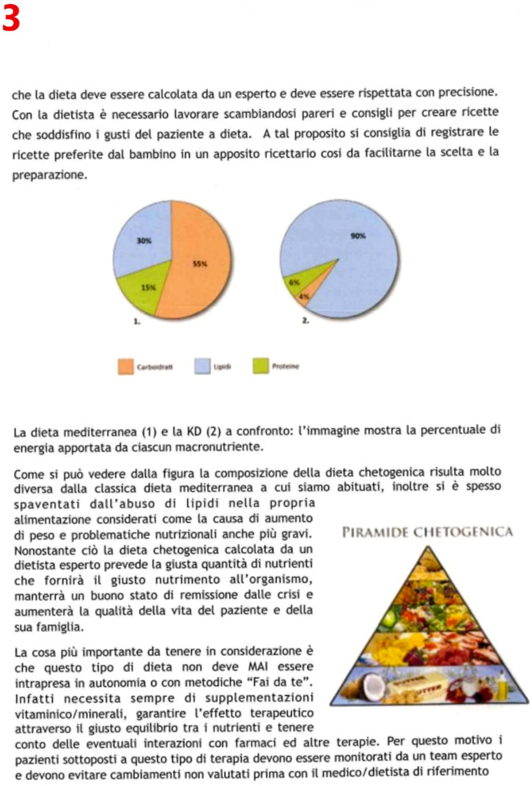
Se la famiglia deve assentarsi per uno o più pasti e il bambino viene affidato a persone estranee o ad altri familiari è necessario fare un piano di programmazione e preparare in anticipo i pasti previsti etichettandoli e datandoli.

IN VIAGGIO

Per le famiglie che desiderano allontanarsi da casa per trascorrere un periodo di vacanza si consigliano alloggi o sistemazioni dove ci sia la possibilità di cucinare.
Utilizzando contenitori termici e piastre refrigeranti si possono trasportare pasti confezionati in precedenza.
Per rendere pratica l'applicabilità della dieta anche in viaggio si possono scegliere dalla lista pasti pronti al consumo, piatti freddi in insalata, "pasto - bevanda" (panna, uova, vaniglia).

Figure 3.2 Example of image in the booklet 2 – BO respectively

3



che la dieta deve essere calcolata da un esperto e deve essere rispettata con precisione. Con la dietista è necessario lavorare scambiandosi pareri e consigli per creare ricette che soddisfino i gusti del paziente a dieta. A tal proposito si consiglia di registrare le ricette preferite dal bambino in un apposito ricettario cosi da facilitarne la scelta e la preparazione.

La dieta mediterranea (1) e la KD (2) a confronto: l'immagine mostra la percentuale di energia apportata da ciascun macronutriente.

Come si può vedere dalla figura la composizione della dieta chetogenica risulta molto diversa dalla classica dieta mediterranea a cui siamo abituati, inoltre si è spesso spaventati dall'abuso di lipidi nella propria alimentazione considerati come la causa di aumento di peso e problematiche nutrizionali anche più gravi. Nonostante ciò la dieta chetogenica calcolata da un dietista esperto prevede la giusta quantità di nutrienti che fornirà il giusto nutrimento all'organismo, manterrà un buono stato di remissione dalle crisi e aumenterà la qualità della vita del paziente e della sua famiglia.

La cosa più importante da tenere in considerazione è che questo tipo di dieta non deve MAI essere intrapresa in autonomia o con metodiche "Fai da te". Infatti necessita sempre di supplementazioni vitaminico/minerali, garantire l'effetto terapeutico attraverso il giusto equilibrio tra i nutrienti e tenere conto delle eventuali interazioni con farmaci ed altre terapie. Per questo motivo i pazienti sottoposti a questo tipo di terapia devono essere monitorati da un team esperto e devono evitare cambiamenti non valutati prima con il medico/dietista di riferimento

Figure 3.3 Example of image in the booklet 3 – MO respectively

4. Concluding remarks

The results of our analysis based on a two-fold textual ethnographic methodology (ISQ assessment and ELF, Clerehan et al. 2005) have proved that written informative materials on the KD can be potentially useful means of empowering caregivers (Dixon Woods 2001) and helping them make a more informed choice about a treatment that would influence their children's lives. However, some of those materials are very lexically dense (8-12 content words per sentence) and in places they contain technical terms and expressions that can be incomprehensible for caregivers with no more than a Junior High school education (40%) or for those originating from foreign countries. Moreover, certain sections of these written documents should be expanded, according to some of the caregivers who completed the questionnaire (i.e. sections on how to deal with side-effects or with aspects of everyday life), and other sections should show a greater respect for caregivers' needs regarding the information they wish to receive (Grime et al. 2007; Raynor et al. 2007). In fact, the booklets seem to be focused more on the medical facts of the KD than on basic information and aspects of the daily management of the dietary treatment; this is also reflected in the impersonal tone of the documents, which creates further distance between healthcare professionals and caregivers. Also, images could contribute much more to facilitating caregivers' comprehension, providing valuable anchoring to their previous knowledge and creating a bridge by which they can acquire new, more technical knowledge, especially in the section with an instructive purpose ('patient education', Dixon Woods 2001). In addition, as highlighted by the answers to the questionnaire, caregivers who had been exposed to web-materials (those followed by the Policlinico of Modena) were more satisfied with them than with paper-based texts (55% of 4=I agree): e-informative documents were considered more useful since they gave practical and "immediate" help in the management of the diet; moreover, the websites can be constantly updated by dieticians. As for the multi-level methodology adopted in the study, it is possible to say that it offers valuable tools with which to improve the quality and effectiveness of informational texts for patients/caregivers, overcoming the limitations of cognitive approaches to readability (Payne et al. 2000) and giving important information on contextual and discursive factors that can be key in the production of informative documents for caregivers.

APPENDIX 1

QUESTIONARIO SUI MATERIALI INFORMATIVI SULLA DIETA CHETOGENICA

Il presente questionario è rivolto ai genitori i cui figli abbiano ricevuto una diagnosi di epilessia farmaco-resistente e che nel loro percorso terapeutico abbiano seguito o seguano tutt'ora la dieta chetogenica.
Lo scopo è quello di indagare la qualità dei materiali informativi che sono stati forniti ai genitori dai Centri che li seguono nell'implementazione della dieta chetogenica.
Tale questionario è un primo step nella raccolta dati del gruppo di ricerca Unimore "Far 2015 – Esplorare la nozione di *health literacy*. I generi comunicativi nella relazione con i *caregivers*: il caso della dieta chetogenica". I risultati di questa ricerca saranno volti ad aiutare i Centri di coinvolti nello sviluppo e produzione di materiali informativi più adeguati alle necessità dei genitori di bambini che seguono il protocollo della dieta chetogenica.

Il questionario è in formato anonimo e su base volontaria ed è indirizzato a tutti i genitori i cui figli siano seguiti presso i centri di Roma, Bologna, Modena e Firenze.

PRIMA PARTE – INFORMAZIONI GENERALI

1. Sesso del genitore che compila il questionario:
- Femminile
- Maschile
- Entrambi i genitori stanno compilando insieme il questionario

- 30-40 anni
- 40-50 anni
- 50-60 anni
- >60 anni

2. Quanti figli ha/avete?
- 1
- 2
- 3
- >3

3. Fascia d'età del figlio/a in trattamento con la dieta chetogenica:
- 0-3 anni
- 4-6 anni
- 7-9 anni
- 10-13 anni
- 13-17 anni

4. **Sesso del figlio/a che segue la dieta chetogenica:**

- Maschile
- Femminile

5. **Presso quale centro è seguito suo/a figlio/a per quanto riguarda la dieta?**

- Pavia
- Roma
- Bologna
- Firenze
- Modena

6. **In questo momento suo/a figlio/a sta seguendo la dieta chetogenica?**

- Sì → da quanto tempo la segue? ____________
- No, l'ha seguita in passato → per quanto tempo l'ha seguita? ____________

7. **Chi si occupa maggiormente della preparazione e gestione della dieta?**

- Madre
- Padre
- Entrambi in egual misura
- ____________

8. **Ha accesso a internet?**

- Sì, quotidianamente
- Sì, almeno una volta a settimana
- Sì, ogni tanto
- No

SECONDA PARTE – COME AVETE TROVATO LE INFORMAZIONI PRELIMINARI SULLA DIETA CHETOGENICA

1. **Dove avete trovato le informazioni preliminari che vi hanno fatto avvicinare alla dieta chetogenica? (scegliere una o più opzioni)**

- Siti web
- Social Media
- Strutture ospedaliere/personale sanitario
- Passaparola
- Materiale informativo cartaceo/brochures
- Altro (specificare)

2. **Dove avete trovato le informazioni utili alla scelta del Centro che vi avrebbe seguito nell'adottare la dieta chetogenica? (scegliere una o più opzioni)**

- Siti web
- Social Media
- Strutture ospedaliere/personale sanitario

- Passaparola
- Materiale informativo cartaceo/brochures
- Altro (specificare)

3. **Che materiali vi sono stati forniti dal Centro che vi segue attualmente nell'adottare della dieta chetogenica? (scegliere una o più opzioni)**

- Materiali informativi cartacei prodotti dal centro stesso
- Materiali informativi cartacei prodotti da case farmaceutiche
- Sito web
- App di elaborazione ricette
- Video
- Altro (specificare)

TERZA PARTE – COME VALUTATE LE INFORMAZIONI OTTENUTE SULLA DIETA CHETOGENICA

Quanto si trova IN ACCORDO o IN DISACCORDO con le seguenti affermazioni? Cerchiare un numero da 1 a 5 dove 1= FORTEMENTE IN DISACCORDO e 5= FORTEMENTE D'ACCORDO

MATERIALE INFORMATIVO		Fortemente in disaccordo	In disaccordo	Non saprei	D'accordo	Fortemente d'accordo
MATERIALE CARTACEO	Le brochure illustrative sono leggibili	1	2	3	4	5
	Le brochure illustrative contengono informazioni facili da capire	1	2	3	4	5
	Le brochure informative mi hanno fornito tutte le informazioni preliminari necessarie alla scelta della dieta chetogenica	1	2	3	4	5
	Le brochure contengono tutte le informazioni necessarie alla gestione della dieta chetogenica (ricette, ecc.)	1	2	3	4	5
	Le brochure informative contengono tutte le informazioni necessarie sui benefici della dieta (nel breve e nel lungo termine)	1	2	3	4	5
	Le brochure informative contengono tutte le informazioni necessarie sugli effetti collaterali della dieta e la loro gestione (nel breve e nel lungo termine)	1	2	3	4	5

MATERIALE CARTACEO	Le brochure informative contengono tutte le informazioni necessarie su quando e come contattare gli specialisti nel caso di problemi con la dieta	1	2	3	4	5
	Le brochure informative sono strumenti utili a motivare le famiglie a continuare il trattamento	1	2	3	4	5
	La mia fiducia nel trattamento è aumentata grazie all'utilizzo di questo materiale informativo	1	2	3	4	5
SITO WEB		1	2	3	4	5
	Il sito web contiene informazioni facili da capire	1	2	3	4	5
	Il sito web ha una grafica che facilita l'accesso alle informazioni	1	2	3	4	5
	Il sito web presenta sezioni di facile navigazione	1	2	3	4	5
	Il sito web contiene un linguaggio adeguato a persone con diversi livelli di istruzione	1	2	3	4	5
	Il sito web mi ha fornito tutte le informazioni preliminari necessarie per la scelta della dieta chetogenica	1	2	3	4	5
	Il sito web contiene tutte le informazioni necessarie per gestire dieta chetogenica (ricette, ecc.)	1	2	3	4	5
	Il sito web contiene tutte le informazioni necessarie sui benefici dieta (nel breve e nel lungo termine)	1	2	3	4	5
	Il sito web contiene tutte le informazioni necessarie sugli effetti collaterali della dieta e la loro gestione (nel breve e nel lungo termine)	1	2	3	4	5
	Il sito web contiene tutte le informazioni necessarie su quando e come contattare gli specialisti nel caso di problemi con la dieta	1	2	3	4	5
	Il sito web è uno strumento utile a motivare le famiglie a continuare il trattamento	1	2	3	4	5
	La mia fiducia nel trattamento è aumentata grazie all'utilizzo di questo materiale informativo	1	2	3	4	5
	L'app contiene informazioni leggibili	1	2	3	4	5

APP	L’app contiene informazioni facili da capire	1	2	3	4	5
	L’app ha una grafica che facilita l’accesso alle informazioni	1	2	3	4	5
	L’app presenta sezioni di facile navigazione	1	2	3	4	5
	L’app è facile da usare con diversi dispositivi(smartphone, tablet, computer)					
	L’app contiene un linguaggio adeguato a persone con diversi livelli di istruzione	1	2	3	4	5
	L’app facilita la gestione della dieta chetogenica nella vita di tutti i giorni	1	2	3	4	5
	L’app facilita la gestione della dieta chetogenica nella gestione di pasti in luoghi pubblici	1	2	3	4	5
	L’app contiene tutte le informazioni necessarie circa quando e come contattare gli specialisti nel caso di problemi con la dieta	1	2	3	4	5
	L’app fornisce strumenti strumenti utili a motivare le famiglie a continuare il trattamento	1	2	3	4	5
	La mia fiducia nel trattamento è aumentata grazie all’utilizzo di questo materiale informativo	1	2	3	4	5
I MATERIALI IN GENERALE	Sono complessivamente soddisfatta/o dei materiali informativi ricevuti dal mio Centro di riferimento	1	2	3	4	5
	I materiali informativi del mio Centro di riferimento hanno cambiato il nostro atteggiamento sulla dieta chetogenica in maniera positiva	1	2	3	4	5
	I materiali informativi ci hanno reso più consapevoli sulla dieta chetogenica e la sua gestione	1	2	3	4	5
	I materiali informativi ci hanno stimolato a far continuare la dieta a nostro/a figlio/a	1	2	3	4	5
	I materiali informativi ci hanno aiutato nello spiegare la dieta a nostro/a figlio/a	1	2	3	4	5
	I materiali informativi mi hanno aiutato a spiegare ad altri le informazioni generali sulla dieta e la sua gestione	1	2	3	4	5
	Utilizzerei i materiali informativi ottenuti dal mio Centro per far avvicinare un’altra famiglia alla dieta chetogenica	1	2	3	4	5

QUARTA PARTE – CONSIGLI e COMMENTI VOLTI AL MIGLIORAMENTO DELLE INFORMAZIONI SULLA DIETA CHETOGENICA

1. **Cosa migliorerebbe nei materiali informativi proposti dal Centro che la segue nell'implementazione della dieta chetogenica?**

2. **Che tipo di informazioni in più avrebbe voluto ricevere che non ha ottenuto?**

3. **Qual è la cosa più utile e meno utile dei materiali che vi hanno fornito al vostro centro di riferimento?**

4. **Quali materiali e che strumenti di informazione ritiene più utili tra quelli citati** (sito web, app di elaborazione ricette, video, materiali informativi cartacei prodotti dal centro di riferimento, materiali informativi cartacei prodotti da case farmaceutiche)

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Parents' narrative about congenital heart diseases: Acquiring knowledge and sharing empathy[1]

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ABSTRACT

This paper tries to describe the narratives of parents with children who have a heart condition and who want to share their experience, as found at healthtalk.org, in order to detect how information, knowledge (and empathy) are deployed with the aim of helping other people in a similar situation to fill a cognitive and emotional gap. The investigation was carried out by detecting the most recurrent discursive patterns in the narratives, followed by an analysis of the most frequently used verb that best expresses parents' cognitive awareness (or lack of it) in their experience with their children with congenital heart disease: *know*. The discourses in these self-narratives follow an emotional flow which varies from story to story but presents a recurrent thread. This does not follow a precise chronological order, as flash-backs and emotions prevail in all the stories, but the main points are found in them all. The analysis of the most frequently used verb, *know*, carried out with Voyant, reflects the described narratives. The leitmotif underpinning all these points is the question of good parenthood: good parents are those who protect their children.

Keywords: discourse analysis, medical popularized discourse, corpus linguistics, empathy, online health communication.

1. Background and aims

I was born with a congenital heart disease which was diagnosed when I was just 6 months old. My parents had no idea why I had it and the only information they had was from the paediatrician who had diagnosed the

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[1] The research on which this study is based is part of the MIUR-funded research project of national interest (PRIN) *Knowledge Dissemination across media in English: continuity*

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disease. They just knew that my only hope of survival was a surgery to be performed in Houston, Texas, USA. When, in 1967, Christopher Barnard carried out the first heart transplant in the world, RAI, the Italian public service broadcaster, aired a late program on TV about that event with a commentary by, at the time, one of the most famous Italian cardiologists, Prof. Renato Donatelli. My father noted down the cardiologist's hospital address and wrote to him. The following month, the cardiologist visited me at Niguarda Hospital, Milan, where it was decided that a surgery could be performed: the following year, when I was 4 years old, I had open-heart surgery. Until the Milan visit, my parents had had very little support, nobody with whom to talk, or people who could give them either medical or psychological support. They were young and desperate; they got relevant information by chance from a TV program and took any decisions they thought were vital by themselves, and on the basis of what they knew. The choice to go to Milan was an odd one and the decision to have me operated on in Italy was taken because they trusted the cardiologist from Milan, who was characterized by an uncommon empathy, as they have always said.

Should this have happened nowadays, things would probably have been completely different. Support groups exist for any health condition and, in this globalized society, getting information is much easier than it was 50 years ago. Web 2.0 has become one of the most powerful resources when it comes to making sense of illnesses and has reduced patients' sense of isolation and their desire to find support (Jaworska 2018). As a matter of fact, if professionals use the Web to deliver information and awareness, laymen use it primarily for peer-to-peer support – which has demonstrated the presence of a disconnect in the use of the Web for medical issues (Robinson et al. 2016). Therefore, carrying out an investigation on the discursive strategies employed by the people who narrate their illness experiences online can be useful, as it may "shed light on what people do when they talk about illness online and how they do it" (Jaworska 2018: 25). The issue, however, is not so much or only to get reliable information, but also to seek and share empathy.

There is a growing body of literature on the dissemination of medical knowledge with the purpose of targeting general and specific groups with health messages (see, for instance, Thurnherr et al. 2016; Turnbull 2015; Daniele – Garzone 2016; Gotti et al. 2015), which is facilitated by online

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and change in discourse strategies, ideologies, and epistemology (COFIN grant no. Prot. 2015TJ8ZAS_002), directed by prof. Marina Bondi of the University of Modena and Reggio Emilia – local coordinator, prof. Maurizio Gotti.

communication, where the distinction between authors and audiences is less clear-cut. In this sense, health professionals are no longer seen as the only providers of healthcare (Harvey – Koteyko 2013). Indeed, in this context, knowledge dissemination is becoming a bottom-up process where laymen reinterpret and re-package medical information (Jones 2013; cf. also Turnbull 2015). While professionals are required to provide reliability and objectivity in health information, (potential) patients "are empowered not only to take more informed and responsible decisions about their health, but to actively contribute to knowledge construction and sharing" (Sokół 2018: 14).

The ways in which illnesses and healthcare are communicated outside doctor-patient interactions have started to be analysed in the literature with increasing interest, particularly in the cases of patients' first-person accounts of serious illnesses, which have revealed a better understanding of the subjective experience of illness (Appleton – Flynn 2014), cancer included, and of the sociocultural aspects of illness that may influence patients' self-perception and social relations (Hanne – Hawken 2007). Indeed, what is important, as also revealed in the corpus I have constructed, is not so much what people say, but rather *how* people – professionals or patients – say what they want to say (Sarangi 2004; Hunt – Carter 2012), which should also include the ways in which people report their illnesses (cf. Demjén – Semino 2017).

One reason why people turn to online health communities for support has been shown to be their desire to share and check relevant factual information (Lamberg 2003), but also to receive and express empathy (Rheingold 1993). As defined by Hojat (2007: 15, quoted in Pounds et al. 2018: 34), "empathy is a vague concept that has been described sometimes as a cognitive attribute, sometimes as an emotional state of mind and sometimes as a combination of both". As a cognitive or emotional phenomenon, empathy is the ability to understand someone's condition or emotional state without making it one's own (Hoffman 1981; MacKay et al. 1990). When empathy is explored from a communicative perspective, the focus is on how this understanding is communicated and how it shapes interactions. The core dimensions of empathy communication in medical settings are described by Pounds (2011), who overviews the verbal realization of empathy from the healthcare professionals' perspective and classifies it into two macro-categories: 1) Eliciting patients' feelings and views; 2) Responding to patients' cues. In this respect, Pounds et al. (2018) have demonstrated how support groups express and perceive empathy in online communication from the interlocutors' perspectives and given their expectations.

The issue of how parents deal with their children's needs and how they must struggle to gain support from the medical and professional community has been dealt with by Brewer (2018), who focuses on the sociological aspects related to (lack of) healthcare and socio-economic support as revealed by parents' – and above all mothers' – narratives. Little, if anything, has been written about the ways in which people narrate their experiences as *parents* dealing with their children's heart issues in order to share their experience and express empathy. To the best of my knowledge, their storytelling has never been properly analysed or investigated. This is relevant, as the analysis of such discourse mediates how people experience their children's congenital heart disease: the ways in which such illness is reported can facilitate or obstruct positive experiences. As Semino et al. (2018) underline, when language works well, it improves information, provisions, diagnoses and support. When it does not work, it creates, of course, misunderstandings, misdiagnoses, frustration, anxiety and disempowerment. It is therefore the aim of this paper to investigate how parents report their children's congenital heart disease with the purpose of providing support (and offering empathy) to other parents in a similar situation. More specifically, drawing on discourse analysis (Jones et al. 2015; Gee 2017), I carried out a corpus linguistics (Bondi – Scott 2010; Baker – McEnery 2015) investigation of the narratives of all the *heart children*'s parents found on healthtalk.org in order to detect how information, knowledge (and empathy) are deployed in parents' narratives in an attempt to help people to fill a cognitive and emotive gap. To this end, an analysis of the discursive patterns of the narratives found will be conducted, as will an examination of the verb that best expresses the parents' cognitive awareness (or lack of it) in their experience with their children with a congenital heart disease: *know*.

Healthtalk.org is a UK website managed by the Oxford-based charity DIPEx, created in order to help and reassure people and give them good advice related to any medical issues. In particular, the main purpose of healthtalk.org is:

- to support patients and their families in the decisions they have to take,
- to help healthcare professionals provide care to patients, and
- to facilitate patient-doctor communication.

The website offers free, reliable information about health issues (such as cancer, autism, neurological diseases, depression etc.) by sharing people's real-life experiences with the aim of helping people who are facing a similar situation and facilitating their decision making about health and treatment;

talking to friends and family; overcoming emotional and practical issues; dealing with any impact the disease may have on work or education.

In order to achieve that goal, this paper will proceed as follows: Section 2 describes the data, methodology and ethics applied in order to carry out the analysis of the findings explained in Section 3, in which data interpretation is also discussed. A conclusion is offered in Section 4.

The results seem to indicate that in these narratives the most recurrent patterns do not follow a traditional chronological order but are rather guided by people's emotional response to stress and trauma and, to a certain point, the societal expectations of good parenthood.

2. Data, methodological approach and ethics

As stated above, the aim of my analysis is to examine how support and knowledge to heart children's parents are communicated. In order to do that, I collected all available narratives from parents whose children are affected by a congenital heart disease which were uploaded to healthtalk.org by the Health Experiences Research Group at the University of Oxford and published by the DIPEx charity (available at: http://healthtalk.org/home). I was able to download 31 interviews and texts whose transcripts are available online (88,489 tokens; 4,100 types).

All downloaded narratives are indicated with the abbreviation CH for *child* followed by a number corresponding to the number of the text found at healthtalk.org, thus CH1, CH2, CH3 etc., which corresponds to the narrative about *child no. 1* family, *child no. 2* family, *child no. 3* family etc.

Consent to use the narratives was not sought from the parents because the terms and conditions of healthtalk.org state that all content published on its site is the sole property of DIPEx and its licensors and the reproduction of any part without written approval is prohibited. Consent to use the data for the purposes of this research was therefore sought from DIPEx, and was granted. Permission to download, use and archive the collected texts from healthtalk.org to carry out the present research was granted by the Health Experiences Research Group and by the DIPEx charity that runs the website.

The corpus thus collected was uploaded to Voyant tools (https://voyant-tools.org). Voyant tools (Sinclair – Rockwell 2016) is a Web-based text reading and analysis environment, an open source project (whose code is available through GitHub under a Creative Commons by Attribution licence), which has been elaborated by Stéfan Sinclair, McGill University and Geoffrey Rockwell, University of Alberta.

In order to carry out discourse analysis and corpus linguistics investigations, all texts were surveyed so as to allow greater contextualization of the content. If a video of an interview or a narrative was available, it was inspected.

All narratives were examined using discourse analysis (Jones et al. 2015; Gee 2017) and a corpus linguistics investigation (Bondi – Scott 2010; Baker – McEnery 2015). The study adopted a *corpus-based* approach (Tognini-Bonelli 2001; cf. also McEnery – Hardie 2012) which – differently from a *corpus-driven* study that explores new categories, frameworks or theories – focuses on existing linguistic categories, frameworks or theories to see whether they can be validated, refuted or refined by the corpus under investigation. Drawing on linguistic research on online health communication (see, for instance, Jones 2010 and Koteyko – Hunt 2016), and in particular digital storytelling (Page 2012), narratives were first examined to identify the existence of common discursive patterns in the construction of empathic discourse, and then scrutinized in more depth in relation to those aspects of *knowledge* via concordance lines, collocates and clusters to unveil the different functions that the verb *know* has in the studied context.

3. Results and discussion

As explained above, the 31 narratives collected from healthtalk.org resulted in a small corpus of 88,489 running words (4,100 types). Examination of all texts revealed a dominant pattern in the narratives: all of them start with statements reflecting the shock parents had at the news of their children's disease. Afterward occur the following components of content, which can occur at different points in the storyline depending on whether parents are recounting a chronological order of events or having flashbacks in their narratives:

- Coping with shock;
- Mothers who blame themselves;
- Looking for support;
- Lack of 'we';
- Parents sharing their experience;
- Winning children.

None of the narratives follow the storytelling framework of Labov and Waletzky (1967) and Labov (1997), which comprises *Abstract*, *Orientation* (comprising *Complication*, *Resolution*, *Evaluation*) and *Coda* stages. The *Abstract*, which prepares listeners for the text that follows and often orients them about the story's themes, is not present in the narratives but is provided via a website link. As to the *Orientation*, which sets the story's reference points (who, when, where, what, why), this is partially given by the DIPEx research team before each text: it is found as a heading before the narrative in the form of background information, such as the diagnosis, child's age at diagnosis, actual health and family situation. The core point of the narrative is represented by the *Complication action*, which in Labov's (1997) terms is the problem culminating in a crisis but differing from the above indicated frameworks. There is not always a *Resolution*, i.e. a way to resolve the crisis, although some children could be operated on (and so there was a *Resolution* for them), others may still need an intervention or be waiting for one (and two other children, unfortunately, died – in this latter case); we cannot see the crisis to be resolved with the children's death as a form of *Resolution*. The *Coda*, which signals the fact that the story is over, is marked as intended by Labov (1997): we do have a shift from past tense to present tense, and yet, instead of having a shift from specific participants to generic ones, we also have a shift from specific participants – the parents – to other specific participants – the heart children.

What is always present and overlapping in all stages is the *Evaluation* phase (Labov 1997). The *Evaluation* is a stage of storytelling which assigns significance to the story (Labov – Waletzky 1967; Labov 1997), as expressed in "the expression of incredulity, disbelief, apprehension about the events on the part of the narrator" (Rothery 1990: 203). It should normally occur between the *Complicating* action and the *Coda*, but in the narratives presented on healthtalk.org it is always found at the beginning of the narratives: it is actually the beginning of the parents' story. Indeed, in terms of *Evaluation*, for all parents the initial shock of discovering that their child has a congenital heart disease mainly means one thing: your child may die. It is with this idea that, after the initial shock, there is a second step, i.e. the re-organization of all family life through the steps indicated above – though not necessarily in that order.

In the following paragraphs, the dominant patterns found in all the narratives will be examined and analysed, and the most significative examples for each of them will be offered.

3.1 Evaluation stage: Shock

All narratives include a storytelling stage in which expressions of shock are revealed, as indicated in excerpts (1)–(5) below, each of them revealing a different degree of shock:

(1) It was very, very hard, it was one of the worst things that I've ever had to go through. At 20 weeks being told that your baby might not even survive, it's horrible. (CH8)

(2) As we say, we were told, weren't we? the last, last January [January 11th] that he had to have this operation and I, I nearly passed out. I just sat in that chair and I was, my head was spinning, I went cold, sweat down my back and I virtually did, virtually passed out I was, I was that close. And all I could hear was everything going on in the background and [my wife] being upset and I was just in a different world […] I was frightened and I was angry and scared. I thought he was going to die, because it's an operation. (CH17)

(3) It's denial really that, yeah, I think it's, I just didn't want to know that there was something wrong with her. (CH23)

(4) And it, it was bizarre, bizarre. I kept thinking 'This isn't really happening.' (CH21)

(5) I suppose, initially, your first reaction is 'Why? Why us? Why my daughter?' That, you know, I think that's a reaction that most people would have. You know, 'Why, why does it happen to us?' You know. And then, I think, I think you have to get over that feeling and we went through many things, it was just, I, I think it was shock. I think we were in so much shock to start with and we couldn't stop crying. None of us could stop crying and I think we were trying to put on a brave face for the children, my husband and I, and trying not to show them too much. But it was just such an emotional time, you know, and it was, it was just so hard to do that. (CH26)

The diagnosis is clearly shocking and difficult to accept. Indeed, parents physically do not want to accept it. In (2), for instance, the shock is so overwhelming that the father "virtually passed out". In (3) and (4), there is a "denial" of the whole situation, and in (5) a sense of impotence because of what is happening to them, to their daughter. As excerpt (5) indicates, the shock is about "why my daughter" but above all "why us? […] why does it happen to us?" The frustration is huge, as there is no answer. It is much bigger in the sense of the moral parenthood (cf. Austin 2016) and responsibility the narrator has: the presence of a congenital disease for which there is no culprit but the malformation itself ("they said that yeah [our daughter] had a hole in her heart" CH26) falls outside the range of parenthood's control over children's care: they can do nothing and yet it is their (social) responsibility to look after their children and take care of them.

3.2 Coping with the shock

Coping with the shock of the child's disease is not easy but it is necessary for the parents because they have to take decisions. Since this type of disease is not common, parents have an urgent desire to get informed. Parents gather information from the right channels – from doctors and specialists, as it should be, and as indicated in the examples below reported in (6) and (7):

(6) There is nobody else who can know better than the doctor. Be very well informed, be very well informed. Read, read, get information there is [the] Internet which has got loads of information. If you don't have access to that information there is so much information available in the libraries. But get information, read, ask questions […] So trust the doctors, go. (CH31)

(7) I think that what I'd say is try and get as much information as possible. Don't be afraid to ask simple questions. Try and make a list of all the questions you want to ask, don't be afraid to go back. (CH10)

Clearly, coping with the shock is not always easy, since the way people react is different. As one of the parents said, "I think we both coped in our own ways" (CH11). Furthermore, the emotional wave may be so devastating that people may miss what doctors say because they are more focused on their children than on medical information, as revealed in (8):

(8) They're great at doing what they're doing but that is your children and you, you've just got no idea of the emotions and everything that you feel from day one and if they explain things a little bit better and tell you about leaflets and help groups that you can go to I think it would help (CH18)

So, in this case, additional information about support groups or where to find information is essential.

All this seems to re-establish the control parents have over their socially-constructed notion of parenthood and the responsibility (Austin 2016) they have for their children: by getting information they can have knowledge about what is going on with their children so that they can protect them in terms of what types of decisions to take or whom to consult, even though they still must rely on doctors to get information, and eventually have their children operated on, on their hearts. In any case, it is parents whom doctors ask for legal consent, and by getting information parents acquire knowledge and hence power.

3.3 Mothers who blame themselves

A ‘good’ mother is a mother who conforms to societal expectations, i.e. one who is aware of her responsibility of protecting her child from harm and promoting health and development (Lupton 2011). Heart children are children who, because they have a congenital heart disease, do not develop well from a physical perspective, and their lives are at risk. Although it is the mother who most of the time realizes that something wrong is happening to her child, and it is thanks to her that the child can be treated, mothers think that their children’s heart disease is their fault:

(9) And in that heartbeat, I thought, ‘Oh my God,’ you know. ‘Does he think, what have I done wrong? Immediate guilt, that, that I’d done something wrong and then, did they think that I’d hurt her, dropped her or, it was some sort of… .’ It was this awful panic. (CH21)

(10) I did go through a stage of thinking it was all my fault and I think everybody does. … And then you start to think ‘Well, it’s my fault. I’ve done something wrong. I shouldn’t have done this, I shouldn’t have done that,’ and the hospital assures me that there’s nothing that causes it. (CH14)

As can be seen in excerpt (9), the mother’s main worry is that her husband believes she has done something wrong, that she is not a good mother. Similarly, in (10), it is the hospital staff who assure the mother it was not her fault, so motherhood has not been compromised. This awareness of others’ judgemental attitudes with regard to the mother’s caring capacities is reflected in the irrational guilt mothers feel for not having been able to protect their children from a congenital disease, which results in an impossibility to conform to societal expectations (Lupton 2011), as explicitly indicated in (11) below, when the mother explains that she decided not to bond with her baby out of fear, and this was “a terrible situation to be in” (my emphasis):

(11) I didn't really bond with my baby at all before he was born because I was afraid to, because I was afraid that I was going to lose him. So, I just didn't want to feel that I was getting too attached to him. **Which is a terrible, a terrible situation to be in.** (CH11)

3.4 Looking for support

In these shocking moments, when parents are afraid for their child's life, when they believe they are not responsible parents and 'good' mothers, and thus think they do not conform to societal expectations, their desire to find support grows. They want to be reassured that everything will be all right, as revealed in (12) and (13):

(12) I just wanted somebody to tell me that she was going to be all, all better, and that she was going to have the surgery tomorrow and when she came out that she'd be absolutely fine and healthy. And that'll be the end of it. (CH23)

(13) All you want is for the doctor or the nurse to say to you, 'Everything's going to be all right. Your baby's going to live and the operation's going to be successful.' And they can't say that. (CH8)

The type of support they are looking for is psychological, from the professionals. Indeed, they would like to find "someone", but not simply anyone, rather a "doctor" or a "nurse", as indicated in (13), who can say that "everything's going to be all right". Yet, according to Fisher (1995) and Sinclair (1997), while nurses are trained to be carers, doctors are trained to be "curers" (Crowe – Brugha 2018: 155). What emerges again is *Evaluation* in the final sentence, "And they can't say that", in (13). This is not so much something said because doctors and nurses need detachment from the family (cf. Crowe and Brugha 2018) but because specialists need to tailor information in terms of what they know and what they do not know – which is the case here.

Parents actually find the emotional and psychological support they need from Heart Associations, liaison nurses and other parents, as indicated in the excerpts below:

(14) So, I do remember people being sympathetic and supportive and appreciating the fact that we were completely unprepared for this. We had no knowledge. And they might have been bombarding me with

a load of information, but I just cannot remember. I just, I just couldn't think straight. (CH9)

(15) I think the most helpful people at that stage were probably the Children's Heart Foundation who were able to send us quite, kind of, clear statistics and put us in touch with other parents, and the cardiac liaison nurse as well, you know, gave [us] telephone numbers of other parents. (CH10)

(16) The British Heart Foundation, they gave us some, an absolutely fantastic booklet that explains everything that you can think of and it was then that we read the symptoms. (CH18)

The support is not simply medical: emotions here find the right empathic 'container', as revealed in (16), where the booklet given to parents was "absolutely fantastic". Elsewhere the "staff were absolutely tremendous" (CH26). The presence of the intensifier *absolutely* and the evaluative adjectives *fantastic* or *tremendous* demonstrates what in their opinion has gone exceptionally beyond their expectations and probably reassured them to a certain extent.

3.5 Lack of 'we'

Together with the desire for support, a sense of isolation grows in and between parents. Both parents are concentrated on their child, who has become the only centre and scope of their life, but such a situation may result in two different conditions.

(17) You, you become selfish in the sense that as a husband and a wife I always put Daniel in front of [my wife]. And vice versa, [my wife] would put Daniel in front of me. And some people could say, 'Well what's wrong with that? You're child's… is absolutely priority'. Yes, but you then build a wall between sets of parents and you need to be together rather than two individuals coping with it. So, you should still take time out to socialise with your friends. You should support each other as well as obviously your family side. Encourage each other to, you know, still go out, go to the pub, go the match, do the normal routines of a married couple. But never ever lose sight of the fact that as parents you were here before the children and when the children came on board. (CH8)

In excerpt (17), above, parents seem to create a wall between themselves as a couple, which may slowly destroy the couple itself. The narrator is no longer thinking about an inclusive *we*, as the example below reveals:

(18) We weren't really sharing and talking about what we were feeling, we were just sort of dealing with it on a day to day basis and not really discussing it, I think I didn't realise what an impact it was making on him and I found out that my husband was actually taking a 'condolence' and talking about it with a colleague at work whereas he, he should have really been talking about it between the two of us. So it was both of our faults really. So it really has made an impact on my marriage. (CH26)

The stress of coping with the situation may have an impact on their life as a couple. In other cases, the narrator thinks about a *we* which is exclusive in terms of socialization: parents simply forget about the world outside the hospital:

(19) When you're in hospital you totally forget about the outside world. (CH20)

Priorities are different, their child is the centre of the world and this is what responsible parenthood requires (Austin 2016).

3.6 Parents sharing their experience

Pounds et al. (2018: 37) have underlined how, in online support groups, expressions of empathetic communication acts can be found, through which people share similar experiences and feelings without any form of advice, such as "I know what it's like being ill." Similar expressions seem to be common in the texts forming my corpus:

(20) This baby's here it, it would help other children. (CH8)

(21) I feel that there was a reason that my daughter had this heart defect. I don't know why, I don't know whether, you know, in later life that she'll go on to be a support to somebody else who's had a heart disorder or what. I really don't know. (CH26)

(22) And now if I ever see a mother who's obviously in that state I try to reassure her and say, 'Look, you know, here's my son, it'll be fine, you'll be OK.' Because it is just all overwhelming and it just made it

so much easier to know the routine the next time one went back and what was going to happen. And then after a while it just becomes a pattern, it's very reassuring. (CH24)

Obviously, these expressions resemble what parents hoped to hear when they came to know their child had a congenital heart disease. This also acknowledges other parent's feelings, while creating empathy (Pounds 2011) by providing implicit and mitigated forms of advice, clearly involving consideration of others' needs (cf. Locher – Hoffmann 2006).

3.7 Winning children

The parents' narratives take an unexpected turn: from descriptions of their feelings, of their experience, of their shock and how they had to cope with all of this, they eventually turn to their child. They never report their child's feelings, whether the child is afraid about what is happening or not. No words are spoken about that. When parents turn to speak about their children, we are at the end of their narrative. The recurrent pattern involved in this part is the child's showing off of the scar. The scar is proudly exhibited as a trophy, as if the child wants to demonstrate his/her own power and control over their heart disease:

(23) My son was there proudly showing his scar off to everybody. [laughs] He's not, not ashamed of his scar, he shows it off. (CH9)

(24) And they said, 'Show them your scar,' and he went, 'Hmm, look at this.' And he was so proud, you know, he was showing everybody his scar. (CH20)

(25) He's kept them in a bottle and he proudly shows people what his stitches look like. (CH24)

This is the *coda* (Labov 1997), indicating that the story is over.

3.8 Corpus linguistics analysis. *Know*

The analysis of the parents' narratives has revealed some dominant recurrent patterns, one of which is the necessity of coping with the shock and getting control over it in order to re-establish parenthood. This is partially achieved by getting information in order to fill the gap caused by the ignorance parents have about the heart disease their child is suffering from. The quantitative analysis of the corpus with Voyant tools seems to confirm this. Indeed, among the top ten most frequent words in the corpus, *know* is the most frequent, as can be seen in Table 1, below, (1009 occurrences):

Table 1. Breakdown of the top 10 most frequent words

Term	Raw Frequency	Relative Frequency	Distribution
know	1009	0.011402547	0.011402547
just	788	0.0089050615	0.0089050615
think	562	0.006351072	0.006351072
it's	471	0.0053226952	0.0053226952
really	470	0.0053113946	0.0053113946
going	367	0.004147408	0.004147408
father	363	0.004102205	0.004102205
sort	362	0.004090904	0.004090904
mother	357	0.0040344	0.0040344
like	351	0.0039665946	0.0039665946

The verb *to know* is a stative private verb, indicating an intellectual state which can only subjectively be verified (Quirk et al. 1985: 202). It is a cognitive verb which can introduce indirect statements with *that*-clauses. When used in this way, the speaker attributes to the sentence a high degree of epistemic certainty about the state of affairs expressed in the *that*-clause (cf. Cappelli 2007: 156).

A breakdown of the use of *know* reveals that the verb is mainly employed with the following:

Table 2. Breakdown of the different functions of know

Use		Occurrences
Comment clauses ("you know")		717
Knowledge	Evidentials ("I / we know that")	154
	Lack of knowledge ("X don't / doesn't know")	112
Negative expression: denial ("X do / does not want to know")		18
Feel ("I know that / it ")		8
	TOTAL	1009

As can be seen in Table 2 above, *know* is mainly used in comment clauses (717 occurrences) and evidential expressions (154 occurrences), but also in expressions related to lack of knowledge (112 occurrences). Comment clauses are parenthetical disjuncts that express the speaker's comment on the matrix clause (my emphasis, here and there below):

(26) I think it, if it is an antenatal diagnosis what my emotions were at first were I didn't want to know. I didn't want to have been told this piece of information because that then gave me a decision to make that I didn't want to have to make but with hindsight that antenatal diagnosis actually saved his life. If he hadn't had that diagnosis he would have been born at a different hospital where they didn't have any paediatric support at all. So, **you know**, it just would have been horrible and because he was, he was that unstable in an intensive care environment without any support at all. (CH3)

These types of comment clauses realised with "you know" are stereotyped in the sense that they imply certainty on the speaker's part and at the same time require the hearer's attention *and* agreement (cf. Quirk et al. 1985: 1114-1115). For instance, in (26) above, the speaker is drawing the hearer's attention to the fact that although she for a moment would have preferred not to be told about her baby's congenital disease during her pregnancy, the antenatal diagnosis was nevertheless important because it saved her child's life. If she had not known, "it would just have been horrible" and the comment "you know" underlines the severity of the baby's condition and the correctness of the mother's decision. Had she not known that, it would have been terrible, and the baby would have died. Good motherhood (Austin 2016) has been maintained. Even when parents do not act, "you know" becomes a comment for agreement sharing:

(27) None of us could stop crying and I think we were trying to put on a brave face for the children, my husband and I, and trying not to show them too much. But it was just such an emotional time, **you know**, and it was, it was just so hard to do that. (CH26)

Epistemic certainty is also expressed when *know* realises evidentiality. Evidentiality is a linguistic phenomenon by means of which the speaker/writer provides the source of information on which a claim is based; such sources may be seen, heard, inferred from indirect evidence or learned from third persons (Aikhenvald 2004). In all but one of the cases found in my corpus, the source of evidence is direct (the parents, the literal authors of the narrative); in one case it is indirect (the doctors whose text is reported by the parents), as can be seen in the excerpts below (cf. Willett 1988):

(28) I know that she's going to need follow up and **I know that** she does still have a small lesion/ hole there so she's going to have to, always have to be careful. (CH12)

(29) For Thomas **we do know that** there's a possibility that he may need a heart transplant in the future, if he doesn't thrive. (CH2)

(30) **I know that** when she has to have more treatment he's going to be a help […] Alex is three, so for 3 years **I didn't know** that information was there. So, it was just by chance that I actually found out. (CH4)

(31) **We didn't know** all the help we could get until the social worker had been in touch with us. (CH18)

(32) **They know that** she does have a heart history as well. (CH12)

Whenever evidentiality is used to indicate the type of knowledge parents have, it is to show that they are aware of their child's health condition and future treatment, so they know what to do. These expressions are always in the present tense, in contrast with the negative form in the past "didn't know", which clearly indicates a lack of knowledge: they did not have any information about medical issues and the story they are about to tell concerns the incredible fact that they managed to get information by chance, as in (30) and in (31). Doctors, in contrast, know that children "have a heart history": they are professionals and have information, as (32) reveals.

When the subject of *know* is "they" referring to doctors, the complement introduced by *know* is a *wh*-clause:

(33) They thought that, they think what caused it is, that it was actually irritating the heart so his blood pressure just started to, to crash and **they didn't know what** was causing it. (CH7)

(34) They couldn't decide why Luke was deteriorating as rapidly as he did and they were discussing him when he actually arrested, by which time it was too late. But **they didn't know why** he was deteriorating. (CH19)

The use of *wh*-clauses implies a lack of knowledge on the speaker's part (Quirk et al. 1985: 1184) which is indirectly expressed through the doctors' inability to explain the reasons for the child's heart failure. If this is so, the blame cannot be put on the parents, and good parenthood is in a way maintained.

There are a number of instances in which *know* in the negative form expresses a form of denial:

(35) I wish I'd had a **blissful ignorant pregnancy** and really been able to get attached to my baby before he was born. (CH02)

Ignorance is in these cases felt as *blissful* because, for mothers, not knowing would not only mean loving their children without any worries but also not panicking, as excerpt (36) shows:

(36) Right, I'll face intensive care when I have to. It's just another thing that, if I see it now, it might freak me out, so **I don't want to know**. (CH17)

In a few cases, *know* seems to indicate the parents' sixth sense when they come to predict what will happen to their children:

(37) You *know*, '**I just know**, I have a good feeling.' You *know*, I think he's, he's, *that's kind of been our way of coping*. (CH25)

Looking after a heart child does not only mean being physically close to their child at all times to provide comfort and keep checking. This proximity creates an emotional bond by means of which mothers become the information brokers of their children in the emotional interdependence which is being created between them (Young et al. 2002).

4. Conclusions

In this paper I have tried to describe the narratives of parents who have heart children and who want to share their experiences, as found on healthtalk.org, in order to detect how information, knowledge (and empathy) are deployed with the aim of helping other people in a similar situation to fill a cognitive and emotive gap. The investigation has been carried out by detecting the most recurrent discursive patterns of the narratives, followed by an analysis of the most frequently used verb that best expresses the parents' cognitive awareness (or lack of it) in their experience with their children with a congenital heart disease: *know*.

Exploration of the narrative pattern has shown that the traditional structure of narratives, as presented by Labov and Waletzky (1967) and

Labov (1997), is not followed, since the story parents tell is constructed in a new unexplored way. The discourses in these self-narratives follow an emotional flow which is different from story to story but presents a recurrent thread. This does not follow a precise chronological order, as flash-backs and emotions prevail in all the stories, but the main features in them are the following:

- Representation of shock;
- Coping with shock;
- Mothers blaming themselves;
- Looking for support;
- Lack of 'we';
- Parents sharing their experience;
- Winning children.

The leitmotif underpinning all these features is the question of parenthood: good parents are those who take care of and look after their children. This is why, after the initial shock, they all try to cope with it in order to reorganize their life – the best way to do so is *to know*: having knowledge grants them access to information and the possibility to make the right choice, which is what is required of good parents. Mothers feel they have a further moral responsibility: since they have not been able to protect their child, they feel morally responsible for this – and blame themselves. The proximity they create with their child, both physical and psychological, allows them to re-establish their social order and re-acquire the position of good mothers: they do what they think good mothers should do.

How parents cope with shock differs from person to person, but, generally, they cope with it by seeking support and information. In this quest for support, they also seclude themselves from the world, and even from each other, in order to focus on their heart child. Once the order is restored, the parents' narrative grants empathetic support to other parents in a similar situation and ends by describing the winning child showing off his/her scar.

The analysis of the most frequently used verb, *know*, carried out with Voyant, reflects in a way the described narratives above: in a comment clause, *know* is used when parents look for the listener's agreement; when it is used to indicate evidence, *know* is employed to show the awareness parents have as to their child's medical condition; in the negative form, the lack of knowledge they have is always expressed in the past, when they were in turmoil due to the shock and *did not know* and had no control, or, where the subject of the negative is 'the doctors', such a lack of knowledge is imputable to others, not to them – and in this case, good parenthood is preserved. In the few cases in which parents prefer *not to know*, this occurs because not knowing allows them not to panic. And last but not least, parents *know* in a sort of *sixth sense* what will or will not happen to their child – which is exactly what society requires for good parenthood.

Undoubtedly, trauma resists language. Emotions must be accommodated, and a lot remains unsaid or is not always or fully reported. Conversely, people in similar situations may appreciate knowledge derived from the narratives reported by parents who previously had similar difficult experiences. For them, reading about and listening to others' experiences may be of greater empathetic value.

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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

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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 revaluating 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 (Burleson 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[1], 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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[1] 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)[2]. 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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[2] 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 peiods 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 inscessant noise in his head caused by the tinnitus.[3]

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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[3] 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.

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The dynamics of popularised discourse for diabetics: Online forums for information and emotional support

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ABSTRACT

The aim of this paper is to examine the discursive strategies of seeking and giving information as well as emotional support for diabetics in online forums. The study analyses a popular website, Diabetes.co.uk, as an instance of a virtual community of practice. The dataset includes news about diabetes and about people with diabetes. The posts are published by Diabetes.co.uk staff and users who share their experiences with the disease. A corpus of news contributions and forum discussions was compiled, and then analysed by generating a software concordance for significant words and expressions. Findings show the website is characterised by a patient-centred discourse. The discursive strategies identified fall into two categories: a popularised medical news genre providing knowledge produced by the website staff and an emotionally-charged, informal, written-to-be-spoken discourse shared by users joining the discussion forum. The discussion forum posts frame diabetics as patients seeking to achieve empowerment and self-management from their peers who transmit experiential knowledge of their chronic condition. The paper attempts to provide further insights into effective computer-mediated diabetic discourse for health professionals and language scholars alike.

Keywords: online healthcare communication, diabetes, popularised diabetic discourse, emotional support, empowerment, self-management.

1. Introduction

It is commonly agreed that the internet has transformed the way in which we communicate. Not only does it facilitate daily inter-personal communication to a massive audience, but it fosters content sharing and collaboration between friends, professionals, experts in all walks of life. The Internet has

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long been recognised as a repository of information, and according to Shaw and Johnson (2011) seeking health information is the third most popular use of Internet technology, as confirmed in recent clinical literature (among others Arduser 2011; da Silva – de Freitas Campos 2016; Powers et al. 2008). Furthermore, medical research has shown that people suffering from a health complaint not only desire to learn more about their condition, but they also seek emotional support online (at Facebook, Twitter, forums) in an attempt to cope with the disease on a daily basis (among others Farrell 2014; Hernandez 2015; Powers et al. 2008; Shaw – Johnson 2011). In this regard, Farrell (2014: 8) observes a changing dynamics in health care, where health professionals are no longer the sole providers of information, but patients join discussions themselves. As far as diabetes is concerned, she notes that among the most commonly discussed topics on Facebook groups are those raised when diabetics share personal clinical information, request disease-specific guidance, and seek and give emotional support. Greene et al. (2011: 287) define this kind of dynamic online communication "Health 2.0" and likewise claim that it "offers patients an opportunity to build and benefit from a social network to learn about their illness and to gain support from others with similar experiences." Indeed, as evidenced in this paper, forum discussion threads contain contributions from patients who, participating on a peer-to-peer basis, not only seek information and guidance but also consolation, comfort and encouragement. This is also in line with Caplan and Turner's (2007) theory of computer-mediated emotional support and comforting communication, as Harvey and Koteyko describe (2013: 165):

> Interactions with peers in self-management programmes offer people with different medical conditions the opportunity to share their concerns with similar others, in this way reducing the sense of isolation associated with many diseases. Such interactions are typically a locus of social support defined as 'transaction of empathy and concern, information or advice, or tangible aid (i.e. goods and services) between two or more individuals' and characterised by the use of verbal or nonverbal behaviours to seek or provide help (Mickelson, 1997: 157). Such support groups are particularly important for those who suffer from chronic illness as clinical research shows that interpersonal networks significantly impact on adaptation to the everyday management of the disease.

Groups such as these are usually managed by health professionals, whose responsibility is to foster a patient-centred approach by understanding the workings and benefits of social media in online communication (Farrell 2014: 9). As Turnbull (2015: 291) notes, a patient-centred approach is one that "views the patient not just in terms of his illness or a set of symptoms, but rather as a person with emotions, feelings, needs and preferences. An essential element of this approach is empathy, which involves the ability to understand another person's experiences and feelings and view them from their perspective (Hojat et al. 2002: 1563)". Furthermore, clinical literature (Caplan – Turner 2007) has shown the advantages of online communication, claiming it guarantees a certain amount of anonymity, which is less face-threatening than a face-to-face meeting. In particular, Powers et al. (2008: 92) report the findings of the PEW Internet and American Life Project (October 2007) and the overwhelming positive reaction of e-patients to the Internet regarding the information they retrieve and their resultant feelings. In general, the information helped them make decisions regarding how to treat the illness, ask a doctor new questions or seek a second opinion, change their approach to maintain their health, cope with a chronic condition, and think about diet, exercise or stress management. As far as their feelings were concerned, the majority of diabetics felt more reassured in making appropriate health care decisions, relieved or comforted by the information they gained, and felt confident they would now be able to raise new questions about their health with their doctor. Very few were overwhelmed or confused by the mass of information available.

This paper, which is part of some ongoing research into diabetic discourse, focuses on the resultant discursive behaviour of the social actors (website administrators and forum discussants) in online social interaction. First, it will examine the discourse of the health provider-administrator in providing news, offering support and stimulating discussion between diabetics, and secondly, it will analyse certain features of the peer-to-peer discussion, both initiated by the website staff and more spontaneously by the stakeholders, the patients themselves. Indeed, the overall aim of this contribution is to highlight, from a linguistic perspective, the affordances of computer-mediated diabetic health communication. Its purpose also triggers from the initial findings of Hernandez (2015: 194) who illustrates the dual benefits that social media provide: "With social media, patients get at least 2 critical things that physicians can't normally offer: the perspective from the point of view of another patient and an almost unlimited amount of time to listen and share experiences. In turn, healthcare providers can add to their education and empathy towards patients by reading articles written in the patients' voices."

The analysis is based on the content of a popular website, Diabetes.co.uk, where news of various aspects of diabetes (e.g. research, treatment, physical exercise, recipes) is published, and where diabetics are encouraged to talk about themselves and their predicaments on a peer-to-peer basis. It examines the metadiscursive features of both informative news and discussion threads, with a view to identifying the interactional styles and rhetorical strategies of the social actors involved. The analysis highlights to what extent and in what way the metadiscourse clearly reflects the above two reasons for social interaction – seeking both information and emotional support. The grammar and lexis of the various kinds of contributions will also be analysed according to their composition in order to stimulate either a non-verbal response (reading more information) or a verbal one (participating in a discussion forum to gain information and support). The structure of the paper is the following. Section 3 presents the corpora compiled and used for the study as well as the methodology adopted. The results will be reported in Section 4 followed by a discussion of the results and concluding remarks in Section 5.

2. Some theoretical background

It is first necessary to cover some theoretical background with which to contextualise the social interaction involved and on which to build the analysis of the data collected. Central to the discussion are the affordances of social media in providing a well-frequented place for online health communication, and more specifically, in fostering collaboration in a community environment.

2.1 The social actors

The social actors are the participants (the health professionals) managing the website in general with diabetic news on the one hand, and patients with similar characteristics, namely their diabetic condition, in the forum discussion area on the other. The interaction, as such, comprises numerous communicative events, taking place within a community of practice. Wenger-Trayner and Wenger-Trayner (2015: online) define communities of practice as “groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly.” This confirms the reason why patients resort to online communication – to cope better with their condition, and the onus on the part of the health professionals is to provide quality information and appropriate encouragement and support. Wenger-Trayner and Wenger-Trayner emphasise, however, that a community of practice is not simply a club of friends or a network of connections between people, but defines its identity as a shared domain of interest (here, the health condition). Justifiably, becoming a member involves commitment, mutual engagement, a shared competence, where the emphasis is on sharing information. Communities of practice thus build relationships that enable individual members to learn from each other. A website is a virtual community of practice, a virtual space containing a repertoire of resources shared by its stakeholders and is accessible to an infinite number of Internet users. In terms of a forum discussion, these resources are experiences, stories, tools, ways of addressing recurring problems – in short, a shared practice that relies on sustained interaction. As far as the website staff are concerned, it is their responsibility to select and disseminate relevant items of interest (i.e. knowledge), stimulate critical reflection in the patient and encourage the sharing of experiences. Gannon-Leary and Fontainha (2007: 2) also emphasise the resulting improvement of knowledge through the sharing of resources:

> A Virtual Community of Practice […] is a network of individuals who share a domain of interest about which they communicate online. The practitioners share resources (for example experiences, problems and solutions, tools, methodologies). Such communication results in the improvement of the knowledge of each participant in the community and contributes to the development of the knowledge within the domain.

Herring (2004: 355) describes the concept of "community" as providing "sociability, support, and identity". With particular reference to virtual community, she identifies six sets of criteria, most of which are relevant to members of an online diabetic community:

1) active, self-sustaining participation; a core of regular participants
2) shared history, purpose, culture, norms and values
3) solidarity, support, reciprocity
4) criticism, conflict, means of conflict resolution
5) self-awareness of group as an entity distinct from other groups
6) emergence of roles, hierarchy, governance, rituals

In fact, the social actors we shall analyse are an active core of participants, self-sustaining in their participation (1); they share a history and purpose (2) due to their health condition or knowledge of the subject, which results in encouraging and exchanging expressions of solidarity, support and reciprocity (3). They are also apt to foreground conflict, such as issues with doctors or the health system in general, when relevant to the diabetic condition, (4). They are well aware they form a group distinct from other groups (non-diabetics in general) (5), and they take up specific roles and identities in the discussion: moderator – staff member providing information and stimulating support through peer discussion, or active member, well-known member, Newbie, Type 1 Expert, and so on among peers (6) (see Section 4).

2.2 The social interaction

Gunawardena et al. (2009: 5) claim that a community of practice has its own discourse and its own way of using language to determine meaning: "it is in examining discourse that we can see 'how a community is shaped by language use and how language use shapes a community' (Creese 2003: 55)". Any analysis of the discursive practice of online interaction must fall into the category of metadiscourse, as defined by Hyland (2005: 14): "The concept of metadiscourse is based on a view of writing (and speaking) as a social and communicative engagement, offering a means of understanding the ways we project ourselves into our texts to manage our communicative intentions." This is clearly relevant if we wish to understand how the pragmatic function of various communicative events is to be understood. Concerning online communication, Herring (2004: 339) states, "Online interaction overwhelmingly takes place by means of discourse. That is, participants interact by means of verbal language, usually typed on a keyboard and read as text on a computer screen."

In the Diabetes.co.uk website, other media such as video and audio files (interviews and presentations) are uploaded for further in-depth consultation regarding items of interest to the community. In a forum discussion, the emphasis is on the written which serves to enact the spoken. Fairclough (1989) adopts the term synthetic personalisation, or synthetically personalised discourse, whereby language is used in such a way that mass audiences appear to be addressed as if they were individuals, through the use of the second person pronoun "you", for example, referring to "one and all". Concerning this form of address, Hunt and Koteyko (2015: 452) categorise the strategic use of "we", "us" and "our" for a more personalised identity of the institution.

2.3 The content – popularisation of scientific discourse

The social interaction of diabetics can be located in the context of the popularisation of scientific discourse. The literature in the field identifies a tripartite model of participants, content and communicative act around which any analysis must revolve. According to Calsamiglia (2003: 139-140), there are two crucial aspects in presenting scientific knowledge to the general public, the first is the role and position of the speakers and the second affecting the content: the conditions of its production, comprehension and interpretation. As Gotti (2014: 16) claims, "Popularization […] addresses not an expert group within the discipline, but an audience of non-specialists." Moreover, he explains the purpose of popularisations in the form of popular scientific magazines, books and news articles published for a wide readership: "Popularizations target […] a wide reading public and deal with specialized topics in a language close to general discourse and to the layman's everyday experience. The purpose here is chiefly informative and seeks to extend the reader's knowledge rather than develop a secondary conceptual system" (2014: 17).

Gotti further defines popularisation as a reformulation process, a kind of redrafting of the disciplinary content, where the language is remodelled to suit a new target audience. Gotti (2013) also refers to the studies of Calsamiglia and Van Dijk (2004) to introduce another concept, that of recontextualisation of scientific knowledge, originally produced without a lay audience in mind. It becomes increasingly clear then that we need to examine the content of the website in order to ascertain where to place the discourse along the scale of popularised text, if we take for granted that diabetics are necessarily familiar with some scientific terminology as part of their living with their condition.

In his definition, Myers (2003: 273) includes the above-mentioned tripartite model: "Popularization is a matter of interaction as well as information; it involves persons and identities as well as messages." Furthermore, he argues, "We need to question who the actors are, how the various discourses interact, what modes are involved, and what is communicated – and we need to consider what these questions imply for text analysis" (2003: 267). This is applicable to the language of a diabetes website. While the discourse revolves around all possible aspects relating to the diabetic condition, website staff identify themselves as the experts and supervisors of content, the bearers of knowledge of the disease, and diabetics identify themselves more closely with their practical knowledge, or current lack of it, and practical experience in relation to their illness. This paper aims to discover how the modes of interaction of both professionals and patients affect the way in which they express themselves and to what extent they use or reformulate specific medical terminology in their discourse.

Lastly, relevant to our discussion is Hyland's (2010: 117) concept of proximity:

> a writer's control of rhetorical features which display both authority as an expert and a personal position towards issues in an unfolding text. It involves responding to the context of the text, particularly readers who form part of that context, textually constructing both the writer and the reader as people with similar understandings and goals. While it embraces the notion of interpersonality, proximity is a slightly wider idea as it not only includes how writers manage themselves and their interactions with others, but also the ways ideational material, what the text is 'about', is presented for a particular audience. It is concerned with how writers represent not only themselves and their readers, but also their material, in ways which are most likely to meet their readers' expectations.

Hyland relates this to Sacks et al.'s (1974: 727) notion of recipient design, that is, how our lexical choice, content and adherence to expected discursive norms in what we say or write, makes sense to our addressees. This is particularly relevant to the ways in which diabetics are given practical information and how they are encouraged to share experiences with their peers. Harvey and Koteyko (2013: 169) observe a number of discourse strategies in peer-to-peer online interaction that achieve legitimacy of a discussant's presence in a forum and at the same time solicit support: 1) indicating one's condition by describing symptoms and/or mentioning the history of the disease; 2) making direct or indirect requests for information; 3) making references to shared experiences; 4) describing personal successes and elaborating on positive improvements.

In sum, our research questions are to examine the discursive devices adopted in two specific kinds of computer-mediated communication: 1) the provision of practical information and emotional support on the part of the website management whose purpose is to trigger peer-to-peer discussion, and 2) the developing peer-to-peer discussion either launched by a member of staff or by a patient him/herself.

3. Materials and methods

3.1 Choice of website

Diabetes.co.uk was chosen as the object of study for the vast quantity of computer-mediated health communication it provides between health professionals and patients on the one hand, and diabetic peers on the other. It has also been the object of other research in the field. Firstly, Turnbull (2015: 298) evidences the duality of social interaction of the site: "a community website whose information is provided by diabetes experts, but, above all, by diabetics themselves who share their knowledge and first-hand experience". Secondly, Hunt and Koteyko (2015: 459) highlight its online sociality "based on shared experiences of diabetes and consumption of health and lifestyle information to manage health risks."

3.2 The website corpora selected and methodology

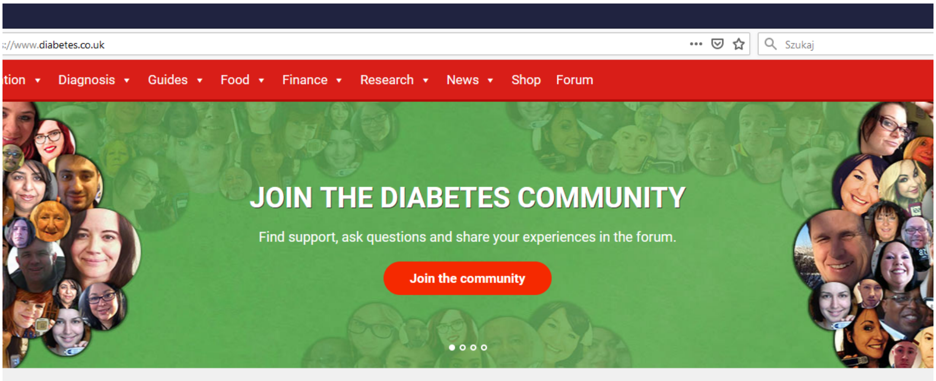
In this small-scale study, two sets of corpora from the Diabetes.co.uk forum app, also downloadable onto a smartphone, were compiled according to their overall content and pragmatic purpose. Corpus A, which was compiled over a 9-month period from July 2018 to March 2019, comprised the publication in the forum area of 488 news items of interest, either relating to diabetes in general, including latest research and technology, or to specific news of patients and their success in coping with their condition. Corpus B was compiled over an 8-month period from July 2018 to February 2019, and was limited to initial thread titles (509 in all) from the section: *Take a look at some of today's top threads*, which were published twice weekly, invariably ten at a time. These were considered representative of the thousands of weekly contributions published from a wide variety of topic threads, and thus representative of the overall content. While both small (Corpus A contains approximately 15,000 words and Corpus B 2,500 words), they nevertheless provided some interesting insights.

The software programme *AntConc* (Anthony 2018) was used to create word lists in each corpus and to carry out subsequent concordances of words and clusters that appeared to be of particular significance. In fact, the first step taken after compiling the two corpora was to create a frequency list in order to gain an idea of the recurrent words. Subsequently, concordances were carried out to investigate key words in their co-text with a view to shedding light on any emerging discursive practices.

Following a more qualitative analysis, the contributions (items of interest, news titles, forum thread titles leading to contributions) were then classified according to the pragmatic function they appeared to express. The analysis is limited to the text found in the preliminary access to a contribution, that is, at the level where the reader is invited to click for further detail, since the overall purpose is to identify the illocutionary intent of the writer and the discursive strategies adopted to stimulate both reading and active participation.

3.3 Forum description

As evident in Figure 1, the Diabetes forum website revolves around the concept of community, calling itself *The Global Diabetes Community*, reinforced by images of smiling faces to the left and right. At the top of the first strip, there is direct access to other sections focussing on various kinds of diabetes (Prediabetes, Type 1, Type 2…, treatment, complications, insurance, food and recipes, and shopping online). Across the lower strip, in capital letters, there is an invitation to join the Diabetes community, with further invitations in a series of imperatives below: (Find support, ask questions and share your experiences in the forum) and below on a separate line a further invitation, yet again in the imperative form (Join the community).



JOIN THE DIABETES COMMUNITY

Find support, ask questions and share your experiences in the forum.

Figure 1. The Diabetes.co.uk forum website

Furthermore, scrolling down the screen, there are some statistics (Figure 2) whose purpose is clearly to encourage newcomers to join, and also a news item in brief to the right to click on for the full text. Again, the imperative form is the only verbal form present (Join, Meet, Speak):

Join **390,599** people on the award-winning Low Carb Program »

Newly diagnosed? Meet 295,123 others in the diabetes community »

Speak to the community about food on the Low Carb Forum »

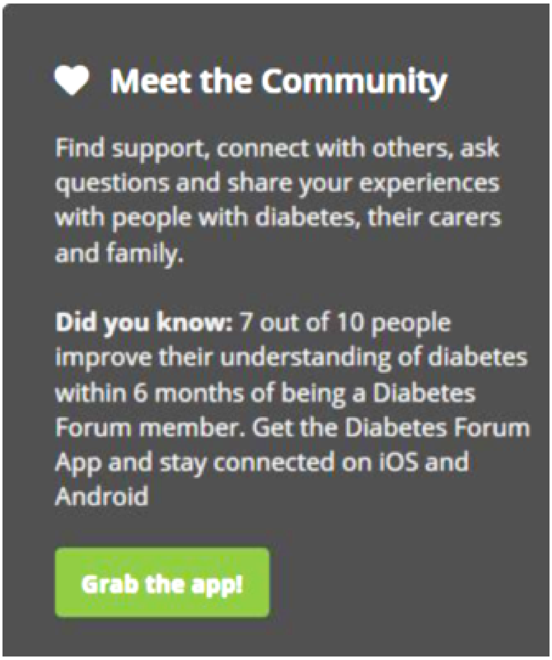
Diabetes News

Amputation rates among people with diabetes not significantly increasing in UK, data reveals

Wed, 03 Apr 2019

Figure 2. Statistics on the Diabetes.co.uk website

Further encouragement to participate by downloading the forum is given in the Meet the Community image (Figure 3) accompanied by a heart. The message is reinforced by a "Did you know" question containing the answer that informs the reader of its success rate in helping people to cope with the condition. The hyperlink, with its lexis, assonance and punctuation mark chosen for the imperative, "Grab the app!", reveals an informal style.



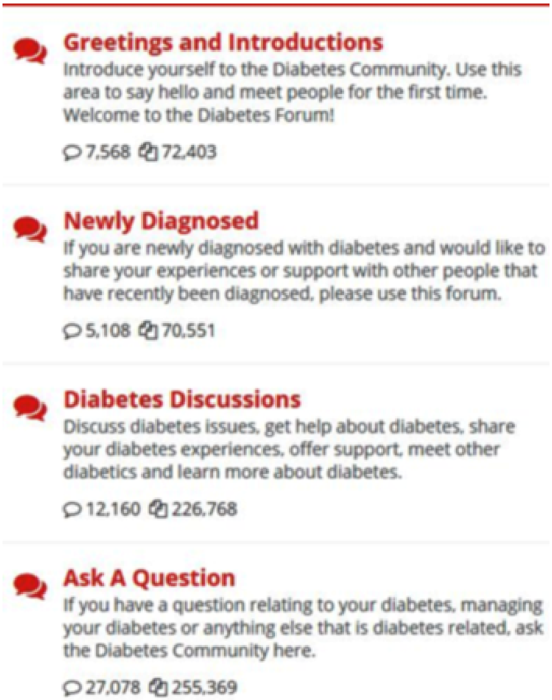
Meet the Community

Find support, connect with others, ask questions and share your experiences with people with diabetes, their carers and family.

Did you know: 7 out of 10 people improve their understanding of diabetes within 6 months of being a Diabetes Forum member. Get the Diabetes Forum App and stay connected on iOS and Android

Figure 3. Discussing the option of the app in today's mobile-first world

As far as the forum discussion is concerned, Figure 4 shows the initial page, explaining what discussants can actually do. The prevalent verbal form is again the imperative, the purpose of which is to involve those interested.



Greetings and Introductions
Introduce yourself to the Diabetes Community. Use this area to say hello and meet people for the first time. Welcome to the Diabetes Forum!
7,568 72,403

Newly Diagnosed
If you are newly diagnosed with diabetes and would like to share your experiences or support with other people that have recently been diagnosed, please use this forum.
5,108 70,551

Diabetes Discussions
Discuss diabetes issues, get help about diabetes, share your diabetes experiences, offer support, meet other diabetics and learn more about diabetes.
12,160 226,768

Ask A Question
If you have a question relating to your diabetes, managing your diabetes or anything else that is diabetes related, ask the Diabetes Community here.
27,078 255,369

Figure 4. Initial page of forum discussion with number of replies and views

Let us now examine the data in order to see how the discourse evolves in the forum and how it continually works in a stimulus-response pattern. As we shall see, the stimulus is either from the website staff to the patients or among the patients themselves in a peer-to-peer exchanges.

4. Data analysis

4.1 Discursive practices that emerge

According to Luzón (2013), in order to foster a dialogic involvement with the reader, the writer adopts several rhetorical strategies with which to engage him/her: 1) title, 2) questions, 3) humour. The two corpora under investigation include titles, the purpose of which in any text is to arouse curiosity and stimulate further reading. This paper examines principally the first two strategies. The third is probably applicable too, since there is a sub-section, *Jokes and Humour*, but there were no humorous titles in those examined in spite of several examples of word play, possibly due to the seriousness of the topic.

4.2 The news section

The news section is the responsibility of the website staff. What is particularly interesting is that while many news items refer to themed topics on diabetes, the forum discussants are often participants in the news stories themselves. Their contributions were considered newsworthy enough to be published as stories in the own right. As we shall note, the group identity concept of "Diabetics R Us" is present throughout.

4.2.1 Words in the news

First, let us see what the word list afforded in terms of key words.

- "Diabetes", predictably, was the first content word, rating 3rd with 292 recurrences (2.02%). In clusters where it functioned in pre-modification, "diabetes forum" was the most frequent, recurring 19 times, followed by "diabetes community" (14 times), "diabetes day" (12) and "diabetes awareness" (10). "Diabetes" appeared even more frequently as the head word, when referring to a particular category of the disease, as in: "Type 1 Diabetes" (44 times), "Type 2 Diabetes" (41 times). Another interesting cluster was "with diabetes", which if expanded was most frequently preceded by "people" (20 times), indicating a human category, i.e. those affected by the disease. Also found were the more specific "children with", "drivers with", "someone with", and "a man with". One might have expected to find the word "diabetic" referring to a person as well, but it only recurred twice ("women", "a diabetic") and once referring to a dog ("diabetic service dog"). The other 3 recurrences were in the context of the illness or the title of a publication. It would seem then that the term "with diabetes" is by far the more popular when referring to people.
- "low" (158 times – 1.09%) was the next most frequent content word in 11th position followed by "carb" in 12th (145 times – 1%). In fact, the two appeared together in a cluster "low carb" (140 times), pointing to the significance of "low carbohydrates" for diabetic patients, as in "low carb diet" "low carb foods" and "low carb snacks". The lexical choice of "carb(s)" rather than "carbohydrate(s)" indicates the more informal register adopted.

- "You/Your/We/Our". We mentioned earlier the concept of personalisation using personal pronouns (paragraph 2.2). In fact, "you" ranked 20th with 102 recurrences (0.70%) and the personal pronoun "your" 24th with 80 occurrences (0.55%). Indeed a concordance of "you" confirmed a plural mass rather than single audience was being addressed (e.g. "What works for you? It's good to talk"), where "you" is also a much less formal choice than "one". "Your" ranked in connection with feelings and a personal condition ("your feelings", "your diabetes", "your diabetes management", "your blood sugar", "your overall health") but again the plural is implied in its use.
- "We" ranked 26th, occurring 76 times (0.53%), and "our" was 47th occurring 49 times (0.34%). As indicated earlier, "we" represents strategically less impersonally the staff at Diabetes.co.uk, as highlighted in the concordance expansion: "How can we do it better? We want to know your feelings on our Diabetes Forum." Likewise "our" gives the idea of an exclusive "we" belonging only to the subscribers to the forum.

4.2.2 The structure of the news

A typical news contribution was of human interest and basically one of two kinds: a) scientific news or b) news of /from a diabetic patient. The structure of each contribution invariably followed a simple pattern: image, headline beneath it or to the side, lead paragraph, below which came the hyperlink on a separate line in a short noun or verbal proposition. This is reminiscent of online news, in particular with its hyperactive devices. The contributions resemble the "News in Brief" section in newspapers, but with the added element of the hyperlink (or teaser) to access further detail. Below is a selection of examples according to the two categories identified in the corpus.

a) Scientific news
These items are the more objective of the two categories of news relevant in some way to diabetics and their condition:

(1)

> Healthy diet, healthy heart
> People with T2D were able to halve their risk of CVD risk depending on their healthy lifestyle choices, a US study found.
> Read the results

(2)

Diet advice shake-up
The University of Oxford has said in a study published in the BMJ that low calorie soups and shakes should be recommended as part of NHS treatment for obesity.
Why soups and shakes?

(3)

EASD 2018 launches T1 vaccine bid
A type 1 diabetes vaccine is being developed based on the findings of a project to prevent another autoimmune condition, celiac disease.
Celiac's link to T1

(4)

Metformin could slow T2
Metformin could be as effective as gastric band surgery in slowing the progression of type 2 diabetes, new research shows.
What metformin does

b) News from patients

(5)

6 Months and reversed my T2
"6 months to the day and I've cracked it," writes Biglain. "Officially reversed my T2 and off the metformin!" Congratulations Biglain!
It can be done

(6)

Police cell with no insulin
"They asked me do I need sugar?" writes dmcx3x who after being arrested was reportedly denied access to her insulin at the police station. She is considering making a complaint.
Read the full story

(7)

The Forum discusses: finding the positives
Between the tabloids and scientists warning us of health risks, it's easy to get caught up in the negatives of diabetes. But if you keep a balanced mind, diabetes can lead to some positives. The Diabetes Forum has been discussing some of the better things about diabetes.
Avoid negativity, embrace positivity

(8)

All for one, one for all
When one of us succeeds, we all succeed. It's really motivating to read success stories such as MikeStrutter who has lost 3.5 stone!
"I've learned so much"

(9)

We Live and Learn
Diabetes is a condition that comes with a learning curve all of us have to climb. But through talking and sharing, that learning curve becomes a little easier. Swapping tips and tricks, sharing recipes that are kind to blood sugar levels, or simply supporting each other through the community all help to make things easier. Why not take the opportunity to share on the Forum today.
Join the conversation

(10)

Trick or treat
We've come up with a few tricks this Halloween to help you treat yourself without diabetes having the last laugh.
Top tips for Halloween

The function of a headline or title is to arouse interest and curiosity, prompting an active response in the reader. Newspaper headlines have been the topic of several studies over the years (among others, Bell 1991; Partington 1996; Morley 1998; Reah 2002; Mansfield 2006), being categorised as summary or connotative according to their content, structure and rhetorical strategy. The examples above mainly fall into the category of summary headlines since they are informative and indicate the content of the bodycopy in the lead paragraph. They all fall into the category of relevance for diabetics. Some titles are more connotative, requiring the reader to move to the bodycopy for full comprehension of the topic. Following the grammar of headlines, the examples above are either noun (1, 2, 6, 8, and 10) or verbal propositions (3, 4, 5, 7, 9). The noun phrases have an added rhetorical strategy in the form of repetition and/or alliteration (1, 8), or popular sayings (10), while (2) and (6) are classic examples of information packaging in wordy headlines. Example (10) also shows that headlines in this forum reflect timeliness and predictability with an event occurring annually. In the verbal propositions, the tense form is the present (3, 7, 9) typical of headline language reporting past events, while example (4) reports a possible advantage of some diabetic medication with a conditional form and example (5) quotes a patient reporting his achievement. Example (9) is a frequently used expression when commenting on experience we can learn from. In this case, it is only by reading the bodycopy below that the reader can gain an idea of the content.

Some headlines posed a question:

(11) Could saliva help diagnose T1D?

(12) In need of motivation?

(13) How can we do it better?

Example (11) introduces a report on a new discovery, emphasised by a question that is an invitation to read further. Example (12) introduces the storytelling of a forum discussant needing support because she was not losing weight and had turned to the forum. In example (13), the website managers launch an appeal to re-impress upon participants that they are there to help and want to improve their support.

The bodycopy is the informative text exuding emotional support, whether it is simply reporting scientific news or stories of interest linked to the forum contributions, or it contains a pressing invitation to participate in the forum or a request for feedback from the subscribers on how to improve assistance. The news from the patients appeals to the emotions and includes evaluative lexis: (5) Congratulations Biglain! and (8) It's really motivating. Examples (7) and (9) are clearly written in order to solicit a positive response from the forum with the bodycopy containing a string of reassurances. Example (14), an invitation from the website staff to join in, gives an insistent message that is relevant to everyone, rather like example (8). It is introduced by a title with contracted lexis, a characteristic feature in the forum threads:

(14)

> Type 1 'Stars R Us
> Whether you have type 1 diabetes, type 2, gestational or any of the myriad of diabetes types, there is somewhere on the Diabetes.co.uk Forum for you. One of the most popular type 1 threads sees people sharing blood sugar levels, getting things off their chests, and simply having a chat.
> Join in »

Note also the informal language in the metaphorical expression "getting things off their chests". The emphasis again is on fostering the benefits of not remaining isolated but becoming involved in the community, as in the "All for One, One for All message" (example 8).

A contribution in (15) introduces practical advice, stating the case, which is enclosed in the relevant title and hyperlink summarising the content. The title is another example of an informal metaphorical expression:

(15)

> Give bad weather the cold shoulder
> No one likes it when the weather gets too cold, and going into November, the mornings are becoming crisp and frost is making an appearance. The cold can wreak havoc with blood glucose levels and so managing diabetes at this time of year can require a slightly closer watch.
> Cold weather management

The hot words of the hyperlink serve as a further prompt soliciting an active response to discover more. They comprise a wide variety of noun and verbal propositions that highlight a particular aspect of the news item. 94 hyperlinks were in the imperative form soliciting further action in order to gain information (1, 6, 9, 14), or they gave advice (7) as in other cases:

(16) Keep a clear head

(17) Don't lose sleep over diabetes

Others were encouraging statements (5, 8). *Wh*-question words (*how, what, which*) implied that by clicking on the link, more practical information could be retrieved. *How*, for instance, occurred 40 times (0.28%). Here are some examples:

(18) How to get back on track

(19) How Rachel achieved it

Other links still were self-contained comments attached to the news item, and informal:

(20) A kick in the bum to diabetes

(21) YES, I AM AN IDIOT

(22) I was hooked

Noun phrases tended to summarise the content of the article:

(23) Low sugar alcohol guide

(24) Gym, snacks + BG

(25) Immune cells discovery

Verbal propositions were statements relating to an essential aspect of the story:

(26) Remission is possible

(27) CGM could increase accuracy

(28) Patients are being heard

In sum, it is clear from the analysis how the language of information and emotional support interweave in these short texts. News is for diabetics and is about diabetics, covering every aspect of their daily lives. As mentioned at the beginning of the section, diabetes is news, but more significantly, the social actors, i.e. the diabetic subscribers to the forum are too, since they become the focus of a news story. Furthermore, "share" appeared 12 times in the corpus (in 185th position), confirming its overall significance in soliciting a response whose function is to narrate their health condition to and gain support from others.

4.3 The forum discussion

The forum discussion is essentially a place where patient expertise is requested and where the website staff encourage participants to share both their problems and their experiential knowledge.

4.3.1 Questions in the discussion

The most frequent word on the frequency list was "What", recurring 58 times (2,32%) out of the 838 word types. This is highly significant, since we usually expect function words such as articles, conjunctions and prepositions to top the list. The concordance revealed all 58 instances in initial clause position, asking a question. Therefore, it seems natural to ask what people with diabetes specifically want to know: simply information or more than that, information enveloped in peer support and advice (see Morrow 2006). The most frequent question was: "What was your fasting blood glucose (or abbreviated to BG)", occurring 19 times over the 8-month period. In fact, this thread was started several years previously:

(29) Discussion in 'Diabetes Discussions' started by NewdestinyX, Jun 30, 2011

As confirmed by frequent reference in the news section, it is obviously a constant theme diabetics return to, a daily problem for them to keep their blood sugar levels under control. Other questions seem to be related to the topic as in "What have you eaten today?" (12 times), initiated on April 20, 2015 by a staff administrator who also guides the contribution content:

(30) Share what you've eaten today with the rest of the DCUK community and maybe steal a few ideas for yourself!

Another interesting question that summarises the practicalities of living with the condition is the following title, which invites self-narration:

(31) What do you find the hardest about living with diabetes?

Other *Wh*-questions were recurrent: *Why* occurs 5 times (0.20%), generally seeking information in the form of an explanation:

(32) Why do diabetics get tired easily

(33) Why can I not get my HBA1C down?

It is clear that many starter threads concern not knowing what to do. *How* occurred 13 times (0.52%), the majority of which were again seeking practical advice:

(34) How can I reduce my insulin resistance?

(35) How do i know my pre and post meal numbers are on track?

Likewise, polar questions require an informative response, with more than a simple Yes/No answer:

(36) Is it possible to have diabetes without sugar in urine?

(37) Am I OK to eat this…

Interestingly, albeit in the minority but more present in the news section, there are 3 topical questions about issues likely to affect their health condition. The British media spread the rumour that insulin supplies might be at risk with the separation of the United Kingdom from Europe, and so it seems only natural to ask:

(38) Are we going to die post-Brexit?

While the pragmatic function of a title may blur into more than one category, 19 starter titles clearly request reassurance that what the discussant is doing or feeling is right or normal:

(39) Think I'm doing ok???

(40) Symptoms Worse After Lowering Sugars?

4.3.2 Key words in the discussion

The next most frequent content words in the word list are predictably those relating to the health condition:

- Type: the third most recurrent word (46 times – 1.84%) refers to the kind of diabetes one has ("Type 1", "Type 2") thus justifying its prominent use.
- blood (36 times – 1.44%), fasting (33 times – 1.32%) and glucose (31 times – 1.24%) appear in 7th, 8th and 9th positions respectively, and often in a noun phrase such as "fasting blood glucose" (22 times). Interestingly in comparison, "sugar" juxtaposed to "blood", appeared 13 times (0.52%). We may then ask, are diabetics more likely to discuss their blood glucose levels or their blood sugar levels? The more scientific term ("glucose" rather "sugar") is the more popular.
- In 13th position, was predictably "diabetes" (29 times – 1.16%), very close to the above content words, which are specific to the condition. In comparison to the news section, it did not come first, probably due to the fact that in the forum discussion, specific conditions within the disease are discussed.

4.3.3 The illocutionary intent

Let us now attempt to classify the other titles according to their illocutionary force. First, numerous titles simply state a problem in one, two or three-word noun phrases, ranging from dietary topics to more strictly medical ones, something affecting the daily routine:

(41) Medication

(42) Eye Problems

(43) Reversed Diabetic Retinopathy

Many titles appeared to be weighing up two nouns joined by “and”:

(44) Hypo And Hyper

(45) Insulin and Hypos

Problems are much less frequently stated in a verbal proposition, albeit in a non-finite clause:

(46) Struggling to eat normally

Other titles seem to reflect other media language genres (e.g. newspaper titles), adding a characteristic drama effect. Appeals for help are more or less explicit, using the word “help” (17 times – 0.68%), or just stating feelings of confusion and frustration:

(47) Really High Cholesterol – 13 – Please Help

(48) Lantus… AGAIN UGH help please

(49) Mum of newly diagnosed 12 yo seeking a friendly ear!

Many discussants expressed their discontent or a problem in the form of negative statements projecting expressions of conflict and discontent where the title precedes self-narration in the post:

(50) Finally seen a Diabetes Nurse Specialist After 19 Months!

(51) Employer and time off – I’m really fed up

(52) Most annoying things about Diabetes

Negativity is also expressed metaphorically:

(53) Fell Off The T2 Wagon

(54) Blood glucose went mental!

Some starter titles nonetheless indicate a positive self-evaluation to be shared with the group:

(55) Early days but progress

(56) Happy day, been accepted for libre

They also express solidarity and thanks:

(57) Diabetics R Us

(58) Update and thanks

These expressions reflect a community spirit, where all discussants form a distinct group – they are in it together.

4.4 Expressing the spoken in the written

It is clear that many of these titles are written in an informal style (see also Morrow 2006; Harvey and Koteyko 2013) and risk categorisation as nonstandard language since they do not follow any rules. This is not the view of the above Computer-Mediated Communication (CMC) scholars. Our findings for titles are in line with their research.

Starter titles undoubtedly reflect the spoken language in a written, typed form, where typographical errors, presumably due to predictive text if discussants are using a mobile app, are very frequent. Contractions and abbreviations are other textual features, as well as R replacing the 2nd person form of the verb "to be" (57):

(59) New Type 1 21yo 4 Friends

(60) GP unsure of Type 1 or Type 2…

(61) Hypo And Hyper

(62) Stomach issues no meds

Rather than using emoticons, discussants show their feelings through the expressive use of punctuation in repeated exclamation and question marks as well as capitalisation:

(63) UGH!!

(64) PR SUCCESSES – GETTING THE WORD OUT THAT LCHF IS THE BEST D.

(65) Stress and Glucose Monitor Readings!!!

As far as disjunctive language is concerned, subject pronouns and auxiliaries are often omitted, as well as the verb "to be":

(66) Remember me?

(67) Losing too much weight

(68) New to the forum! 5 years as a T2

(69) New HBa1c Result… Not good.

Lastly, the 2nd person pronoun *you* is used inclusively, confirming direct address to a mass audience, where individuals single themselves out with a response. Likewise, the inclusive "we"/"us" implies all diabetics, or at least subscribers to the forum.

5. Concluding remarks

The results of our analysis confirm the bond between cognition and emotion that emerges in popularised texts relating to health (Merhy 2016: 147) where "emotions accompany and carry information". Merhy (2016: 148) discusses the fact that

> the globalization of scientific information has pushed discourse experts to look again at the concept of "style" in scientific discourse. The style in question here is one that speaks the mind through emotions, that arouses laypersons' and experts' curiosity at the same time and promotes research, reading, understanding and action, i.e. activities that require some cognitive contribution. In this regard, it is interesting to consider the interaction between emotion and cognition which purpose would be to succeed in transmitting and acquiring knowledge, including scientific information.

What is particularly significant is that the website managers exploit the forum area to make diabetics feel important. Their stories are newsworthy and are published on a par with those relating to breakthroughs in research. The use of the headline Diabetics R Us captures the sense of solidarity that regularly emerges in the overall social interaction. The style of the website staff in reporting diabetic topics is that of the newspaper genre in the headline and lead paragraph. The added hyperlinks below the bodycopy are quite varied from a linguistic point of view; they are either formal, as in a news summary headline, or more informal if they refer in some way to storytelling by a patient. The underlying reason for the publication of the story is obvious – the offering of practical knowledge and support, a message which is continually repeated in every contribution. Furthermore, the website staff present themselves as wanting to learn from diabetics. In turn, diabetics find themselves in a position of gaining not only knowledge about their condition from the website, but also experiential knowledge from their peers in an emotional bid for support in order to cope better on a daily basis.

If we consider the discursive features of the contributions, there is a clear distinction between those of the website staff introducing news relating to diabetes in general, and those selected and copied from the forum discussions. We have noted the informal style of the latter as discussants communicate with their peers, with generally succinct titles reflecting the spoken code in comparison to the popularised text that reports items of interest to the diabetic population following the structure of newspaper headlines. However, to these texts are added solicitations to respond, seek and follow advice, ask questions from those having the same condition. The illocutionary force of the news headlines, hyperlinks and thread titles, whatever their linguistic form, implies a precise perlocutionary effect, that of improving self-management and achieving empowerment with a chronic disease.

This paper has taken its premise from recent clinical literature, which claims that diabetics seek information and emotional support in online communication. It has attempted to show how, on a discursive level, a dedicated website responds to this need. It also gives examples of how discussants take up the stimulus and enter into dynamic interaction. Hernandez (2015: 194) summarises the justification for the kind of communicative support offered:

> Connecting with your peers and having an open dialogue about your experiences with this chronic condition make people start feeling understood and empowered and engage in a transformative way with their condition […] Also, patients who become empowered by social media connections become better advocates for themselves.

Patients seek to share information with and from their peers about their experiences in order to place their own in a so-called frame of daily normality. They do this by initiating an emotionally packed dialogue in an informal style typical of everyday conversation between people sharing a health condition. Through a social dissemination of knowledge in a virtual community of practice, and given the opportunity that social media affords, diabetics clearly attempt to achieve their goal of empowerment and self-management in the everyday normality of coping with their condition.

To conclude, this contribution has attempted to analyse diabetic discourse with a view to shedding further light on the ways in which computer-mediated health communication affords a more relaxed and informative environment in which diabetic patients interact with their peers, free from any inhibition many are likely to feel in face-to-face meetings, as confirmed by the clinical literature. It also shows how peer-to-peer interaction offers a positive contribution to improving the daily condition of living with a chronic disease, when it is not possible to expect a physician to be constantly available with an immediate answer. Since the discussion is mediated by the website site staff, it offers some guarantee regarding the quality and accuracy of contributions where patients relate their own practical knowledge and experience of coping. The paper has also shown how the presentation of news reporting on diabetes is characteristic of popularised scientific discourse as well as news media language in general. It is hoped that it has given a deeper insight into effective health communication for health professionals in order to fill an "institutional" gap in health provision. Furthermore, it has confirmed the relevance of strategic language choice in a virtual community that is not simply a powerful tool with which to inform, but just as importantly, to give emotional support to members who need to feel they are one of the group, as clearly advocated by the slogan "Diabetics R Us".

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Figuration and obesity: Warning bells from *TheGuardian.com*

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ABSTRACT

This study investigates the use of figuration in online articles related to the topic of the obesity epidemic. By using *SketchEngine* software tools, it analyses a corpus collected from *TheGuardian.com* (2009-2019) with the aim of identifying the figures of speech that are used to disseminate health information to non-experts. While a quantitative analysis of the key words collocating with the lemma *obesity* shows its relevance to health problems and diseases, such as diabetes, heart attacks, or depression, a qualitative analysis of figurative language in the corpus demonstrates that reporters privilege the use of metaphor, simile, metonymy, and hyperbole to increase individuals' health literacy and to help people make appropriate decisions related to nutrition, healthy eating, and physical exercise. The prevailing metaphors in the corpus and their related frames emphasise the damaging effects of obesity by triggering its association with 'destruction' (*obesity time bomb*) and 'death' (*fat, salt and sugar are killers*). The study demonstrates how health literacy through the media can raise people's awareness of the dangerous consequences of obesity and encourage them to 'fight' against this epidemic starting from an early age, or to undertake their 'journey' towards weight loss with perseverance.

Keywords: figuration, metaphor, metonymy, hyperbole, framing, health literacy, obesity.

1. Introduction

Health literacy (HL) concerns the knowledge, competences, cognitive and social skills necessary for lay persons to meet the complex health demands of modern society (Lorini et al. 2017). According to the Institute of Medicine (2004: 8), HL specifically involves "the individuals' capacity to obtain, process and understand basic health information and services needed to

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make appropriate health decisions”. In other words, an individual with an adequate level of health literacy has the ability to take responsibility for his own health, as well as his family and community health. Therefore, thorough information and clear communication between health professionals and non-experts are crucial to improving individuals’ health literacy, and, consequently, their health and the quality of healthcare.

As recently observed (Murphy 2010; Bondi et al. 2015; Cavalieri – Diani 2018), Web 2.0 has significantly changed the health communication environment by increasing accessibility to health information and aiding patients and citizens to make more informed decisions about their health and healthcare. Nowadays, several web-based popularising genres are used to disseminate scientific knowledge to a wide and inclusive audience, ranging from scientific blogs (Garzone 2012; Luzón 2013; Mauranen 2013) and wikis (Leuf – Cunningham 2001) to popular scientific journals (Vicentini 2013) and websites (Turnbull 2015a, 2015b), from Social Networks (Riboni 2014) to TED Talks (Scotto di Carlo 2013, 2014; Mattiello 2017, 2019).

The analysis of these new digital genres evidences linguistic strategies, such as the use of epistemic adjectives, deixis, narratives, humour, metaphor, etc., that bloggers, reporters, or TEDsters use to build and share information among heterogeneous discourse communities. The popularisation of science generally involves a reformulation or “recontextualisation” process (Calsamiglia – van Dijk 2004) which entails simplification of vocabulary and the use of analogies and associations of scientific concepts with everyday objects, thus favouring knowledge dissemination to the lay audience. This paper investigates the role of figuration in online newspaper articles on the topic of obesity, a medical condition in which excess body fat has accumulated to an extent that it may have negative effects on health.

Medical research demonstrates that obesity is most commonly caused by a combination of excessive food intake, lack of physical activity, and genetic susceptibility (Yazdi et al. 2015). According to the World Health Organization (2000) and the U.S. Department of Health and Human Services (2001), it has become a public health and policy problem because of its prevalence and health effects. Public health efforts seek to understand and correct the environmental factors responsible for the increasing prevalence of obesity in the population and comprehensive approaches are being looked at to address its rising rates. Measures for prevention and decrease include not only downstream policies trying to treat currently afflicted people, but especially mid- and up-stream policies trying to 1) alter individuals’ behaviour to achieve and maintain a healthy body weight, 2) promote the recognition of obesity as a major public health problem, 3) identify effective and culturally appropriate interventions to decrease it, and finally 4) encourage environmental and societal changes that help prevent obesity and corpulence. Due to its nationwide epidemic proportions, obesity is a central issue in health communication and the principal UK newspapers, such as *The Guardian* or *The Independent*, devote numerous articles to this topic in their health and wellness sections.[1] On the other hand, this is an under-researched aspect in health literacy, thus representing a gap in linguistic enquiry and communication research.

The aim of this paper is to examine the figuration strategies that reporters use to describe obesity as a major public health concern, resulting from a constant and complex interplay among environmental stimuli, wrong behaviours, and predisposing genes, as in this extract from *TheGuardian.com*:

(1) As a nation, we're getting fatter – and with obesity linked to a **myriad** of diseases the UK is facing a public-health '**time bomb**'. (30/01/2014)

combining hyperbole (*myriad*) and metaphor (*time bomb*) to describe obesity and its consequences.

The paper adopts a corpus-based approach (Sinclair 1991) to analyse a collection of 67 articles published in *TheGuardian.com* between 2009 and 2019. By using *Sketch Engine* software tools (Kilgarriff 2003), the paper integrates a quantitative analysis of the relevant keywords collocating with the lemma *obesity* with a qualitative analysis of the figures of speech that are used to enhance readers' health literacy in the three domains of health: i.e. healthcare, disease prevention, and health promotion.

In particular, the following research questions will be addressed in the paper:

1) What is the role of figuration in the improvement of readers' health literacy on the matter of obesity epidemic?
2) What are the most common associations triggered by obesity metaphors, similes, metonymies, and hyperboles, and what do they imply?
3) What are the possible consequences of figurative language use on people's behaviour and the choices of policymakers for themselves and society?

For the analysis of metaphor, hyperbole, and related tropes, the study integrates a cognitive approach (Lakoff – Johnson 1980; Lakoff – Turner

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[1] An advanced search of 'obesity' in *The Independent* website gives 12,500 results and the same search in *The Guardian* website gives 25,000 results (see § 3.1).

1989; Ruiz de Mendoza – Díez 2002; Herrero Ruiz 2008; Ruiz de Mendoza – Pérez 2011) with a discourse-based approach (Semino et al. 2016, 2017) in order to show the forms and functions of figuration in authentic language use, especially for communicating about sensitive topics such as obesity.

The paper especially uses the interdisciplinary concept of framing – often studied for its implications in political communication and competitive environments (e.g. by Chong – Druckman 2007; Scheufele – Iyengar 2014) – in order to investigate the dynamics of how journalists choose specific frames in health communication and how frames in communication influence people's frames in thought and may affect their opinion, a process which is often referred to as "framing effect" (Chong – Druckman 2007: 101).

Semino et al. (2016) have shown that the framing power of metaphor is particularly relevant in the area of healthcare, where the choice of different descriptions of diseases can have both positive and negative implications for the general well-being of people and guide them in taking informed decisions and making wise choices, such as avoiding energy-dense, fast-food meals and a sedentary lifestyle. In this paper, the emphasis is on the potential consequences for individuals of the use of non-literal language and framing to define, describe, and explain obesity to the lay public.

The discussion is divided into four main parts. Section 2 provides background on health literacy, science popularisation, figuration, and the framing concept. Section 3 explains how the corpus of relevant articles has been collected and the methodology and tools used for the analysis. Section 4 is devoted to the quantitative investigation of the semantic areas and collocations occurring in the corpus and to the qualitative study of the figures of speech and related frames. The discussion of results is followed by a concluding section claiming the importance of framing and figuration in obesity communication.

2. Background

2.1 Health literacy

Health literacy is a term introduced in the 1970s (Simonds 1974) and of increasing importance in public healthcare. Its current relevance to people's making accurate judgements and taking informed decisions has recently become evident, as remarked by Sørensen et al. (2012):

> Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (2012: 3)

In particular, four typologies of health literacy have been identified in the literature (Manganello 2008; Nutbeam 2008):

1) *Functional health literacy* refers to the basic skills in reading and writing that are necessary to function effectively in ordinary situations;
2) *Interactive health literacy* refers to more advanced cognitive and literacy skills which can be used to extract information and derive meaning from different forms of communication;
3) *Critical health literacy* refers to more advanced cognitive skills which can be applied to critically analyse information and use it to exert greater control over situations;
4) *Media literacy* refers to the ability to critically evaluate media messages.

These different typologies represent levels of knowledge and skills that progressively support greater autonomy in health-related decision-making, as well as engagement with a wide range of health knowledge that extends from personal health management to social and public health. The role of social media and the Internet in individuals' achievement of these basic and advanced cognitive and critical skills is fundamental.

In the United States, the Office of Disease Prevention and Health Promotion has developed three health websites – i.e. *health.gov*, *healthfinder.gov*, and *healthypeople.gov* – on the one hand, to help people obtain ready and reliable information on health topics, and, on the other, to aid professionals share scientific knowledge in ways that non-professionals can access. Unsurprisingly, special emphasis in these websites is placed on food and nutrition, which play a crucial role in health promotion and chronic disease prevention. In addition, every five years, the U.S. Department of Health and Human Services publishes the *Dietary Guidelines for Americans*, which serves as the science-based foundation for vital nutrition policies and programmes across the United States, and helps health professionals and policymakers guide Americans to making healthy food and beverage choices, and preventing diseases by recommending regular physical activity. Other web-based information can be accessed via different forms of science popularisation.

2.2 Popular science

New digital media are now having a significant impact on all types of specialised communication, both on the way specialists communicate with peers and on the dissemination of science to the lay public (Caliendo 2014). E-journals, e-magazines, blogs, and articles in online newspapers, in particular, provide an open space for specialised communication, where a diverse audience (with different degrees of expertise) may have access to information intended both for non-specialist readers and for experts. Popular science texts target a wide reading public, including non-specialists, due to their higher accessibility to large communities. The language of popularisations is close to general discourse and to the layman's everyday experience. In other words, terminology is not specialised, sector-specific terms are given only occasionally, and definitions are provided using descriptions or juxtaposition rather than copular structures.

This study concentrates on obesity and the way it is presented by reporters in *TheGuardian.com*. Obesity is a leading preventable cause of death worldwide, according to the World Health Organization (2018), with increasing rates in adults and children.[2] The study shows how the language of figuration can activate correspondences and associations in peoples' minds and assist them in taking more informed decisions about their health and healthcare, with special attention related to their diets and lifestyles.

2.3 Figuration

In the Contemporary Theory of Metaphor, or CTM (Lakoff – Johnson 1980; Lakoff 1993), metaphors are seen as mappings (or sets of correspondences) across different domains in conceptual structure. Expressions such as *He attacked my idea* or *I defended my position* are regarded as linguistic manifestations of conceptual metaphors, such as, in this case, ARGUMENT IS WAR. This conceptual metaphor involves the mapping of aspects of the 'source' domain of WAR onto aspects of the 'target' domain of ARGUMENT, where the source domain is less abstract (i.e. more accessible to sense perception) than the target. For example, within this metaphor, the arguers correspond to 'opponents' or 'enemies', criticising another person's ideas corresponds

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[2] Worldwide obesity has nearly tripled since 1975. In 2016, more than 1.9 billion adults, 18 years and older, were overweight. Of these over 650 million were obese. Over 340 million children and adolescents aged 5-19 were overweight or obese in 2016. (*WHO*, 16 February 2018).

to 'armed attack', defending one's position corresponds to 'defence from enemy', and so on. Lakoff – Johnson (1980: 10-13) emphasise that the choice of a source domain highlights some aspects of the target domain and hides others. For example, ARGUMENT IS WAR highlights the competitive aspect of arguments, but hides their potentially cooperative aspects. Metaphors are therefore regarded as important because they influence how we think about different kinds of experiences, and how we may consequently act.

In Cognitive Linguistics, metonymy is also viewed, like metaphor, as conceptual mapping. In particular, it is reference to an entity in a schema by referring to another entity in the same schema (Lakoff – Johnson 1980). An example of metonymy is COUNTRY STANDS FOR CITIZENS, as illustrated by *China is an obese nation*. In this metonymic expression, 'China' stands for the 'Chinese', who are described as an obese people. Unlike metaphor, which involves two conceptual domains, metonymy involves only one conceptual domain (and one of its subdomains) (Lakoff – Johnson 1980: 35-40; Lakoff – Turner 1989: 103). Thus, while metaphor involves a cognitive operation of domain highlighting, metonymy may involve either domain highlighting or domain expansion/reduction (Ruiz de Mendoza – Díez 2002): e.g., the citizens are a subdomain of the country.

Within the same framework, the cognitive process that underlies the generation of hyperbole is strengthening. According to Herrero Ruiz (2008), from the speaker's perspective, hyperbole is commonly held as a sort of reinforcement. It entails an increase or augmentation in the scalar magnitude of a linguistic utterance or word. An exemplification of this is in the expression *My suitcase weighs a ton!* or that of *She is as heavy as an elephant*, in which the speakers intentionally increase the weight of an object or person by using hyperbolic (exaggerated) words such as a *ton* or an *elephant*, thus implying 'excessive burden to carry' or 'being overweight'.

In the literature, the notion of hyperbole is often confused or conflated with extreme case formulations. Actually, although both concepts involve exaggeration, there are both similarities and differences between them. According to Norrick (2004: 1728), hyperbole and extreme case formulation involve overstatement. However, while extreme case formulations are extreme expressions which do not follow any fixed structure or formula (e.g. *all food producers*), hyperbole interacts with figurative meaning. For instance, in *She is as heavy as an elephant*, hyperbole interacts with simile: i.e. ELEPHANTS are large mammals commonly associated with large size and huge weight. Hence, the comparison with an elephant suggests 'overweight'. Like metaphorical language, hyperbole may be regarded as a way to highlight some aspects of a person or thing, such as excessive weight, and to encourage the others' response, such as helping someone with his/her heavy baggage, going on a diet, etc.

This study aims at showing how some specific uses of metaphor, simile, metonymy, hyperbole, or a combination of them can exploit different conceptual domains, such as DESTRUCTION or DEATH, to frame the topic of obesity in a way that should increase people's engagement in self-limiting prevention behaviours (e.g. not eating junk food) as well as in self-bolstering prevention behaviours (e.g. taking regular exercise).

2.4 Frames and framing effects

A large number of discourse-based studies have analysed choices of metaphorical or figurative expressions in authentic data to consider their implications for rhetorical effects, identities, social relations, ideologies, and so on. These studies are mainly concerned with the role of metaphor within the specific domains of communication from which textual data are drawn, such as politics (e.g. Musolff 2004) or healthcare (Semino et al. 2017). Many studies within this line of research explicitly adopt the notion of 'frame' (Fillmore 1985) to explain how choices of metaphor may relate to people's views and opinions on specific issues in specific contexts. Framing, indeed, is a process involving the use of language to reflect and facilitate different ways of understanding and reasoning about things. Cameron et al. (2010: 138), for instance, describe conceptual metaphors as "overarching frames which inform and influence discourse".

Given its interdisciplinary roots in sociology (Gamson – Modigliani 1987; Goffman 1974), the term 'frame' is used in two ways by communication scholars and political scientists (Scheufele 1999; Chong – Druckman 2007). First, a "frame in communication" refers to the words, phrases, and presentation styles that a speaker, such as a politician or a media outlet, uses when relaying information about an issue to an audience (Gamson – Modigliani 1987). For instance, when a journalist chooses the metaphor 'time bomb' to describe obesity. Second, a "frame in thought" refers to an individual's cognitive understanding of a given situation (Goffman 1974), such as interpreting the above metaphor as implying the destructive effects of obesity. Thus, while frames in communication reflect a speaker's emphasis, frames in thought refer to what an audience member believes to be the most salient aspect of an issue. Indeed, Entman (1993) provides a definition of 'framing' which stresses its aspects of selection and salience:

> Framing essentially involves *selection* and *salience*. To frame is to *select some aspects of a perceived reality and make them more salient in a communicating text, in such a way as to promote a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation* for the item described. (Entman 1993: 52; italics in original)

In framing research, Scheufele (1999) further distinguishes between the processes of "frame building", which focuses on the dynamics of how speakers choose specific frames in communication, and "frame setting", which concerns the influence of frames in communication on frames in thought, and the psychological processes at work. In this paper, the processes of frame building (how media outlets choose some frames) and frame setting (how the audience may interpret these frames) are investigated. Our focus is on framing effects:

> [F]raming effects refer to communication effects that are not due to differences in *what* is being communicated, but rather to variations in *how* a given piece of information is being presented (or framed) in public discourse. (Scheufele – Iyengar 2014: 2-3, italics in original)

We specifically examine how media outlets present (or frame) the topic of obesity in an online newspaper, i.e. *The Guardian*, and investigate how the use of figuration may contribute to influencing people's opinions and may ultimately have an impact on their behaviour.

3. Material and methods

3.1 Material

Articles on the obesity epidemic were systematically drawn from the website *TheGuardian.com* and collected to obtain a cohesive corpus on the topic. The *Guardian* website was chosen as a data source because (1) it offered several recent articles on the topic of obesity which were directly retrievable from the newspaper homepage, and (2) its readership is wide and comprehensive, including not only expert scientists, but also non-experts. Moreover, unlike other online health forums previously studied (Semino et al. 2016), where writers are heterogeneous (i.e. patients, family carers, and health professionals), an online newspaper can offer the more homogeneous and less spontaneous viewpoint of journalists.

To retrieve the articles, an advanced search of the lemmata *obesity*, *obese*, and *overweight* was carried out. This search of the website gave a total of 25,100 results, which were sorted by relevance. Close reading was then necessary to select relevant articles. Included were eligible articles which met the following criteria: (1) they concerned obesity or an overweight condition, and (2) they were dated within the time span 2009-2019.

The eligible articles were 67 and ranged in date from January 2009 to January 2019. They constitute our corpus (henceforth, Obesity Corpus), consisting of 60,004 running words, 71,203 tokens, and 2,646 sentences.

3.2 Methodology

Corpus-based and corpus-driven approaches are often used in linguistic research to integrate qualitative results (Sinclair 1991). In addition, recent studies by Elena Semino and colleagues (Semino et al. 2016, 2017) have shown that corpus linguistic methods are appropriate and needed in research on health(care) communication and demonstrate how corpus linguistics can contribute in terms of research findings, practical applications, and methodological 'bridge-making' between quantitative and qualitative approaches in health research.

For the corpus-based analysis conducted in this paper, Wordlist and Word Sketch,[3] the linguistic tools available on *Sketch Engine*, were used. Firstly, the Obesity Corpus was created on the platform by uploading the texts selected. Secondly, frequency lists of the most common nouns, adjectives, and verbs in the Obesity Corpus were automatically generated by the Wordlist tool. These lists allowed us to identify semantic areas and keywords related to the issue of obesity. Third, collocations and word combinations with obesity were identified by using Word Sketch.

These combinations suggested some figurative uses of language and allowed us to distinguish some main conceptual associations. In particular, inspired by previous research on frame semantics and the use of linguistic units to activate certain cognitive frames in argumentation (Bigi – Morasso 2012), keywords and collocations were considered in terms of the frames that they activate and of the overall rhetorical implications and inferential mechanisms involved.

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[3] *Sketch Engine* (Kilgarriff 2003) is a corpus tool which generates Word Sketches for a relevant word – i.e. corpus-based summaries of a word's grammatical and collocational behaviour.

Moreover, for the qualitative analysis of metaphorical and hyperbolic language, the *Guardian* articles were scrutinised and the language used was examined in depth in order to discriminate between literal and figurative uses of language. For the identification of figurative language use, the Pragglejaz Group's (2007) "metaphor identification procedure" (MIP) was used. This is an explicit and reliable method developed by a group of metaphor scholars, from a variety of academic disciplines, for identifying metaphorically used words in spoken and written language.[4] The results from the quantitative and qualitative analyses are discussed in Section 4.

4. Analysis, results, and discussion

4.1 Semantic areas

Table 1 displays the main results obtained from a Wordlist creation. The first column shows the semantic areas identified in the corpus. The other columns show the nouns, adjectives, and verbs (in order of frequency) belonging to the areas taken into account. Raw frequencies are provided after each word. Words under 5 occurrences have not been included.

Table 1. Semantic areas in the Obesity Corpus

Semantic area	Nouns	Adjectives	Verbs
WEIGHT	obesity 480, weight 243, size 43, overweight 43, BMI (body mass index) 40, amount 31, measure 31, loss 31, gain 26, mass 18, weight-loss 12, malnutrition 9, anti-obesity 6, fatness 6, thinness 5, waist (circumference) 5	obese 245, fat 163, overweight 127, thin 40, heavy 14, slim 11, obesity-related 8, fatty 7, underweight 7, skinny 5	lose 67, increase 54, reduce 50, weight 9, gain 8, measure 8

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[4] Researchers often differ in their intuitions about what constitutes a metaphorical word or phrase, and they generally do not provide objective criteria for specifying what is, and what is not, metaphorical. MIP was instead chosen for its objectivity, reliability, and precision in determining metaphorical uses of language.

FOOD and DRINKS	food 345, sugar 167, diet 128, drink 77, fat 70, calorie 66, fruit 53, junk 41, vegetable 40, consumption 36, nutrition 34, eating 32, Coca-Cola 30, fructose 29, meat 25, chocolate 23, energy 20, meal 20, salt 20, appetite 18, intake 17, restaurant 16, sweet 16, carbohydrate 15, kcal 15, snack 15, dinner 14, fish 13, alcohol 13, beverage 12, burger 10, hunger 10, McDonald 10, breakfast 9, glucose 9, biscuit 8, cheese 8, yoghurt 8, bacon 7, coke 7, chicken 7, confectionery 7, pasta 7, potato 7, cola 6, drinking 6, eater 6, feeding 6, lunch 6, rice 6, apple 5, carrot 5, ingredient 5, juice 5, pizza 5, salad 5, spaghetti 5	sugary 32, sweet 13, hungry 11, nutritional 11, dietary 9, sugar-sweetened 6, vegetarian 6, low-fat 6, saturated 6	eat 165, consume 32, overeat 17, cook 13, drink 11, feed 11, diet 9
HEALTH	health 277, doctor 33, smoking 23, drug 20, scientist 19, hospital 16, healthcare 15, nutritionist 14, cigarette 13, metabolism 13, care 11, insulin 10, cholesterol 8, medical 7, tobacco 7, dietician 6, wellbeing 5	healthy 132, medical 31, unhealthy 31, metabolic 10	smoke 7
AGE	child 247, adult 61, childhood 56, age 50, baby 31, adolescent 16, generation 16, kid 16, puberty 16, teenager 7, children 5, teen 5	young 36, old 12, teenage 8	
DISEASE	diabetes 83, patient 63, disease 62, heart 42, cancer 39, surgery 31, dementia 27, epidemic 27, endometriosis 17, medicine 16, stroke 16, blood 14, prevention 11, disability 11, Alzheimer 9, depression 9, fertility 9, addiction 8, disorder 8, illness 7, attack 6, anorexia 5, infertility 5	psychological 22, chronic 11, cardiovascular 10, morbid 5	affect 31, suffer 15, prevent 14, diagnose 6

GENETICS	gene 46, genetics 10, cell 7, obesogenic 6	genetic 30	
PHYSICAL EXERCISE	body 76, exercise 56, activity 42, lifestyle 31, sport 17, habit 17, fitness 10, gym 10, training 6, cartoon 5	physical 49, sedentary 13	move 23, run 19, walk 19, fit 13, exercise 12
ECONOMY	industry 78, company 49, product 48, tax 36, market 25, marketing 24, supermarket 23, promotion 23, business 22, consumer 21, sale 16, price 15, retailer 15, cost 11, funding 11, trade 11, manufacturer 9, money 9, economy 8, employer 7, profit 7, purchase 7, executive 6, customer 5, poverty 5	poor 33, cheap 16, rich 12, economic 10, expensive 6	promote 26, buy 21, spend 21, sell 13, fund 7
INSTITUTIONS	government 99, school 58, university 46, organisation 22, association 19, institute 19	public 52, social 46, political 5	
LAW	minister 15, ban 13, regulation 12, recommendation 9, order 8, law 6, legislation 6, guideline 6, authority 5, ministry 5, norm 5	right 16	ban 14, accuse 5
PROBLEM	problem 118, crisis 30, concern 19, solution 19, discrimination 13, prejudice 8, difficulty 5	serious 22	tackle 47, urge 17, worry 10, discuss 7, solve 5
DANGER	risk 105, damage 9, danger 7	severe 14, dangerous 6	warn 16, concern 9
DEATH	death 9, mortality 5		die 13, kill 5
WAR	fight 15, war 6, taskforce 5		fight 11, struggle 9, hit 8, combat 8, challenge 6
DESTRUCTION	time bomb 5		explode 5

It is not surprising that two wider areas in the corpus are related to 'Weight' and 'Food and Drinks'. Within 'Weight', the use of prefixes – *over-* (*overweight*), *anti-* (*anti-obesity*), and *mal-* (*malnutrition*) – suggests that, as far as weight is concerned, we are going in the excessive or wrong direction. Adjectives such as *thin*, *slim*, or *skinny* counterbalance the prevalence of *obese*, *fat*(*ty*) and *overweight*,[5] in the same way as the verbs *lose* and *reduce* compensate for *increase* and *gain*. Within 'Food and Drinks', we can notice two opposite directions. On the one hand, there is a tendency to highlight the foods and beverages that may be dangerous and cause obesity (e.g. *sugar*, *junk food*, *chocolate*, *sweets*, *carbohydrates*, *snacks*, *burger*, *bacon*, *Coca-Cola*, *coke*, *alcohol*, etc.). On the other hand, there is a trend to focus on the foods that are recommended in balanced diets (e.g. *fruit*, *vegetable*, *fish*, *carrot*, *salad*).

Other relevant data come from the area of 'Age', where the prevalence of words connected with young age (e.g. *child*(*ren*), *childhood*, *baby*, *puberty*, *adolescent*, *kid*, *teen*(*ager*)) implies that obesity especially affects people in their childhood or adolescence.

In the areas of 'Health' and 'Disease', we find medicine-related information. Obesity indeed increases the likelihood of various diseases and conditions, particularly *cardiovascular diseases*, *Type-2 diabetes*, certain types of *cancer*, *depression*, *dementia*, *Alzheimer's disease*, *infertility*, *endometriosis*, and eating disorders, such as *anorexia*.

As we understand from the areas of 'Genetics' and 'Physical exercise', obesity is the result of an interplay between genetic and environmental factors. It is mostly preventable through a combination of personal choices and social changes. Changes to diet and physical exercise are the main treatments. Diet quality, for instance, can be improved by reducing the consumption of energy-dense foods, such as those high in fat or sugars, and by increasing the intake of dietary fibre. Recourse to experts (*nutritionist*, *dietician*) may increase the capacity to control *appetite* and *metabolism*. *Smoking*, instead, has a significantly bad effect on an individual's weight, in that it commonly happens that those who quit smoking, generally gain weight ('Health').

Other causes of obesity appear to be correlated with economic and social factors, such as wealth or social class ('Economy'). For instance, in the developing world, men, women, and children from high social classes have

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[5] In idioms, such as *fat cat*, the adjective *fat* acquires a completely different meaning and is rather associated with wealth.

greater rates of obesity. On the other hand, the wealthy are able to afford more nutritious food and have more opportunities for physical fitness, therefore decreasing their risk of obesity.

The roles of the 'Institutions' and 'Law' may instead contribute to preventing obesity. For instance, the verb *ban* is used in the corpus as related to: (1) banning the advertising of junk food during breaks in children's programming, (2) banning fast food outlets from opening near schools, (3) banning the sale of sugary drinks and unhealthy foods from the school environment, or also (4) banning multi-buy offers on junk food. By contrast, experts should call for schools to *promote* health and nutrition literacy and physical activity.

Less numerous but still significant data come from the areas of 'Problem', 'Danger', 'Death', 'War', and 'Destruction'. Obesity is a leading cause of death worldwide, with increasing rates in adults and children. It is viewed as a *problem*, a matter of *concern*, a *crisis* with no *solution*. Nouns such as (*mortality*) *risk*, *danger*, even *death* cannot but alarm readers, who can perceive obesity either as a *time bomb* which is going to *explode*, or as a *fight*, a *struggle* to *combat*. The latter expressions suggest a metaphorical use of the language.

In general, the language used in the *Guardian* Obesity Corpus is not highly specialised. With the exception of *body mass index* (*BMI*) – i.e. a measurement obtained by dividing a person's weight by the square of the person's height – sector-specific vocabulary is also accessible to non-professionals. Let us check now the specific words collocating with *obesity*.

4.2 Collocations

Table 2 shows the main results obtained from a Word Sketch of the word *obesity* (480 occurrences). The first column shows the syntactic patterns of the combinations. The second column shows the collocations with their frequencies. (Obesity is abbreviated as 'o.')

The most common words pre-modifying *obesity* are *childhood* (33 occ.) and *child* (9 occ.), whereas *adult obesity* occurs only twice. The adjectives *severe* and *morbid* suggest that, especially early in life, this condition is becoming pathologic. As a modifier, *obesity* occurs with nouns having negative connotations, such as *crisis*, *epidemic*, or *problem*. These combinations confirm the alarming tone, in that obesity increases the risk of many physical and mental conditions, all listed as coordinated nouns in the corpus (*overweight*, *malnutrition*, *thinness*, (*type* 2) *diabetes*, *weight gain*).

Table 2. Collocations of "obesity" in the Obesity Corpus

Pattern	Collocations
MODIFIER + obesity	childhood o. 33, child o. 9, severe o. 6, morbid o. 5, adult o. 2
Obesity + NOUN	o. crisis 18, o. rate 14, o. epidemic 12, o. problem 7, o. expert 4, o. programme 4, o. gene 2, o. plan 2, o. trend 2
VERB + obesity	tackle o. 10, combat o. 3, fight o. 3, prevent o. 3, rise o. 3, treat o. 3, o. is linked 3, help (tackle) o. 3, cause o. 2, eliminate o. 2, o. is determined 2, reduce o. 2
Obesity + VERB	o. is 50, o. has 10, o. has become 3, o. is costing 2, o. has lead 2
Obesity and/or X	overweight and o. 8, o. and diabetes 7, metabolism and o. 3, o. and health 3, diet and o. 2, malnutrition and o. 2, thinness and o. 2, weight gain and o. 2, weight and o. 2, o. and type 2 diabetes 2
Obesity is a X	o. is the new smoking 3, o. is increasingly a problem 2, o. is the cause 2

The frequent occurrence of *obesity* with the copular verb *be* lastly implies that this condition is variously defined in the corpus. One of the definitions – *obesity is the new smoking* – introduces a form of metaphor associating obesity with the practice of inhaling tobacco smoke. Obesity and smoking actually share a set of correspondences: they generally target a young or adolescent public and have negative consequences on the body, increasing the risk of developing diseases and causing death by cancer.

Definitions of obesity in the corpus are traditionally given in the form *obesity is…*. However, the copular verb is mostly followed by atypical definitions, which avoid specialised vocabulary or scientific names, and rather opt for simple vocabulary (e.g. *obesity is a chronic disorder of appetite regulation*), and often just emphasise its causes or consequences. In general, in the Obesity Corpus, obesity is not scientifically defined, but rather variously described as a problem (*a growing* (*health*) *problem*, *a complex problem*, *increasingly a problem among young Americans*, *a biological problem*), a risk (*a risk to health*), a challenge (*a global public health challenge*), the consequence of economic growth (*a natural extension of an advancing economy*), or of a psychological disorder (*the consequence of an underlying psychological problem*). It is also described as a choice (*a lifestyle choice*), or even as a form of prejudice (*the last socially acceptable form of prejudice*).

Some definitions regard obesity as the cause of some disease, such as diabetes (*one of the leading causes of Type 2 diabetes*), or more often cancer (*the leading cause of the cancer deaths in the US*, *the cause of one in five cancer deaths*, *second only to smoking as the biggest preventable cause of cancer*). Still other definitions describe obesity by specifying what it is not, i.e. by negation (*obesity is no one's choice, as everyone wants to be thin*, *obesity isn't a psychological problem*, *obesity is not a disability*). Although all these definitions warn *Guardian* readers against obesity, especially from an early age, and advise them of its dangerous consequences, it is by the use of figuration that reporters better depict obesity as one of the most serious public health problems of the 21st century.

4.3 Figurative language

The Obesity Corpus was then manually analysed for metaphorical expressions and other figurative comparisons. For the analysis, we followed the metaphor identification procedure (MIP) (Pragglejaz Group 2007), according to which an expression is regarded as metaphorically used when its 'contextual meaning' contrasts with a more physical and concrete 'basic meaning', and where the former meaning can be understood via a comparison with the latter (e.g. the use of 'time bomb' in the expression 'the obesity time bomb', or the use of 'mountains' in 'mountains of burgers'). Each metaphorical expression or other figurative use was further allocated to a semantic field such as 'War', 'Destruction', 'Death', 'Journey', on the basis of its basic meaning. Finally, the latter fields were considered in terms of framing effects on the audience.

4.3.1 'War' metaphors

A qualitative analysis of the Obesity Corpus shows the use of several violence-related metaphorical expressions. We have identified in our data expressions which can be seen as instances of traditional 'violence', 'military', or 'war' metaphors (cf. Semino et al. 2016), such as those in examples (2)–(7):

(2) British cardiologist-led team accuse food and drink firms of over-emphasising how sport can **fight** obesity. (29/11/2017)

(3) The **fight** against obesity starts in the head, not in the stomach. (17/10/2013)

(4) Egypt's obesity **battle**: 'No one cares about calories here'. (28/11/2017)

(5) The discovery of a gene that is so central to how the body uses energy and puts on weight could lead to therapies that help **combat** obesity more generally. (24/10/2013)

(6) The NHS is **struggling** to cope with the burgeoning obesity crisis. (18/08/2018)

(7) If you look at the **fight** against childhood obesity as a **war**, which it should be looked at as, it has to be multifaceted – business, home and government. (29/04/2018)

Following Lakoff – Johnson (1980), expressions such as 'fight', 'battle', 'combat', 'struggle', or 'war' have tended to be interpreted as realisations of conceptual metaphors involving WAR as the source domain. At a general level, these metaphors can be explained in terms of a basic metaphor, DIFFICULTIES ARE OPPONENTS, which, in Grady's (1997) terms, can be seen as a 'primary metaphor' arising from an experiential correlation between difficulties and aggressors. Obesity in these examples is regarded as an enemy to fight. The fighters include physical activity (*sport* in 2), psychological influences (*head* in 3),[6] diet (*calories* in 4), medical and public health system's help (*therapies* and *NHS* in 5-6). On the other hand, the underlying opponents involved in the 'war' are manifold (*business*, *home and government* in 7).

In terms of framing effects, presenting obesity in the negative context of war triggers the implication of conflict, violence, aggression, and mortality on the one hand, but also struggle to overcome, or even effort to win, on the other.

4.3.2 'Destruction' metaphors

The Obesity Corpus also evidences the use of metaphorical language to lay emphasis on the destructive effects of obesity. Instances of 'destruction' metaphors are:

(8) The sugar tax was a start – but on its own won't beat the obesity **time bomb**. (26/11/2018)

(9) Obesity is linked to other health issues, such as diabetes and strokes, so the cliché of the "public-health **time bomb**" is probably apt. (30/01/2014)

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[6] Here 'head' is used metaphorically and metonymically to refer to one's 'mind' (i.e. HEAD IS CONTAINER, HEAD STANDS FOR MIND) (cf. STOMACH IS CONTAINER, STOMACH STANDS FOR FOOD in the same example).

(10) It is this body-mass **time bomb** that is the most worrying aspect of China's nutrition status. (06/10/2017)

(11) Peter Gluckman, a co-chair of the commission, said childhood obesity had become "an **exploding** nightmare" in the developing world. (29/11/2017)

(12) Today, many countries in the global south are seeing an **explosion** of these [diabetes and obesity] afflictions. (13/08/2018)

(13) China has the opportunity and the means to show the rest of the world how to slow and reverse the apparent **tsunami** of obesity. (06/10/2017)

Expressions such as 'time bomb', 'exploding', 'explosion', or 'tsunami' are realisations of conceptual metaphors involving DESTRUCTION as the source domain. At a general level, these metaphors can be explained in terms of a primary metaphor, DRAMATIC INCREASE IS VIOLENT BURST, arising from a correlation between the uncontrollable and violent spread of obesity and devastation.

As these examples show, one of the commonest associations is between obesity and a 'time bomb', stressing the idea that obesity is a condition difficult to deal with and control. The 'explosion' and 'tsunami' metaphors support the same associations between obesity and a violent burst or movement, as that provoked by an explosion, or an ocean wave that is caused by an earthquake under the sea. In (11), the idea of destruction is accompanied by fear, as suggested by the metaphorical expression *exploding nightmare*.

Again, obesity is presented in a negative frame of destruction, violence, and damage. This frame triggers the idea of ruin and physical devastation which attends the overweight and is associated with the diseases or medical disorders that may affect people carrying excessive weight.

4.3.3 'Death' metaphors

The Obesity Corpus also shows the use of metaphorical language to call attention to the lethal effects of obesity, ultimately leading to death or end of life. Examples (14)–(19) illustrate 'death' metaphors:

(14) Obesity […] is the **HIV** of our age. It is **killing** millions of our patients. (14/02/2018)

(15) We mustn't let morbid obesity **kill** our potential. (02/08/2018)

(16) Tough action must be taken to show fat, salt and sugar are **killers**, like cigarettes. (26/11/2018)

(17) Sugar, not fat, exposed as **deadly** villain in obesity epidemic. (20/03/2013)

(18) Obesity […] results in the tragic **waste of lives**. (02/08/2018)

(19) Producers of bad food must be made ashamed for **poisoning** our bodies. (26/11/2018)

Obesity is described as a disease which 'kills' people, both physically and morally. It is even associated with the virus that causes AIDS, like a modern 'HIV'. Expressions such as 'killer', 'deadly (villain)', 'waste of life', and 'poisoning' are all realisations of conceptual metaphors involving DEATH as the source domain. In these examples, the killer is either obesity (14, 15, 18), or bad food, such as fat, salt, and sugar (16, 17). In (19), producers of junk food are also described as 'poisoners', who are killing people by producing unhealthy food. At a general level, these metaphors can be explained in terms of a primary metaphor, DISEASES ARE KILLERS, arising from a correlation between disease and decease.

Death metaphors as illustrated in (14)–(19) activate a negative frightening frame of mortality risk and reduction of life expectancy. Obesity is presented as one of the leading causes of negative health effects and death worldwide, competing only with smoking or HIV. This terrifying frame contributes to scaring the audience and to activating an idea of alarm, warning of danger, as well as to creating anxiety and fear.

4.3.4 'Journey' metaphors

In the Obesity Corpus, we can also identify instances of metaphorical language that evoke a journey. Examples (20)–(25) specifically illustrate 'journey' metaphors:

(20) The food industry is beginning to provide "healthier" options, but these are only the first **steps** of a long **journey** to tackle and reverse the obesity epidemic. (16/05/2013)

(21) The important issues in any weight-loss **journey** are the individual's desire to lose weight and the reason why they are obese in the first place. (17/10/2013)

(22) The **journey** to best-in-class nutrition and food safety science research has been a circuitous one. (10/01/2019)

(23) South Africa is already far along this obesity **trajectory**, with many other African countries following along that **course**. (29/11/2017)

(24) In short, your DNA is not a **barrier** to weight loss. (14/02/2018)

(25) The aim of treatment should be to address the mental state which caused the weight gain in the first place, thereby removing the main **barrier** to successful weight loss. (15/01/2009)

In the CTM (Lakoff – Johnson 1980), classical examples of analysis of conceptual metaphor are LOVE IS A JOURNEY and LIFE IS A JOURNEY. Similarly, in our corpus, the notion of motion along a path towards a destination is used in order to reason about the process of weight loss, as revealed by linguistic expressions like 'journey', 'steps', 'trajectory', 'course', and 'barrier' in examples (20)–(25). These expressions reveal the existence of an underlying system of conceptual correspondences between weight loss and journey (SLIMMING IS A JOURNEY), in which obese people are seen as travellers on a journey, weight loss is the destination or goal, the right direction or trajectory to achieve this goal is that balancing a healthy level of physical activity with eating a nutritious diet, and barriers are obstacles on the journey. In this case, journey metaphors are complex forms of the primary metaphor PURPOSES ARE DESTINATIONS (Grady 1997).

In terms of framing effects, the positive frame triggered by journey metaphors offers support, and encourages self-esteem, hope, and persistence. The audience affected by corpulence can be reassured by the concept of a journey implying that there is a possible path to weight loss and a healthy life.

4.3.5 Similes

Similes are less common than metaphors in the Obesity Corpus. They are mainly illustrated by examples (26)–(29):

(26) Obesity is a bit **like smoking**: the tumours don't start growing right after the first cigarette. (05/01/2019)

(27) It's wrong to focus on obesity as a 'national risk' **like terrorism**. (29/11/2017)

(28) For children's health, the government has to treat sugar **like cigarettes**. (05/01/2017)

(29) It's [sugar is] addictive and toxic, **like a drug**, and we need to wean ourselves off it, says US doctor. (20/03/2013)

These examples equate obesity with smoking, or even terrorism, and sugar with cigarettes or drugs. The explicit association (*like*) between obesity and 'smoking' and between sugar and 'cigarettes' creates a conceptual correspondence based on the bad consequences for one's health. Like smoking cigarettes, eating sugary food and suffering from obesity are considered as leading causes of cancer. On the other hand, the association with 'terrorism' creates a relationship based on the national spread of both the obesity crisis and terrorism, as well as the risk and danger that they involve. Finally, comparing sugar with 'drug' activates the ideas of addiction, dependence, on the one hand, and toxicity on the other.

The framing effects are here produced by competing frames, simultaneously triggering danger, risk, and dependence on food as main concepts.

4.3.6 Metonymies

A qualitative analysis of the Obesity Corpus also shows the use of some metonymic expressions, as illustrated in (30)–(35):

(30) This places the blame for **our expanding waistlines** directly on the type and amount of calories consumed. (29/11/2017)

(31) This total makes China the second most **obese nation** after the USA. (06/10/2017)

(32) The UK is the most **obese nation** in western Europe. (18/08/2018)

(33) But the social facts suggest **Britain would get thinner** if everyone had enough of life's opportunities to be worth staying thin for. (02/08/2018)

(34) When China's healthcare researchers first uncovered a significant expansion in **the nation's waistline** they were looking to investigate something else entirely. (06/10/2017)

(35) We need to **de-sweeten our lives**. We need to make sugar a treat, not a diet staple. (20/03/2013)

In these expressions, we can identify a metonymic 'stands for' relationship between a domain and one of its subdomains. For instance, in (30), the 'waistline', which is increasing in size, stands for the whole body, here typically represented by the imaginary line going round the narrowest part of one's waist. In (31)–(33), reporters play on the adjectives 'fat', 'obese', and 'thin' applying them to nations (*China*, *UK*, *Britain*). These metonymic mappings associate citizens with their nations (NATION STANDS FOR CITIZENS), thus suggesting that the obesity crisis is affecting whole countries and is becoming a problem at a national level. In (34), we even have a combination of the two former metonymies WAISTLINE STANDS FOR BODY and NATION STANDS FOR CITIZENS, in that the 'nation's waistline' stands for the 'nation's body', and the latter stands for the 'citizens' body'. The activated frame is again a negative one, triggering such ideas as widespread risk and national problem.

Finally, in (35), a metonymic mapping occurs between 'life' and 'diet'. The verb *de-sweeten* is indeed applied to people's *lives*, but it actually refers to the act of removing sugar and other sweets from people's diet.

4.3.7 Hyperboles

Hyperbolic language in the Obesity Corpus tends to be used to exaggerate the dangerous effects of either obesity or sugary foods and beverages causing it. Some instances of hyperbolic language are reported in (36)–(42):

(36) Obesity is going to surpass cigarette smoking as the **leading** cause of the cancer deaths in the US. (20/09/2017)

(37) Ready meals and the **thousands** of other products available in supermarkets have a real impact on public health. (30/01/2014)

(38) The **rivers** of Coca-Cola and Pepsi consumed by young people today have as much to do with obesity as the **mountains** of burgers. (20/03/2013)

(39) Junk food companies seeking growth markets are **flooding** poor countries with cheap, unhealthy food. (13/08/2018)

(40) To reach these potential consumers, large food corporations are infiltrating, **inundating** and taking over traditional food distribution channels around the world. (13/08/2018)

(41) From child hunger to obesity: Brazil's new health **scourge**. (19/05/2014)

(42) Budget day rarely brings huge victories for public health like last week's **bombshell** – a sugar tax on fizzy drinks. (26/11/2018)

Example (36) specifically illustrates extreme case formulation, which involves a quantitative shift between the concept encoded and the concept contextually constructed. Obesity is here described as *the leading cause of the cancer deaths in the US*. This amplified or exaggerated statement is meant to emphasise the serious medical condition caused by obesity, which in the US is considered to be one of the main causes of cancer deaths, comparable to smoking. The extreme expression *leading* used in (36) aims at making readers aware of the devastating consequences of excessive weight. Similarly, the extreme expression *thousands* in (37) exaggerates the number of products sold in supermarkets which may have a bad influence on people's health.

Examples (38)–(42) instead provide instances of hyperbolic metaphors, which involve both a qualitative and a quantitative difference between the concept encoded and the concept contextually constructed. Some of these hyperboles are based on the conceptual metaphors FLOOD IS LARGE AMOUNT (*rivers of Coca-Cola and Pepsi*, *flooding poor countries with cheap, unhealthy food*, *inundating traditional food distribution channels around the world*) and MOUNTAIN IS LARGE QUANTITY (*mountains of burgers*). Another hyperbolic metaphor maps obesity on widespread suffering (*obesity: Brazil's new health scourge*), whereas the last one describes the shocking news on sugar tax as an explosion (*last week's bombshell – a sugar tax on fizzy drinks*). The related hyperbolic metaphors are WIDESPREAD SUFFERING IS EPIDEMIC and SHOCKING NEWS IS EXPLOSION. The framing effects obtained via the use of hyperbolic metaphors do not depart from, but rather confirm, the negative frame of danger and destruction already envisaged.

4.4 Discussion

A combined quantitative and qualitative analysis of our corpus shows the importance of making people aware of the seriousness of the obesity epidemic, as a problem per se and as the main cause of many negative physical and mental conditions. The identification of frequent semantic areas and their relevant lemmata shows that obesity is a leading preventable cause of *death* worldwide ('Death'), with increasing rates in adults, but above all in *children* ('Age'). Semantic areas such as 'Food and Drinks' and 'Physical exercise' suggest that obesity is mostly preventable through a combination of lifestyle changes and personal choices. Changes to diet – e.g. preferring *vegetables* and *fruit* to *snacks*, *chocolate*, or *alcohol* – and exercising – e.g. *physical activity* and *gym* workout – are the main treatments. The semantic areas of 'Health', 'Disease', 'Problem', and 'Danger' lay emphasis on the fact that obesity increases the risk of displaying health problems later in life. Medical disorders include *diabetes* mellitus type 2, *cancer*, cardiovascular diseases (*heart attack/stroke*), etc., whereas neurological and psychiatric diseases include *dementia* and *depression*.

The quantitative analysis of both frequencies and collocations shows that in *Guardian* articles obesity is mainly regarded either as a *morbid/severe epidemic* to *prevent*, or as a *problem* to *tackle* and possibly *reduce* or *eliminate*. The collocation *obesity is the cause* focuses on the main consequences of this condition, among which cancer death seems to prevail.

The collocation of obesity with verbs such as *fight* or *combat*, as well as the phrase *obesity is the new smoking* evidence a use of figurative language in the corpus, which is confirmed by a close reading of the articles and a qualitative analysis of some metaphorical expressions, or similar non-literal language use.

The different kinds of metaphorical expressions that we previously captured in terms of the broad source domains WAR, DESTRUCTION, DEATH, and JOURNEY can be grouped and labelled according to the more specific types of framing that they suggest. In our data, *fight* as noun and verb, *battle*, and *war* are used as parts of expressions that suggest a framing of war, with OBESITY IS ENEMY TO FIGHT as conceptual metaphor. Words such as *time bomb*, *explosion* and *tsunami* instead suggest a framing of destruction, with DRAMATIC INCREASE IS VIOLENT BURST and SPREAD IS EXPLOSION as related conceptual metaphors. In addition, words such as *kill*, *killer*, and *poison* activate a framing of death, with both obesity and sugar as killers, respectively connected with the primary metaphors DISEASES ARE KILLERS and BAD DIET IS DEATH. Still another group of metaphorical expressions describe weight loss as a *journey* (SLIMMING IS A JOURNEY), with a right *trajectory*, different *steps*, and some possible obstacles or *barriers* on the pathway. The role of multiple competing frames in the frame-building process in health communication shows how journalists try to activate either a negative frame of destruction, alarming risk, and mortality on the one hand, or a positive frame of encouragement and hope on the other, mainly triggered by journey metaphors.

Other figurative uses of language include simile, equating obesity with smoking (*obesity is like smoking*), and metonymy (*obese nation*), whereby the individual's condition of being obese is transferred to a national level, thus becoming a country's problem (NATION STANDS FOR CITIZENS). Lastly, hyperbolic language contributes to increasing the alarmed, worried tone of the *Guardian* reporters: expressions such as *thousands*, *rivers*, *mountains*, or *flood/inundate* suggest that the amount of unhealthy food and sugary drinks that are entering our supermarkets (and our homes) is huge and out of our control, and government intervention would be necessary in the economy and the marketplace.

5. Conclusions

In this article we have focused on figurative language and the 'framing' function of metaphor as a phenomenon that is relevant from the different perspectives of cognition and discourse. We have used a corpus of articles on obesity taken from *TheGuardian.com* as a case study to demonstrate the value of quantitative (corpus-based) investigation integrated with qualitative analysis to identify patterns of metaphor in context, as well as other non-literal language used to describe and explain obesity, its causes, and consequences.

The analysis shows that metaphors, metonymies, and hyperboles are used to increase people's awareness of the various issues and concerns that revolve around obesity, but they do not work in the same way. Some war-related metaphors, for instance, can be motivating and encouraging for patients who suffer from obesity, but they might also have negative and frustrating consequences on those patients who feel that they are not going to 'win the battle'. Destruction-related and death-related metaphors are certainly used to increase people's awareness of the overflow of the obesity epidemic, of its morbidity rates, and lethal force. A much more positive attitude is instead underlined by journey-related metaphors, describing the patient's weight loss process as a 'journey', with different treatment and care plans referred to as 'pathways'. The latter metaphors especially play a role in the creation of positive framing effects.

Country-related metonymies are also used in our corpus to inform people of the national interest in obesity, which has grown from an individual's problem to a general nation-wide one, affecting most of the population, especially from an early age. The intrinsic exaggeration of hyperbolic language contributes to amplifying the problem not only of the obesity crisis, but also of the unhealthy food and sugary drinks 'flooding' the supermarket's shelves. The presence of competing frames in communication, both positive and negative, can have opposite effects on the audience, hovering between the alarming frames of risk and end of life and the reassuring frame of journey towards a healthy life.

As for health literacy, the use of figurative language can facilitate people's access to and understanding of health information in order to make appropriate judgements and take informed decisions about healthcare and disease prevention. In particular, being more aware of the consequences of figurative language use can have implications for practice in communication.

From the writer/speaker's perspective, awareness can help reporters and healthcare professionals to pay close attention to specific word choices and to use language more cautiously, avoiding 'war' and 'fight' metaphors, which may create expectations about treatment or disillusion and disappointment with poor results, and favouring 'journey' metaphors that encourage obese people to undertake a long 'path' with perseverance, and to proceed 'step by step'. Metonymies in which the 'country stands for its citizens' can also be used to focus people's attention on the vastness of the problem, which is large-scale rather than individual. This metonymy can be used to make people feel they are not 'travelling alone' in their weight loss 'journey'.

From the reader/hearer's perspective, awareness can help non-experts to take more informed decisions about their healthcare and the health of their families, especially in daily choices. For instance, 'destruction' and 'death' metaphors can be interpreted as warnings about the dangerous effects of obesity, and help people realise that their current actions will have future consequences. Similes matching obesity with 'smoking' or 'drug' especially focus on the harmful effects of overweightness, while the equation with 'terrorism', as well as 'explosion' and 'tsunami' metaphors signal the violence of the phenomenon. In addition, hyperbolic metaphors referring to the 'rivers' of sugary drinks and 'mountains' of hamburgers and similar junk food sold by fast food companies and supermarkets can alert readers to the risks to which (especially) the young are exposed, and perhaps guide them in their choices, such as taking a walk rather than using their cars, or reducing daily amount of sugar intake rather than buying unhealthy food.

In general, this study demonstrates the important role of figuration and appropriate language when communicating with the public or patients about healthcare. It supports previous findings from the analysis of health online forums (Semino et al. 2016) that sensitive communication can improve information-provision, support, self-management, and self-esteem, and especially confirms the power of hyperbolic metaphors in effective communication.

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Online health information for the elderly[1]

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ABSTRACT

The aim of this paper is to investigate how health information and advice is communicated to the elderly on the Internet, which can be considered one of the main sources of information nowadays, even for the older generations. Recent studies have shown that there is a worryingly low level of health literacy among the elderly. As a consequence, the quality of health information made available to the public is of utmost importance. The analysis is made using a theoretical framework that takes into consideration both the cognitive and communicative dimensions of knowledge transfer, as well as the use of multimodality. The cognitive aspects cover the strategies adopted to explain 'technical' information to the reader, as for example through the use of definitions, examples, scenarios, metaphor in order to facilitate understanding, whilst the communicative strategies aim to establish a relationship of trust between the addresser and addressee. The study will also consider the role of lay knowledge.

Keywords: health information, the elderly, technical knowledge, advice giving.

1. Introduction

In recent years the medical profession has been paying greater attention to the question of health literacy as a means of empowerment for individuals to make informed decisions about their health and well-being (Sak et al. 2017). Health literacy may be defined as "the capacity that an individual

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has to access and effectively use health-related information, in order to promote and maintain good health" (https://ecdc.europa.eu/en/health-communication/facts/health-literacy). However, recent studies have shown that there is a worryingly low level of health literacy, both in the EU, where on average 47% of the population have limited health literacy (Sørensen et al. 2015), and in the UK, where only 43% of participants in the survey reached a threshold level (Rowlands et al. 2015). Among the risk factors quoted are socio-economic status, race, cognition, education level and age, which is, in fact, one of the highest correlates (Chesser et al. 2016: 1). Several age-related changes could account for low level literacy among the elderly, such as decline in cognitive ability, physical impairment including hearing or vision loss and psychosocial factors. The problem is compounded by the fact that, as people age, they face more and more health challenges and become increasingly vulnerable, often having to learn to manage and live with a number of chronic conditions. They may also feel embarrassed as they become aware of their failing cognitive abilities (Chesser et al. 2016: 1).

Limited health literacy has been shown to be associated with worse health status and higher rates of hospitalization. The human, social and economic consequences of low health literacy among the elderly will therefore become a major challenge in the near future as the share of elderly persons (aged 65 and over) among the population rises, and in particular with a rapid increase in the number of very old persons (aged 85 and over) (Eurostat 2015: 134). As a consequence, the quality of health information made available to the public has become of fundamental importance and the subject of many studies.

The aim of this paper is to investigate how health information is communicated to the elderly on the Internet, which can be considered one, if not the main source of information nowadays, even among the older generations. Indeed, the Eurostat survey (2015) reported that in 2014 38% of the elderly population in the EU, defined as those aged 65-74, used the Internet on a regular basis, at least once a week. This is compared with just 7% ten years earlier. And certainly, as younger generations who have used the Internet move into the older age groups, the number of 'silver surfers' will continue to increase. What is more, there has been a shift in the role of the patient from passive recipient to active consumer of health. Nowadays, a patient may want to gather information on the Internet about illnesses and conditions for personal interest, but often he will go to the doctor "armed" with that medical information ready to discuss and perhaps even challenge advice.

2. Health information

Specialized knowledge is not just a problem of technical content, but also of a specialized register and terminology. For knowledge to be transferred from expert to layperson it has to undergo a process of simplification that remodels both the language and content to suit the new target audience. This rewriting enables the reader/listener "to construct lay versions of specialized knowledge and integrate them with their existing knowledge" (Calsamiglia – van Dijk 2004: 370).

However, health information aims not only to improve the factual knowledge of the patient, but above all to convince him of the necessity and advantages of adopting a particular treatment or lifestyle. The information, therefore, has to be presented in a form of argumentation that has been described as "info-suasive", in which information and persuasion are blended inextricably (Schulz – Rubinelli 2008). The traditional, paternalistic approach to patient care tends to ignore personal preferences, but nowadays a focal point of health care is the patient-centred approach. It views the patient not just in terms of his illness or a set of symptoms, but rather as a person with emotions, feelings, needs and preferences (Mead – Bower 2000). An essential element of this approach is empathy, which involves the ability to understand another person's experiences and feelings and view them from their perspective (Hojat et al. 2002: 1563).

Another important element that needs to be taken into consideration is trust, as information and advice will be accepted only if trust is established between writer and reader. The source of the information needs to be credible (Neubaum – Krämer 2015: 872) and trust is greatest between people who share group identities and have similar values (Earle 2010: 543). The asymmetrical relationship between doctor and patient, expert and layman, may therefore constitute a problem in effective communication, especially if there is "a tendency to over-emphasise his role as the doctor and expert" (Gülich 2003: 258).

In any case, as Harvey et al. (2013) and Adolphs et al. (2004) suggest, giving advice is a delicate task, because it is generally considered face-threatening in Anglo-Western contexts. Certainly the addresser is giving recommendations of what he thinks is best, which leaves an option open to the patient to adhere to the advice or not. The reader, nevertheless, may not be very receptive and view advice as indirect criticism. This means that the argument presented to persuade the reader needs to be not only 'reasonable' in the sense of logical, but also 'acceptable' to his point of view (Grasso et al. 2000: 1078).

3. Online communication

Although there is an abundance of information available on the Internet, searching and gathering information is not as simple as it would appear. The sheer amount of information available on the Internet can be overwhelming, which means that complex metacognitive skills are needed, such as planning, search strategies and evaluation of information. "Internet literacy is not the ability to use a set of technical tools: rather it is the ability to use a set of cognitive tools" (Johnson 2007: 433). It involves reading text, interpreting images or watching a video, and, as a consequence, there is a need to be multiliterate (Caballero 2008: 15), placing further demands on the reader.

However, the channel itself does go some way to help. Firstly, information can be presented in small, independent, self-contained pages, which are then subdivided into sections or paragraphs filtering and streamlining information, and thus making the acquisition of the information gradual and accumulative.

Secondly, communication involves much more than just language; it draws on a multiplicity of modes, which include visual, spoken, gestural, written and other resources, all of which contribute to meaning and can be realized online. The use of visuals can enhance understanding of information and the learning process, whilst videos and animation can be used to explain a complex object, structure or process through a demonstration.

A distinctive feature of online communication is the opportunity it gives to readers to express their feelings and thoughts, and not just through structured and scripted videos. Neubaum and Krämer (2015) point out how personal anecdotes and emotionality play an important role in the persuasiveness of health information in blogs as opposed to official websites, though nowadays forums linked to websites provide many opportunities to visitors to share their experiences, ask for advice or simply express their empathy and solidarity.

One of the problems of online one-to-many communication is the unknown, heterogeneous audience, making it hard to define the level of shared, cultural, institutional and "world" knowledge and adjust the rewriting accordingly (van Dijk 2005). The terms elderly, seniors or older people may cover a range of situations and people at different stages of the ageing process. To accommodate the variety of readers, the text may become completely depersonalized, tend towards dumbing down or aim at too high a level of information, making it more difficult to engage with them.

4. Corpus

The study has been carried out using a corpus of texts giving information about age-related conditions that have been downloaded from three British websites, each of which has a different function and promoters. *Patient.info*, as the name suggests, is run by doctors giving health and medical information and advice in the form of a "comprehensive directory of evidence-based clinical information". The *BUPA* website belongs to a healthcare group that is responsible for running health centres, care homes as well as offering health insurance. Apart from its promotional purpose, the website also provides information about health conditions, covering topics of interest to all age groups.

Table 1. Corpus

	patient.info	BUPA	AgeUK
Main topics	*Senior health* – What are the normal signs of ageing? – The secrets of living to 100 years old – How to have a great sex life in later life – Ageing feet – What's causing your cold hands and feet? – Swollen legs – Osteoarthritis – Metatarsalgia – Ingrown toenails – Ageing – Age-related long sight – Hearing loss – Frailty and multi-morbidity – Polypharmacy – Memory loss and dementia	*A-Z topics* – Exercise for older people – High blood pressure – Coronary heart disease – Stroke – Type 2 diabetes – Osteoporosis – Back pain – Stress – Breast cancer – Bowel cancer – Parkinson's disease – Dementia	*Conditions and illnesses* – Dementia – Eye health – Hearing loss – Incontinence – Osteoporosis – Depression and anxiety – 7 ways to boost your heart health – High blood pressure – Influenza (flu) – Seasonal affective disorder
Total words	38,000 approx.	47,000 approx.	23,000 approx.

Although neither website presents a link to information about the elderly immediately on its home page or in the main menu, they do deal with age-related problems. *Patient.info* includes a section called *Senior health*, which covers ageing and specific age-related conditions, and also directs the reader to more general pages about certain conditions. *BUPA* does not have a special section, though there are pages dedicated to age-related issues stemming from a page called *Exercising for the elderly* and the selection for the corpus followed these.

In contrast, *AgeUK* is not focused exclusively on medical issues, but is "the country's largest charity dedicated to helping everyone make the most of later life". Its purpose is therefore the general wellbeing of the person, though there is a section called *Conditions and Illnesses* which has been used for this study.

5. Theoretical framework

Given its highly sensitive but also technical nature, the complex process of transferring health information from expert to layman must work in two different dimensions at the same time, the cognitive and the communicative. As far as the cognitive dimension is concerned, a number of studies on knowledge dissemination have identified a series of verbal strategies used to transfer expert knowledge, generally grouped under Illustration and Reformulation strategies (Ciapuscio 2003, Gülich 2003, Calsamiglia – van Dijk 2004). Illustration strategies are verbalization strategies chosen by writers/speakers according to the context, the purpose and the interlocutors, including:

- description – to explain unknown things
- definition – to explain unknown technical terms
- exemplification – to explain complex concepts in everyday terms
- scenario – to explain a complex event by presenting a possible, but hypothetical situation
- metaphorical language – including metaphor, analogy and comparisons
- concretisation – the rewording of abstract information in a non-abstract manner.

Reformulation strategies change or modify what has been said to clarify the meaning and make it more comprehensible. In spoken discourse the speaker 'doubles back' on his own or interlocutor's speech in order to produce a new, reworded version that is considered more satisfactory to avoid a breakdown in understanding and communication. In written or scripted texts, reformulation strategies aim to pre-empt any misunderstanding or difficulty in understanding. These strategies are repetition and paraphrasing and are formally marked by relative clauses, apposition, parentheses, dashes and metalinguistic expressions.

For knowledge transfer to be effective, the interpersonal dimension of communication is as important as the cognitive dimension (Giannoni 2008, Hyland 2010). Although these studies were concerned with academic discourse, the basic idea of the writer/speaker having to negotiate the social relationship with the reader/viewer to establish his authority and credibility remains valid in all contexts of knowledge transfer. Specific features, such as the use of questions, metaphors, marked lexis, personalization and humour, can be used to attract the attention and engage the reader. Adolphs et al. also provide a useful guide for the analysis, because it is specifically concerned with healthcare encounters and focuses in part on "enlisting the participation or involvement of the recipients of health advice [which is] by no means automatic or straightforward" (2004: 16). They identify the use of personal pronouns, modals and the logical operators *if* and *or* as important devices for focussing attention on the patient and consequently involving him in the discourse, as well as presenting advice as possible solutions without imposing too heavily on the reader.

Table 2. Knowledge transfer strategies

Cognitive dimension (Ciapuscio 2003; Gülich 2003; Calsamiglia – van Dijk 2004)	*Communicative dimension* (Hyland 2010; Giannoni 2008; Adolphs et al. 2004)
Illustration or explanation – description – definition – exemplification – scenario – metaphorical language – concretization Reformulation – paraphrase or repetition	– personalization – politeness markers (modality, hedges, vagueness) – questions – humour – metaphors – marked lexis

Research, especially in health communication and education, shows that an integrated approach of text and images enhances knowledge transfer

(Michielutte et al. 1992, Houts et al. 2006). Illustrations can help readers to understand and retain information in a way that text alone cannot by drawing on the four fundamental aspects of the learning process, namely attracting attention, enhancing comprehension, aiding retention and creating a context. They present simultaneously all the information needed to explain a topic, to give an overall view of it, and to represent the relationship between its different elements. Videos can also give a physical, albeit virtual, presence either to a professional/expert to replicate more closely a consultation or to people who have had first-hand experience of a situation and want to share their story. All these modes will make the information more direct and engaging.

This theoretical framework has already been adopted by the author in a number of studies on Knowledge Dissemination in the field of economics (Turnbull 2015c), the law (Turnbull 2018) and health information for adults, adolescents and children (Turnbull 2015a, 2015b). The latter, which focused on information about diabetes in which patients of all ages need to have a very clear understanding of their condition, found that the full range of cognitive strategies were adopted in all sections regardless of the target audiences. The information load varied according to the age group, but technical terms were introduced even for very young children. The importance of multimodal affordances, whether visuals or videos, also emerged because they enhanced the explanation of technical content, but also lent a voice to fellow sufferers who could give accounts of their own experiences of the condition. In the following section the analytical framework will be applied to online health information for the elederly to see which strategies have been adopted in this particular context.

6. Analysis

6.1 Cognitive dimension

6.1.1 Use of cognitive strategies

Various cognitive strategies were adopted to simplify the information conveyed. Definitions (1) and (2) were used extensively in the ‘medical’ websites, *patient.info* and *BUPA*, as in the following examples.

(1) What is polypharmacy?

Polypharmacy is the use of multiple medications at the same time by one person. In other words, it means being on lots of different medicines. Usually a person who is on quite a few different pills has more than one medical condition. (patient.info)

(2) About osteoarthritis
Arthritis is a general term meaning inflamed, stiff and painful joints. Osteoarthritis is the most common form of arthritis, affecting around a third of people aged 45 and over in the UK (around 8.75 million people). You're more likely to develop osteoarthritis the older you get. (BUPA)

Description was also used to explain complex processes taking place in the body. (3) talks about the physical act of focusing on close-up objects as part of a webpage on age-related long sight. It introduces the topic, *In order to see close-up objects, our eyes have to accommodate*, which is then reformulated, *this means*, into a long, step-by-step description of the mechanisms involved. This general information is then applied to the context of ageing. Similarly, (4) uses short sentences to describe the stages leading up to coronary heart disease.

(3) Presbyopia is long-sight (hypermetropia), caused by age.
In order to see close-up objects, our eyes have to accommodate. This means that the lens changes its thickness. Its thickness is adjusted by the ciliary muscles that attach to the suspensory ligaments at either end. As these muscles tighten, the ligaments lengthen and the lens becomes more thickened and curved. Light rays from close objects are brought into sharp focus on the retina.
As we become older the lens becomes more stiff and less elastic. This makes it more difficult for the lens to change shape – the ciliary muscles have to work harder to make it do so. Eventually they are unable to do this at all and the lens cannot be thickened. With the lens in its normal resting position you are still able to focus on objects in the distance – long sight. However, because the lens cannot thicken, it cannot manage the extra degree of focus (accommodation) which is needed for near objects. (patient.info)

(4) Coronary heart disease happens when fat and cholesterol from your blood build up over many years inside your artery walls. They form what are called plaques and the process of fat building up is called

> atherosclerosis. As a plaque forms, this narrows your artery and reduces the blood flow so the result is your heart muscle doesn't get all the oxygen it needs. And sometimes a plaque may rupture, and a clot can form on top which suddenly blocks your artery completely (causing a heart attack). (BUPA)

In both (3) and (4) there are a number of medical terms, both anatomical (*ciliary muscles*, *suspensory ligaments*) and technical (*accommodate, plaques, atherosclerosis*). Technical language can act as a barrier or a bridge in expert-layman communication, but here the terminology is preceded by a gloss in (3) *Presbyopia is long-sight (hypermetropia)*, reformulated in (4) *the process of fat building up is called atherosclerosis* or illustrated in a detailed anatomical diagram that summarizes the text (Martinec – Salway 2005: 352). As previous studies have shown, definitions and the introduction of highly technical terms are frequent (Gülich 2003: 240), as they enable the reader to orient himself when he comes into contact with medical professionals and during hospital appointments.

Description (5) and exemplification (6) are also used at times to help patients recognise symptoms.

(5) Women are also much more prone to a condition called Raynaud's syndrome […] In Raynaud's, your fingers and sometimes toes turn cold and white, then go blue and numb when exposed to cold. (patient.info)

(6) Stress is a term used to describe how you feel and respond when the pressure you're under exceeds your ability to cope.
Mental effects of stress can include:

- *feeling that you can't cope*
- *constantly worrying*
- *finding it hard to concentrate and remember things*
- *feeling disappointed with yourself*
- *lacking confidence*
- *seeing only the negative things in life* (BUPA)

Similarly, scenarios are used to present what may happen with tests or different types of treatment and medication.

(7) Treatment
If you are diagnosed as having high blood pressure (hypertension) then you are likely to be examined by your doctor and have some routine tests which include:

- A urine test to check if you have protein or blood in your urine.
- A blood test to check that your kidneys are working normally and to check your cholesterol level and sugar (glucose) level.
- A heart tracing, called an electrocardiogram (ECG).

  The purpose of the examination and tests is to:
- Rule out (or diagnose) a secondary cause of high blood pressure, such as kidney disease.
- Check to see if the high blood pressure has affected the heart.
- Check for other risk factors such as a high cholesterol level or diabetes. (patient.info)

6.1.2 Information load

The examples given above come from just the *patient.info* and *BUPA* websites. Although the information was framed into short, simple paragraphs with clear, meaningful headings that guide the reader and facilitate understanding (Nielsen 1997), as has become standard practice in websites, the information in (3) and (4) was extremely detailed. If we compare directly information about a topic that appears in all three websites, namely high blood pressure, we can see noticeable differences in approach. Once again both medical websites give detailed explanations of what happens with high blood pressure and its consequences.

(8) High blood pressure happens when the force on the walls of blood vessels (caused by the blood within them) is more than normal. This means the heart has to work harder and the blood vessels are under more strain, making it a major risk factor for heart disease, stroke and other serious conditions. Healthcare professionals sometimes call high blood pressure ‘hypertension’. (patient.info)

(9) High blood pressure (hypertension) is a serious condition that can affect anyone.
Every time your heart beats it pumps blood to the rest of your body through arteries. Blood pressure is created by the force of blood against the artery walls. If it is consistently too high, it puts extra strain on your heart and blood vessels. This may increase your risk of a heart attack, heart failure, stroke and other conditions including kidney disease and dementia. (BUPA)

In contrast, the *AgeUK* website introduces the topic from a patient’s more pragmatic point of view, going straight to the core of the question, the need to check your blood pressure regularly, following the principle of the inverted pyramid style, where the most important information is given first (Nielsen 1997). It then lists five questions which could be asked by the patient to attract his interest and attention.

(10) High blood pressure

One of the simplest health checks, but also one of the most important, is your blood pressure level. Find out *why you should get checked regularly for high blood pressure.*

- *How many people are affected?*
- *Why is it important to measure?*
- *Wouldn't I know if I have high blood pressure?*
- *What are the risks associated with high blood pressure?*
- *What happens if I'm diagnosed with high blood pressure?*

An example of one of the answers is given below:

(11) Why is it important to measure?
Persistently high blood pressure (also known as hypertension) is a major cause of premature death and disability in the UK, because it can lead to strokes, heart attacks and heart disease.
If left untreated it can increase your risk of heart disease, kidney disease and dementia.
<u>You can find out more about complications on the NHS website</u>
(AgeUK)

Here the sentences are short and clear with one idea per paragraph, but there is no explanation or description of high blood pressure. The cognitive load is very limited, improving the readability and enabling more efficient processing of the information. The reader is, nevertheless, invited to find out more, if he wants, at the link provided, where the information given is very similar to that on the *patient.info* and *BUPA* websites. *AgeUK* informs the reader of the need to measure blood pressure, but it also intends, in an implicit way, to 'shock' him into taking action. Whereas the *BUPA* website talks more vaguely about the possible risk of high blood pressure, *this may increase your risk of*, *AgeUK* says *it can lead to strokes, heart attacks and heart disease.* The difference between *may* and *can* is slight, but *can* gives added force to the statement, as it is not just a possibility, but also expresses the capability/potentiality (Palmer 1990) of high blood pressure causing strokes, heart attacks, heart disease and so on.

6.2 Communicative dimension

6.2.1 Empathy

The most immediate way of engaging with a reader is through the use of the 2nd person pronoun *you* to address the individual reader (11), or through the generic *you* referring to everybody (12) (Quirk et al. 1985: 354), which makes the tone less formal. This is found in all three websites.

(12) Your body mass index (BMI) is a ratio of your weight and height. Your practice nurse will be happy to work yours out for you. (patient.info)

(13) Type 2 diabetes is more common among older people, but you can develop it at any age. (BUPA)

The *patient.info* website appears to use a number of strategies to engage with the reader by creating a sense of solidarity. (14) shows the use of an inclusive *us* (Quirk et al. 1985: 354), as ageing touches everybody sooner or later, and colloquial and informal expressions, while (15) tries to align with the feelings of elderly people, firstly by sharing a positive view that *maturity* has at least one advantage, before giving some reassurance and encouragement about the problems of ageing.

(14) You may not feel old on the outside, but age catches up with all of us and it's important to know the conditions you need to keep an eye on as each birthday rolls around. (patient.info)

(15) Whoever said 'getting old is not for the faint-hearted' was only partly right. Maturity has much to commend it – who would want to relive teenage angst?
These days, medical advances mean we never have to suffer in silence with serious medical conditions, and many everyday ailments can be effectively relieved, if not cured. But when is a change 'normal' and when should you worry? (patient.info)

This website also uses humour, *youngsters* (i.e., over-90s), though it could sound a little condescending, and marked lexis such as *skew the odds*.

(16) By 2016, there were 14,900 people over 100 years old in the UK – 65% more than there were in 2005. 850 of these are over 105 – double the number a decade ago. As for the youngsters, there are over half a million over-90s living in the UK today. So how can you skew the odds in your favour? (patient.info)

However, at times, the information is totally depersonalized, as for example in the section dealing with dementia, where the 'patient' is referred to in the 3rd person as *a person*, *someone*, *the person*.

(17) For example, a person with early stages of dementia might go to the shops and then cannot remember what they wanted. It is also common to misplace objects. […] Someone with dementia may not know common facts when questioned (such as the name of the Prime Minister). […]
The person may also have difficulty keeping up their home. Shopping, cooking and eating may become difficult. (patient.info)

Only further down the page is the reader addressed directly, when the information concerns advice about what to do if you personally suspect dementia.

(18) The first step if you are concerned that you may be developing dementia is to see your doctor. Or, if you are worried that someone close to you may have dementia, you should encourage them to see their doctor. They may agree for you to see their doctor with them. (patient.info)

The reason may be that the website wants to approach the subject of dementia in a more indirect, 'softer' way because of the strong social stigma attached to it. It is a very challenging condition for patients and carers alike and feared by most people.

BUPA deals with the subject in a similar manner, but at times shows a little more explicit empathy:

(19) *It can be frightening* to hear dementia explained in this way, but you should know that dementia is not inevitable when you get older. (BUPA)

(20) What does a diagnosis of dementia mean for you or your loved one? (BUPA)

Once again, this approach is in contrast with the *AgeUK* website that addresses the reader directly in the introductory lines of the page *Understanding dementia*. It tackles the problem head on, probably because if someone is searching for information, he already suspects there is something wrong. At the same time, it is also reassuring the reader that forgetfulness does not always mean dementia.

(21) You may have had problems remembering things that have happened recently, or have found yourself getting confused in familiar places. You may be worried these are signs of dementia, though being forgetful doesn't necessarily mean you have dementia. […] If you're worried about someone else, try to encourage them to see their GP. You could offer to go with them for support if they seem a bit reluctant. (AgeUK)

Although *AgeUK* generally adopts a more personal approach, it too uses the depersonalizing strategy when introducing an embarrassing condition, such as incontinence. Here the topic is introduced with a general *people*, thus suggesting the reader is not alone in this situation, before addressing him more directly, *interfere with your everyday life* and giving suggestions on how to cope with the situation.

(22) People of all ages can have a problem controlling their bladder or bowel, and this can have a real impact on their daily lives. Some people avoid going out or need to plan their activities around a toilet.

People can be reluctant to talk about bladder or bowel problems, but in most cases the problem can be cured or managed so it doesn't interfere with your everyday life. (AgeUK)

6.2.2 Giving advice

The delicate task of giving advice, which is fundamental for the successful or effective outcome of health information, is performed in different ways by the websites. Imperatives, the most direct way of imparting advice, are used quite frequently by the *patient.info* website.

(23) How can ingrown toenails be prevented?

- Cut your nails straight across; do not cut them too short or too low at the sides. The corner of the nail should be visible above the skin. (Tip: it is easier to cut nails after a bath or shower, when they are soft.)
- Keep your feet clean and dry. Let air get to your toes when possible.
- Avoid tight shoes and use cotton socks rather than synthetic. (patient.info)

It also uses a softer approach at times, as in the following example where advice is presented using the gerund and the logical operator *if* creates an option (as per Adolphs et al. 2004: 18).

(24) Can I get my blood pressure down without taking medication? Sometimes there is quite a bit you can do with lifestyle changes, and in some people this may help them to avoid medication. In particular, the following help:

- Losing weight if you are overweight.
- Reducing the salt you have in your food.
- Taking regular exercise.

Stopping smoking doesn't reduce your blood pressure as such, but smoking and high blood pressure put you at risk of the same conditions. So if you can quit smoking, you'll reduce your risk of strokes, heart attacks, etc. (patient.info)

Advice in the *BUPA* website is usually given using informal introductory expressions, such as *try to*, *aim to, it's good to, you're probably already familiar with, this means you, you're more likely*, *you can still choose to try them if you wish*, so that suggestions are given without imposing on the patient. When imperatives are used, they too are introduced as options leaving the choice to the patient.

(25) There are a number of things you can do to help relieve back pain.

- Stay active and continue your daily activities as normally as you can. However, remember to take care when lifting or twisting your back. Doctors used to advise bed rest, but now we know it can make back pain worse. Try to avoid sitting for long periods.
- Do exercises and stretches – see our section on exercises for lower back pain below. […]
- You may want to try applying heat or cold treatments to your back. Remember not to apply ice directly to your skin.
- You may find it helps to sleep with a small cushion between your knees, if you sleep on your side. Or with some firm pillows under your knees, if sleeping on your back. (BUPA)

A piece of advice is less imposing when a suggestion is made through the use of an impersonal, neutral gerund, especially after an introductory phrase expresses empathy and understanding of feelings:

(26) It can be difficult to be optimistic when you've had back pain for a long time. But staying positive as well as staying active can help you recover and avoid it becoming long term. (BUPA)

A similar strategy is adopted by *Age UK* to present advice about dealing with the difficulties of living with dementia. Imperatives are used, perhaps because they are more straightforward, easier to understand and therefore more appropriate in this context. However, this direct approach is 'softened' by the introduction saying they are *tips*, useful ideas that have already been experimented with by other fellow sufferers.

(27) Tips to help you live well with dementia
Everyone deals with the challenges of dementia in their own way, but here are some ideas that have helped others.

- Follow a routine. Doing things at the same time each day or week can reassure you and stimulate your memory.
- Pin notes up in prominent places if there are things you need to do regularly, like locking the doors at night or putting out the recycling.
- Carry a notebook to write down daily tasks.
- Put important things, like glasses or keys, in the same place every time so that you know where to find them.
- Ask questions if you don't understand or have forgotten what was said.
- Put important telephone numbers by the phone.
- Stay in touch with family and friends rather than isolate yourself.
- Carry a help card that can let people know you have dementia and includes the contact details of a chosen contact.
- Make sure other people don't take over – they may think they're helping by doing as much for you as possible. (AgeUK)

6.2.3 Doctor patient relationship

Trust is a fundamental element in a doctor-patient relationship. Pronouns may create empathy and a closer relationship with the reader, but they may also reinforce the asymmetrical relationship that exists between expert and layman, as in the following example where exclusive *we* refers to doctors.

(28) Having a high one-off blood pressure reading may not be of much concern because we know that blood pressure can fluctuate throughout the day and even between days. (patient.info)

The *patient.info* website frequently explicitly forefronts the role of the expert by underlining the use of technical terms by specialists (29) or a specific reference to the professional status of the addresser *my patients* (30).

(29) Healthcare professionals sometimes call high blood pressure 'hypertension'. (patient.info)

(30) Lots of my patients complain of putting on weight after the menopause (patient.info)

This demarcation between the doctor and patient is not so noticeable in the *BUPA* website as shown in the paragraph about advice giving, though at times it does emerge:

(31) Doctors used to advise bed rest, but now we know it can make back pain worse. (BUPA)

AgeUK also adopts a less marked position of the doctor, though it maintains the authority of the professional. Using an example from the questions on blood pressure again, we can see the answer consists in a tag question, as if it were a natural response in a conversation/dialogue between doctor and patient, showing empathy and understanding. However, it then continues in a more formal, impersonal manner, as well as adding a strong warning, *the silent killer*.

(32) Wouldn't I know if I have high blood pressure?
You'd have thought so, wouldn't you? However, more than 5 million people don't know that they suffer from hypertension – this is what gives it its other name: the silent killer. (AgeUK)

6.2.4 Personalization

In this context the term personalization is not intended in the sense of the way the writer addresses the reader to create communicative immediacy, but rather how the information itself is presented in the form of personal narratives. In other words, people, peers, are talking about their experiences of living with a particular condition, explaining how they cope and perhaps giving advice. The asymmetrical relationship which naturally occurs in specialized discourse between expert and layman can lend authority to the information, but as Gülich says "the so-called non-experts (in this case the patients) are also experts of a kind" (2003: 258) and provide their experiential knowledge.

However, very few personal stories about age-related conditions are actually presented in the websites. *BUPA* has a video of a daughter talking about her experience of her father having dementia, whereas *AgeUK* has some videos of patients with depression and dementia, in which people give their first-hand accounts of the condition, describing their difficulties, feelings and offering solutions or advice. They talk openly, realistically but also positively about what it is like to live with these socially alienating conditions.

(33) People do ask me, people do ask how does the dementia affect me now and I suppose one way of describing having it is to use the analogy of the weather. Most days are sunny days for me and I maintain a clear outlook and life is pretty good, but other days it's a bit cloudy and I'll come in and out of being able to function effectively. (AgeUK)

The *AgeUK* website also presents an interview with Prunella Scales, a very popular actress well-known to the British public, who suffers from dementia, and her equally famous actor husband, who talk about how they manage to cope. This may encourage people with a diagnosis of dementia to be more open themselves and not feel so alone.

Somewhat surprisingly, the *patient.info* website, where the presence of the medical professionals is perceived most forcefully, provides a forum with numerous threads that the visitors may open as they wish. There is no interference or mediation on the part of the doctors and advice, sympathy and encouragement are freely exchanged.

6.3 Multimodality

Although the focus of the study is on the communication of health information to the elderly, within the context of online communication multimodality is also an important feature (Kress 2010). Different visual and auditory modes can provide opportunities for more effective meaning-making, thus facilitating the transfer of knowledge. The use of multimodal affordances – diagrams, visuals, videos – can, in fact, have both cognitive and communicative purposes.

In the two medical websites images in the form of diagrams are used to help with anatomical descriptions, whilst infographics clearly and promptly convey dietary and exercise schemes or symptoms to recognize in emergency situations, as for example in the case of a stroke or heart attack. Where videos were used in the *patient.info* and *BUPA* websites, it almost always involved a doctor talking to the camera, which simulates a visit to his surgery. The information was, however, often very similar to that given in the written text. These websites also use basic animations to explain how certain conditions, such as osteoporosis, diabetes, breast cancer, develop or tests are carried out. In contrast, videos are used in *AgeUK* to share peer lay information, as discussed in the section above. Interestingly, *AgeUK* also includes recordings of experts being interviewed on the radio, and therefore audio only, perhaps as older people are used to listening to the radio or can focus more clearly on the information without visual distractions.

7. Final remarks

Online communication has to cater for an unknown and heterogeneous audience, of different backgrounds and educational levels, and in the case of the elderly the difficulty of calibrating the level of information, both in terms of the quantity of detail and the depth of explanation, may be accentuated and complicated by age-related issues, such as vision loss or failing cognitive abilities.

Perhaps contrary to expectations, there seem to be very few differences in the strategies adopted to communicate health information for the elderly and for adults, especially as often the elderly visitor will be invited to follow links to pages aimed at the general public. Ageing does not necessarily change the intellectual level of a person, but at the same time researching on the Internet makes heavy demands on the reader (Johnson 2007) and the findings of this study suggest that little adaptation is made to facilitate understanding, perhaps excluding those who most need the information.

Almost all the cognitive and communicative strategies outlined in the theoretical framework were adopted by the websites. The only exception was metaphor, which was used very rarely as either a cognitive or a communicative device. However, the level of information load is much heavier in the medical websites than in *AgeUK*, which reflects their different origins and functions. The 'medical' websites tend to give very detailed, technical information, often including what might at times be considered unnecessary information from the point of view of empowerment and being able to take informed decisions. Instead, *AgeUK*, rather than imparting specialized knowledge, wants to raise awareness of problems that may arise in ageing and how they can be avoided, or at least managed. It takes a much broader view of the issues under consideration focusing on the well-being and quality of life of the person, which are, in any case, fundamental aspects of health.

As we have seen, the three websites analysed in the study show different approaches and different information loads which may, each in its own way, meet the varying expectations and needs of readers. Some readers may just want to find general information about health issues without having a ‘tutorial’ on human anatomy, whilst others may want to know the whys and the wherefores of a medical condition out of curiosity or to have a better understanding. The websites also propose different doctor-patient relationships, which once again may satisfy very diverse readers. On the one hand, the older generation may be used to the traditional view of the doctor as the expert and be willing to accept his advice and decisions; they may even expect it. On the other hand, many older people actively take part in the social media world of today and therefore may expect more peer, lay knowledge to be available, as well as want the possibility to share and exchange information and experiences.

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A study of closings in nurse-elderly resident consultations at a mobile integrative health centre

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ABSTRACT

The study examines the genre of nurse-elderly resident consultations in Hong Kong to find out how the closings of their interactions are structured; specifically, it aims to ascertain the extent to which the patterns of closings conform to the canonical closing, or archetype closing, identified in telephone calls and conversations in American English. The study also compares how frequently the nurse and the elderly resident initiate different patterns of closings, and examines suspension or delay of a closing in the medical consultations. Not only the patterns of closings, but also in what way important meanings are negotiated by the two groups of interacting speakers over a small number of turns, ranging from one to four, have been investigated. Findings show that the closing structure and relative frequencies of closings are genre-specific, dependent on such factors as institutional roles and communicative goals, conversational contexts, and relationships of the speakers.

Keywords: nurses, elderly residents, consultations, closing patterns.

1. Introduction

Nurse-patient communication has been an important research topic in healthcare studies, which have often examined communication barriers or problems and interaction patterns and styles. Research has examined nurse-patient communication issues in different clinical or medical settings, including Accident and Emergency (Baillie 2005), midwife hospital (Ferndale et al. 2017), neonatal intensive care unit (Jones et al. 2007), oncology care

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(Dowling 2008; Jarrett – Payne 2000), and Mobile Integrative Health Centre (Cheng – Chung – Wong 2013).

For decades, international research in nurse-patient communication has examined different areas of communication. Mallett – A'Hern (1996) found that humor can be an indicator of patients' anxiety and difficulties in connection with 'needling'. Studies have confirmed the effectiveness of a patient-centered style of communication that elicited a positive effect on the health provider-patient relationship (Berry 2009) and the provision of individualized care and encouragement of patient participation during the interaction (Bolster – Manias 2010).

An increasingly important area of nurse-patient communication in healthcare studies involves the elderly patient (Anderson et al. 2003; Black et al. 2006; Park – Song 2005; Wengryn – Hester 2011). Park – Song (2005), for instance, investigated communication barriers perceived by the elderly hospitalized patients and by nurses in South Korea. They identified nurse-related barriers, including "using medical terminology", "working without sincere attitude", "authoritative attitude", "sudden change of subject", and "being unfriendly" (Park – Song 2005: 161), and patient-related barriers, including "being hard of hearing", "having poor articulation", "not feeling well", "forgetting things easily", and "being tired" (Park – Song 2005: 162). In another study, Anderson et al. (2003) found that it was difficult to establish or maintain mutual understanding between nurses and elderly patients when the patients were regarded as being in a different world or in a divided world. Both studies recommended considering health-related issues from the perspective of elderly patients to achieve better and more effective communication.

In Hong Kong, like in many parts of the world, a huge challenge for the 21st century is health ageing (Ng – Leung 2010: 2), pointing out an urgent need for the society to adopt a holistic approach toward maintaining the well-being of the elderly, encompassing "physical, mental, diet-and-nutrition, communication, social and psychiatric" aspects. In some ways, the need was realized by the operation of the PolyU-Henry G. Leong Mobile Integrative Health Centre (MIHC), with the mission of integrating "Western medicine and technology with traditional Chinese medical theory and purpose of preserving good health". The aim of the MIHC is to "enable needy elderly residents to attain a healthy lifestyle so that their daily lives are enjoyable and fruitful through achieving the tenets of harmony and equilibrium of body, mind and soul" (media release, The Hong Kong Polytechnic University, 18 Dec 2007). The MIHC is housed in a truck, and since it was established in 2007, it has been going to different districts in Hong Kong to provide needy elderly residents with free medical services, including a physical health check, general health assessment, pain assessment, happiness test, and referral service.

In order for the MIHC to achieve its aim, it is considered important that the nurses there effectively communicate with the needy elderly residents to understand their medical needs and problems, to deliver appropriate medical services, and to conduct relevant consultation activities with the elderly residents. It is equally important that the elderly residents visiting the MIHC are supported, verbally and emotionally, in such a way that they feel at ease to describe and discuss their health conditions and concerns during the medical consultation. Specifically, the present study examines a small and focused, but important, part of the consultation, namely the closing of the nurse-elderly resident consultation.

2. Literature review

In linguistic research, especially conversation analysis (CA), an approach to the study of social interaction and talk-in-interaction in human communication (Sacks – Schegloff – Jefferson 1974), telephone conversation closings in American English (Schegloff – Sacks 1973) have been investigated. Findings show that the speakers work jointly to close conversations; conversations do not just end but must be closed through an elaborate ritual because of the turn-taking mechanics of conversation. Schegloff – Sacks (1973) observed conversational procedures in closings, which they described as having a universal character, where speakers signal their desire to close the conversation, and others to actually close it. The signal to bring the conversation to an end is realized as a pre-closing adjacency pair which occurs only when the first turn is placed at the "analyzable end of a topic" (Schegloff – Sacks 1973: 305), meaning the pre-closing pair has to be preceded by a "closing down the topic" sequence, with, for example, the interlocutors uttering 'Okay?' and 'Alright.' The *canonical closing* consists of four turns, organized in two adjacency pairs: a pre-closing, followed by a terminal exchange that has accepted the pre-closing.

Button (1987) expanded on Schegloff – Sacks's (1973) work, suggesting that the occurrence of optional components, such as arrangements, back-references, and topic initial elicitors, can result in the closing sequence being delayed, deferred or even abandoned. Button (1987) calls the closing sequence the "archetype closing" and provides an illustration, as follows:

Table 1. Archetype closing

[SBL: 1:1:1:8]

Bea:	And thanks for calling.	
Dianna:	Alright dear,	[Turn 1: A offers to close (pre-closing)]
Bea:	Alright	[Turn 2: B accepts (second close component)]
Diana:	Bye	[Turn 3: A takes the first terminal turn]
Bea:	Bye	[Turn 4: B reciprocates]

End call

Martinez (2003) observed that the closing structure is genre-specific, dependent on such factors as communicative goal, conversational context, and relationship of the interlocutors. Other research conducted comparative studies of telephone closings between Greek and German (Pavlidou 2000) and between Chinese and English (Sun 2005). Research also examined how the ‘ownership’ of the closing sequence was claimed by an interlocutor, by filling a slot with a turn-initial high-grade assessment such as ‘lovely’ or ‘brilliant’ to indicate a readiness to close the conversation (Antaki 2002). Other studies identified new topics raised in the closing environment (Bolden 2017).

In healthcare communication research, the method of conversation analysis has been widely employed to evaluate the effectiveness of medical consultations (see Maynard – Heritage 2005; Robinson 2001; Campion – Langdon 2004; Jones 2003). Some studies examined the closings of medical interactions. Silverman et al. (1998), for instance, investigated the closing session in doctor-patient consultations, suggesting that an unsuccessful closure, i.e. when the doctor and the patient were uncertain about what had happened and what would be expected in the future, could lead to communication difficulties at the beginning of the next consultation. Robinson (2001) studied how the final-concern sequence was arranged and the implications for topicalization of patients’ additional concerns. The researcher found that the arrangement sequence did not provide patients with an opportunity to topicalize additional concerns. In contrast, in Maynard – Heritage’s (2005) study, it was found that pre-closing turns could be delayed by inviting discussion of new topics or arrangements for tests, next visits, and so on to evoke a standing doctor-patient relationship, and thus achieving “continuity of care” (Maynard – Heritage 2005: 433).

3. The present study

The present conversational analysis focuses on an important stage of the nurse-elderly resident consultation in the PolyU-Henry G. Leong Mobile Integrative Health Centre (MIHC), namely the *conversational closing*, where the nurse makes sure that the elderly resident's illnesses and health concerns are taken care of before sending the elderly resident off, and where the elderly resident makes sure that the nurse provides advice and assistance relevant to the purpose of the visit, including making an appointment for the next visit. The study specifically aims to find out the extent to which the patterns of closing sequences conform to *canonical closing* (Schegloff – Sacks 1973), or *archetype closing* (Button 1987), how the nurse and the elderly resident compare in initiating closing or terminating interaction, as well as the contextual and interactional reasons for any suspension or delay of closing in the nurse-elderly resident consultations.

4. Methodology

The study analysed naturally-occurring talk-in-interaction in Chinese, Cantonese in the majority of cases, between nurses and elderly residents in the MIHC. At the time of data collection, in the MIHC, there were five Advanced Practice Nurses working, all female, on rotation. Some of these nurses were also nutritionists, Bowen therapists, or Traditional Chinese medicine practitioners.

The data were collected from the MIHC during April-June 2011. Throughout the period of data collection, a project associate was collecting data in the MIHC. She acted as an observer, audio-recording and taking notes of the consultations, upon consent of the elderly residents concerned. The audio-taped data analysed in this study was collected in April 2011, with 143 consultations between 5 Advanced Practiced Nurses and 61 elderly residents, 13 male and 48 female. Some of the elderly residents had visited the MIHC more than once before April 2011.

Analysis of the data involved listening to the closing sequence in the audio-recordings and identifying the patterns of closing sequences. The main clue to the onset of the closing sequence was when the nurse gave the elderly resident an appointment slip for the next visit. After the closing sequences in all the 143 consultations had been identified, individual turns in each closing sequence were analysed in terms of who initiated the turn and the specific function of the turn, with reference to the sequence of *canonical closing* (Schegloff – Sacks 1973) or *archetype closing* (Button 1987).

In this paper, quantitative findings are supplemented by qualitative findings, with examples illustrating the contextual and interactional reasons for the patterns identified. Examples presented are in English, translated from Cantonese. The translator was the project associate who adopted the method of free translation, whereby she listened to the recording to understand the meaning of the original Cantonese and then produced English words and clauses that mean the same. The translation was then checked by the author of the paper.

5. Findings and discussion

In this section, first of all, quantitative findings will be presented and discussed. The findings focus on the relative frequencies of the different patterns of closing sequences identified in all the 143 closings audio-recorded in April 2011 in the MIHC, the relative frequencies of closings initiated, as well as those of the closings initiated exclusively by the nurses and the elderly residents, respectively. Notably, the quantitative findings show both typical and atypical closing sequences in the specialized genre analysed, compared to Schegloff – Sacks (1973) and Button (1987). Quantitative findings will then be exemplified to illustrate how the individual patterns of closings are realized in the talk-in-interaction. They will also be discussed with reference to data collected from interviewing some nurses and from field notes taken.

Data analysis shows that the 143 closings identified in the nurse-elderly resident medical consultations can be classified into twelve different patterns, in the specific context of interaction examined, the physical context being the MIHC in Hong Kong in 2011, the social context being a nurse giving medical consultation to an elderly resident, and the linguistic context being Cantonese exchanged on topics related to a physical health check, general health assessment, pain assessment, happiness test, and referral service. Table 2 presents the twelve patterns of closing sequences in nurse-elderly resident consultations in the MIHC.

Turn 1 refers to speaker A offering to close (pre-closing), turn 2 speaker B accepting the offer to close (second close component), turn 3 speaker A taking the first terminal turn, and turn 4 speaker B reciprocating.

Table 2. Patterns of closing sequences in nurse-elderly resident interactions in MIHC

Patterns of closing sequence in nurse-elderly resident interactions	Frequency (percentage) of initiation of closings by the nurse and elderly resident
(1) **Turn 1 + Turn 2**	60 (41.9%) Nurse: 39 (27.3%) Elderly resident: 21 (14.7%)
Turn 1 + Turn 2, … …, Turn 1 + Turn 2	
Turn 1 + Turn 2, Turn 1 + Turn 2	
Turn 1, … …, Turn 1 + Turn 2	
Turn 1, Turn 1 + Turn 2	
Turn 1, … …, Turn 1 + Turn 2, … …, Turn 1 + Turn 2	
Turn 1+3, … …, Turn 1 + Turn 2	
(2) **Turn 1**	27 (18.9%) Nurse: 20 (14%) Elderly resident: 7 (4.9%)
Turn 1, … …, Turn 1	
Turn 1, Turn 1	
(3) **Turn 3**	10 (7%) Nurse: 7 (4.9%) Elderly resident: 3 (2.1%)
Turn 1, … …, Turn 3	
Turn 1 + Turn 2, … …, Turn 3	
Turn 1 + Turn 2, … …, Turn 1 + Turn 2, … …, Turn 3	
Turn 1 + 3, … …, Turn 1 + Turn 2, … …, Turn 3	
Turn 1 + Turn 2, Turn 1 + Turn 2+4, Turn 1 + Turn 2, … …, Turn 3	
Turn 1+3 + Turn 2+4, … …, Turn 3, Turn 3	
(4) **Turn 3 + Turn 4**	9 (6.3%) Nurse: 2 (1.4%) Elderly resident: 7 (4.9%)
Turn 1 + Turn 2, Turn 1 + Turn 2, … …, Turn 3 + Turn 4, … …, Turn 3 + Turn 4	
Turn 1 + Turn 2, Turn 1 + Turn 2, … …, Turn 1 + Turn 2, … …, Turn 3 + Turn 4	
Turn 1 + Turn 2, … …, Turn 1 + Turn 2, … …, Turn 3 + Turn 4	
Turn 3, … …, Turn 3 + Turn 4	
(5) **Turn 1 + Turn 2 + Turn 3**	8 (5.6%) Nurse: 7 (4.9%) Elderly resident: 1 (0.7%)
Turn 1 + Turn 2, … …, Turn 1 + Turn 2 + Turn 3	
Turn 1, … …, Turn 1 + Turn 2, … …, Turn 1 + Turn 2 + Turn 3	

(6) **Turn 1 + Turn 2 + Turn 3 + Turn 4** (archetype closing)	6 (4.2%) Nurse: 3 (2.1%) Elderly resident: 3 (2.1%)
Turn 1, … …, Turn 1, Turn 1+ Turn 2 + Turn 3 + Turn 4	
Turn 1 + Turn 2, Turn 1 + Turn 2 + Turn 3 + Turn 4	
Turn 1 + Turn 2, … …, Turn 1 + Turn 2 + Turn 3 + Turn 4	
Turn 1 + Turn 2, … …, Turn 1, … …, Turn 1 + Turn 2 + Turn 3 + Turn 4	
(7) **Turn 1+3**	6 (4.2%) Nurse: 6 (4.2%) Elderly resident: (0%)
Turn 1 + Turn 2, … …, Turn 1+3	
(8) **Turn 1+3 + Turn 4**	5 (3.5%) Nurse: 5 (3.5%) Elderly resident: 0 (0%)
Turn 1 + Turn 2, … …, Turn 1+3 + Turn 4	
Turn 1+3, Turn 1 + Turn 2, … …, Turn 1+3 + Turn 4	
Turn 1, … …, Turn 1 + Turn 2, Turn 1 + Turn 2, … …, Turn 1 + Turn 2, Turn 1+3 + Turn 4	
(9) **Turn 1 + Turn 2+3 + Turn 4**	4 (2.8%) Nurse: 2 (1.4%) Elderly resident: 2 (1.4%)
Turn 1, … …, Turn 1+ Turn 2+3 + Turn 4	
(10) **Turn 1+3 + Turn 2**	3 (2.1%) Nurse: 1 (0.7%) Elderly resident: 2 (1.4%)
Turn 1 + Turn 2, … …, Turn 1 + Turn 2, … …, Turn 1+3 + Turn 2	
(11) **Turn 1+3 + Turn 2+4**	3 (2.1%) Nurse: 1 (0.7%) Elderly resident: 2 (1.4%)
Turn 1 + Turn 2 + Turn 3, … …, Turn 1+3 + Turn 2+4	
(12) **Turn 1 + Turn 2+3**	4 (1.4%) Nurse: 0 (0%) Elderly resident: 2 (1.2%)
Turn 1, … …, Turn 1+ Turn 2+3	
Total	143 (100%) Nurse: 93 (65%) Elderly resident: 50 (35%)

A number of findings, eleven in total, are observed in Table 2. First and foremost, the study has identified a wide range of twelve patterns of closing sequences. Second, interestingly, in the face-to-face nurse-elderly resident consultations in the MIHC, only 4.2% of closings have the sequence of the *canonical closing* (Schegloff – Sacks 1973) or *archetype closing* (Button 1987) identified in telephone conversations in American English. It is Pattern 6: Turn 1 + Turn 2 + Turn 3 + Turn 4, with the nurses (2.1%) and elderly residents (2.1%) initiating the same infrequent percentages of instances.

Third, another fascinating finding is the different types of patterns of potential closings that come before the actual closing occurs for all the twelve patterns. It is found that, generally, the more frequent patterns of closings are characterized by a larger number of types of potential closings, as shown in Table 3.

Table 3. Number of potential closings before the actual closing across twelve patterns

Pattern	Per-centage	Number of potential closings preceding actual closing	Pattern	Per-centage	Number of potential closings preceding actual closing
1	41.9	6	7	4.2	1
2	18.9	2	8	3.5	3
3	7.0	6	9	2.8	1
4	6.3	4	10	2.1	1
5	5.6	2	11	2.1	1
6	4.2	4	12	1.4	1

Take the frequent pattern, Pattern 1: Turn 1 + Turn 2 (41.9%), as an example. As summarized in Table 4, six types of patterns of potential closings have been found to precede the actual closing of the nurse-elderly resident consultations, which is highlighted in bold.

Table 4. The six types of patterns of potential closings

1.	(Turn 1 + Turn 2), … …, (Turn 1 + Turn 2)
2.	(Turn 1 + Turn 2), (Turn 1 + Turn 2)
3.	(Turn 1), … …, (Turn 1 + Turn 2)
4.	(Turn 1), (Turn 1 + Turn 2)
5.	(Turn 1), … …, (Turn 1 + Turn 2), … …, (Turn 1 + Turn 2)
6.	(Turn 1), … …, (Turn 1 + Turn 2), … …, (Turn 1 + Turn 2)

All the six patterns of potential closings are found invariably to begin with Turn 1 (pre-closing), in some cases accepted, and this is followed by more talk, and then perhaps another pre-closing-acceptance pair with even more talk, before the consultation is finally brought to an end. This finding will be exemplified in Example 13, and further discussed.

Fourth, the most frequent pattern is Pattern 1 (41.9%): Turn 1 + Turn 2, without the terminal adjacency pair. From these findings, it can be said that the *quintessential* pattern of closings in this specialized genre of nurse-elderly resident consultations is Pattern 1, consisting of only the pre-closing pair (Schegloff – Sacks 1973), or the first two turns described in Button (1987):

Turn 1: A offers to close (pre-closing)
Turn 2: B accepts (second close component)

This means that this *quintessential* pattern of closings does not contain Schegloff – Sacks' (1973) second adjacency pair, namely a terminal exchange that has accepted the pre-closing, or Button's (1987) third and fourth turns, as follows:

Turn 3: A takes the first terminal turn
Turn 4: B reciprocates

Fifth, the most frequent pattern of closings, Pattern 1: Turn 1 + Turn 2 (41.9%), is followed by Pattern 2: Turn 1 (18.9%). There is quite a big difference, 23%, between these two patterns; together they constitute 60.8% of all the closings. The remaining ten patterns, amounting to 39.2% of all the instances of closings, have rather low frequencies, ranging from 7% to 1.4%.

Sixth, among the 143 instances of nurse-elderly resident consultation closings, 93 instances (65%) are initiated by the nurses, and 50 instances (35%) are initiated by the elderly residents, which is quite a noticeable difference. The difference is noticeable not only in the frequencies of occurrence, but also in reflecting the relative institutional role and power differences between the two groups of speakers in the medical consultations, with the nurses in the MIHC playing a more active role in determining at which point the consultation comes to an end. Having said that, it is, however, noted that the elderly residents do, in one-third of cases, initiate closings. Field observation notes show that many elderly residents have become familiar with the rather routinized sequence of events in the consultation. When the elderly residents sense that it is about time for the consultation to finish, especially when the nurses introduce the topic of making an appointment for the next visit, verbally or non-verbally, they sometimes initiate a closing.

Seventh, in terms of frequencies of occurrence, the nurses are found to initiate six of the twelve patterns of closings more frequently than the elderly residents. They are:

Pattern 1: Turn 1 + Turn 2 (27.3% vs. 14.7%)
Pattern 2: Turn 1 (14% vs. 4.9%)
Pattern 3: Turn 3 (4.9% vs. 2.1%)
Pattern 5: Turn 1 + Turn 2 + Turn 3 (4.9% vs. 0.7%)
Pattern 7: Turn 1+3 (4.2% vs. 0%)
Pattern 8: Turn 1+3 + Turn 4 (3.5% vs. 0%)

Compared with the nurses, the elderly residents initiate four of the twelve patterns of closings more frequently. These patterns are, however, relatively infrequent. They are:

Pattern 4: Turn 3 + Turn 4 (4.9% vs. 1.4%)
Pattern 10: Turn 1+3 + Turn 2 (1.4% vs. 0.7%)
Pattern 11: Turn 1+3 + Turn 2+4 (1.4% vs. 0.7%)
Pattern 12: Turn 1 + Turn 2+3 (1.2% vs. 0%)

Also concerning frequencies of occurrence, the nurses and the elderly residents initiate the same two patterns of closings equally, and infrequently. They are:

Pattern 6: Turn 1 + Turn 2 + Turn 3 + Turn 4 (archetype closing) (2.1% vs. 2.1%)
Pattern 9: Turn 1 + Turn 2+3 + Turn 4 (1.4% vs. 1.4%)

Eighth, certain patterns of closings are initiated exclusively by one of the speaker parties in the medical consultations. The nurses are found to initiate all the patterns of closings, except one:

Pattern 12: Turn 1 + Turn 2+3

The elderly residents initiate all patterns except two:

Pattern 7: Turn 1+3
Pattern 8: Turn 1+3 + Turn 4

Ninth, two of the twelve patterns consist of only one turn, and so strictly speaking, these cannot be termed a sequence type. They are:

Pattern 2: Turn 1 (18.9%)
Pattern 3: Turn 3 (7%)

Together, these two patterns account for one quarter (25.9%) of all the instances of closings. These single turn closings rank second and third among the twelve patterns of closings, accounting for 44.8% of all the instances of closings by pattern.

Tenth, six of the twelve patterns consist of one turn with two speech functions. These are Patterns 7, 8, 10 and 11 having Turn 1+3 in one turn, as well as Patterns 9, 11 and 12 having Turn 2+4 in one turn. Pattern 11 has two turns: Turn 1+3 + Turn 2+4.

To be specific, Pattern 7 (4.2%), Pattern 8 (3.5%), Pattern 10 (2.1%), and Pattern 11 (2.1%) all begin with Turn 1+3; that is, the speaker is offering to close (pre-closing) and taking the first terminal turn within one turn. Both Pattern 9 (2.8%) and Pattern 12 (1.4%) begin with Turn 1, followed by Turn 2 + 4 in one turn. This means that in one turn, speaker B both accepts the offer to close (Turn 2) and reciprocates (Turn 4), without the occurrence of Turn 3, which is speaker A taking the first terminal turn (Button 1987). Pattern 11 (2.1%): Turn 1+3 + Turn 2+4 is unique as it is made up of two turns with two speech functions in each.

Eleventh, both Pattern 3 (7.3%) and Pattern 4 (6.3%) begin with Turn 3 (the speaker taking the first terminal turn), without any pre-closing (Turn 1) and second close component (Turn 2).

In the following, examples of closings are discussed to illustrate the twelve different patterns.

Example 1 concerns the most frequent and quintessential pattern, Pattern 1: Turn 1 + Turn 2 (41.9%), which is characterized by an absence of a final exchange; that is, it does not have the first terminal turn (Turn 3) and the reciprocating turn (Turn 4) (Button 1987).

(1) **Pattern 1: Turn 1 + Turn 2**

NR: hey I'll arrange it that you come back at 1:45 in the afternoon on the 20th of July I know you are worried I'd rather let you do it twice in three months you can come back less often later when your indexes are stable **yea that's it**

ER41: **yea okay alright**

The nurse's '**yea that's it**' signals to the elderly resident that she is ready to close the consultation (pre-closing) and the elderly resident's '**yea okay alright**' serves to accept the offer (second close component). There is absence of a terminal pair.

Example 2 below illustrates Patten 2: Turn 1 (18.9%).

(2) **Pattern 2: Turn 1**

NL: alright hey (EC11) this is your membership number yea 26th of April Tuesday yea 10:15 am

EC11: 26th of this month

NL: 26th of the month which means two weeks later it's the 12th today two weeks later when will be after the Easter holiday if you are not able to come that day you can call the office yea unless there is a very hot weather warning or anything else then we will be coming yea okay alright remember to bring the medicine with you **okay**

In the last utterance by the nurse, '**okay**' in 'remember to bring the medicine with you **okay**' is a pre-closing. At this point, the elderly resident (EC11) stands up and leaves without any verbal response, and so there is absence of a second close component to show agreeing to close consultation.

Example 3 shows Pattern 3, consisting of one single turn, Turn 3 (7%). This turn occurs without a pre-closing pair (Turn 1 and Turn 2) and without a reciprocating Turn 4. This can happen when a nurse has finished the consultation and then immediately bids goodbye to the elderly resident.

(3) **Pattern: Turn 3**

NL: **bye bye**

Pattern 4 Turn 3 + Turn 4 (6.3%) consists merely of a final terminal pair without a preceding pre-closing-acceptance pair. As discussed, the elderly residents (4.9%) initiate Pattern 4 more frequently than the nurses (1.4%). See Example 4 below:

(4) **Pattern 4: Turn 3 + Turn 4**

NR: EC3 okay alright wait a second huh

EC3: **bye bye** ((pause)) **hey bye bye**

NR: **oh bye bye** ((laugh))

In Example 4, the nurse's utterance begins with calling the elderly resident's name 'EC3 okay alright wait a second huh'. She does not seem to have finished the consultation and is asking the elderly resident to 'wait a second'. In other words, she is not yet ready to initiate a pre-closing. The elderly resident, however, takes the first terminal turn by saying '**bye bye** ((pause)) **hey bye bye**' which is then reciprocated by the nurse '**oh bye bye**'.

Pattern 5: Turn 1 + Turn 2 + Turn 3 (5.6%) is similar to Button's (1987) *archetype closing*, minus the last turn that reciprocates the first terminal turn. Example 5 below illustrates Pattern 5.

(5) **Pattern 5: Turn 1 + Turn 2 + Turn 3**
EC43: alright thank you **I can leave now eh**
NR: **yes sure**
EC43: **okay bye bye**

In Example 5, the pre-closing is initiated by the elderly resident, saying '**I can leave now eh**'. The nurse accepts the offer to close with '**yes sure**'. Then the elderly resident takes the first terminal turn by saying '**okay bye bye**', which the nurse does not reciprocate.

Example 6 below shows Schegloff – Sacks' (1973) *canonical closing*, or Button's (1987) *archetype closing*, having all of the four turns. In this study, Pattern 6: Turn 1 + Turn 2 + Turn 3 + Turn 4 occurs only rarely (4.2%).

(6) **Pattern 6: Turn 1 + Turn 2 + Turn 3 + Turn 4**
NL: **okay thank you** [Turn 1: Nurse L offers to close (pre-closing)]
EC16: **thank you everyone** [Turn 2: Elderly resident 16 accepts (second close component)]
NL: **bye bye** [Turn 3: NL takes the first terminal turn]
EC16: **bye bye bye bye** [Turn 4: EC16 reciprocates]

Pattern 7: Turn 1+3 (4.2%) comprises one turn, performing two functions. The standalone turn has a pre-closing showing an offer to close the interaction, immediately followed by the first terminal turn. Findings show that all the three instances of Pattern 7 are initiated by the nurse. See Example 7:

(7) **Pattern 7: Turn 1+3**
NL: really I remember what you have said **alright alright alright yea bye bye**

Example 7 shows the nurse uttering '**alright alright alright**' to offer to close the consultation, and then '**yea bye bye**' to take the first terminal turn. The elderly resident does not give a response.

Pattern 8 has the structure of Turn 1+3 + Turn 4 (3.5%). See Example 8:

(8) **Pattern 8: Turn 1+3 + Turn 4**
NL: okay you will come back in two weeks **okay that's it for today bye bye**
EC18: **bye bye**

Example 8 shows that in the turn taken by the nurse, a pre-closing '**okay that's it for today**' is combined with the first terminal turn '**bye bye**'. The nurse's turn is reciprocated by the elderly resident saying '**bye bye**'.

Pattern 9: Turn 1 + Turn 2+3 + Turn 4 (2.8%) is illustrated in Example 9.

(9) **Pattern 9: Turn 1 + Turn 2+3 + Turn 4**
NM: alight then you will get more of this pills next time **okay**
EC22: **good right thank you nurse bye bye**
NM: **bye bye**

In Example 9, the nurse offers to close the consultation with '**okay**' after making a remark about the next consultation. The elderly resident accepts the offer to close by saying '**good right thank you nurse**' and then takes the first terminal turn by bidding the nurse goodbye with '**bye bye**'. The nurse says '**bye bye**' in response.

Pattern 10 takes the structure of Turn 1+3 + Turn 2 (2.1%), as illustrated below.

(10) **Pattern 10: Turn 1+3 + Turn 2**
EC5: **thank you nurse bye bye be bye**
NL**: oh no problem**

In Example 10, the elderly resident, in the same turn, introduces a pre-closing '**thank you nurse**', and then takes the first terminal turn '**bye bye bye bye**'. The nurse accepts the pre-closing with '**oh no problem**' but does not say anything to reciprocate the first terminal turn.

Pattern 11 has the sequence of Turn 1+3 + Turn 2+4 (2.1%). See Example 11:

(11) **Pattern: Turn 1+3 + Turn 2+4**
EC8: **thank you bye bye**.
NL: **you are welcome bye bye**

Each of the two turns performs two speech functions. In one turn, the elderly resident offers to close the consultation with '**thank you**' and then takes the first terminal turn by uttering '**bye bye**'. In the turn that follows, the nurse accepts the offer to close by saying '**you are welcome**' and reciprocates the first terminal turn by saying '**bye bye**' also in one turn.

The last of the twelve patterns, Pattern 12: Turn 1 + Turn 2+4 (1.4%), is exemplified below:

(12) **Pattern 12: Turn 1 + Turn 2+3**
EC27: **thank you thank you**
NW: **uh huh bye bye**

In Example 12, the elderly resident offers to close the consultation with a pre-closing, saying '**thank you thank you**'. The nurse accepts it with a second close component '**uh huh**' and, immediately after this, says '**bye bye**' to take the first terminal turn in the same turn. The elderly resident does not reciprocate.

Example 13 below shows a longer interactional extract, with more turns preceding the closing sequence in order to demonstrate the finding that different patterns of potential closings can take place before the actual closing occurs. This finding applies to all of the twelve patterns, especially to frequently occurring patterns of closings. Example 13 shows that the nurse-elderly resident consultation eventually closes with Pattern 8: Turn 1+3 + Turn 4 (3.5%).

(13)

1. NM: **alright [Turn 1 pre-closing]** ((pause)) don't drink too much
2. water
3. EC22: er when is it in May
4. NM: on the 25th of May at 2 pm in the afternoon
5. EC22: yea yea yea
6. NM: remember not to drink too much water walk more and do more
7. exercise
8. EC22: yes yes yes
9. NM: right then I'll check your blood pressure again next time **okay**
10. **[Turn 1 pre-closing]**
11. EC22: **good right thank you nurse [Turn 2 second close component]**
12. NM: **uh huh alright take care [Turn 3 first terminal turn]**
13. EC22: **alright [Turn 4 reciprocates]**
14. NM: get your things packed
15. ((pause))
16. NM: sometimes it's not good to have an excessive amount in any-
17. thing drinking too much water is not good for your health
18. EC22: right right
19. NM: you may need to go to the toilet often
20. EC22: thank you nurse.
21. NM: go to the restroom first before going home yea
22. EC22: yes yes
23. NM: **uh huh take care [Turn 1 pre-closing]**
24. EC22: **uh huh thank you [Turn 2 second close component]**
25. NM: **alright okay bye bye [Turn 1+3 first terminal turn]**
26. EC22: **bye bye [Turn 4 reciprocates]**

Example 13 shows that the closing is found to be preceded by a few potential closings, organized as follows:

Turn 1, … …, Turn 1 + Turn 2 + Turn 3 + Turn 4, … …, Turn 1 + Turn 2 +
Turn 1+3 + Turn 4

In line 1, before the nurse says **'alright'**, she has just handed out an appointment slip to the elderly resident, and so she is ready to close the interaction. There is no response from the elderly resident. After a pause, the nurse continues to speak. The second potential closing begins in line 9, when the nurse utters **'okay'**. This offer to close is accepted by the elderly resident, replying with '**good right thank you nurse**' (line 11). This pre-closing pair is then followed by the terminal pair, with the nurse saying '**uh huh alright take care**' (line 12), and the elderly resident responding with '**alright**' (line 13). After this 'closing' sequence, however, the nurse continues with more talk. Another potential closing takes place in line 23, where the nurse initiates an offer to close '**uh huh take care**' which is responded to by the elderly resident with '**uh huh thank you**' (line 24). The consultation, however, does not close at this point. The nurse goes on with '**alright okay bye bye**' (line 25), which is a combination of offering to close and the first terminal pair, to which the elderly resident responds by bidding the nurse goodbye with '**bye bye**' (line 26). Altogether there have been three attempts to close the consultation before the actual closing takes place.

Apart from analyzing the textual data, the study also asked the nurses of the MIHC to share their own experiences and perceptions related to the way in which closings are performed. One of the nurses remarked that there was no actual or real closing of consultation because the care that they delivered to the elderly residents was continuous, and that there was an expectation of a next consultation, and more. Generally, the nurses are concerned about the sustainability and continuity, as well as the well-being of the members of the community, of healthcare service. The relationship between the nurses and elderly residents in the MIHC is a longer-term one, compared with other clinical or medical settings, such as Accident and Emergency (Baillie 2005) and public health clinics and private clinics in Korea (Kim 2017). In fact, during the three months of data collection in the MIHC, the project researcher had not found any case closed. This is strong evidence for the emphasis of "continuity of care" (Maynard – Heritage 2005) by the organisations which operate the MIHC.

Since the duration of one single consultation is 45 minutes, there is more time for the nurse to communicate with the elderly resident to understand their needs and concerns. This partly explains the predominant finding regarding the occurrence of multiple potential closings before a consultation is eventually brought to a close. This finding is comparable to that of Maynard – Heritage's (2005) study, showing that a standing doctor-patient relationship is promoted and continuity of care is achieved by means of delayed pre-closing turns, which function to enable further talk on new topics or arrangements for tests and next visits. In this study, the various patterns or sequences of closings, as well as occurrence of closings that are initiated by either the nurse or the elderly resident, have been observed to be equally effective in terms of the provision of individualized care and encouragement of elderly resident participation during the medical consultative interaction (Bolster – Manias 2010), having a positive effect on the 'health provider-patient' relationship (Berry 2009).

Most of the pre-closing turns are initiated by the nurses, showing that they are the ones granted with institutional power and authority in the MIHC setting, and in fact, they are in control of the entire consultative interaction. However, the nurses do not dominate closing initiations; elderly patients also share some of the responsibilities. In addition, this study does not yield any findings that constitute an unsuccessful closure, compared with the closing session in doctor-patient consultations in Silverman et al.'s (1998) study when the doctor and the patient were uncertain about what had happened and what would be expected in the future.

6. Conclusion and implications

The study sets out to ascertain the extent to which the patterns of closing sequences conform to *canonical closing* (Schegloff – Sacks 1973), or *archetype closing* (Button 1987), how the nurse and the elderly resident compare in initiating closings, as well as the contextual and interactional reasons for any suspension or delay of closings in the nurse-elderly resident consultations. The aim of the study has been addressed. The main conclusion is aligned with that of Martinez (2003); that is, the closing structure is genre-specific, dependent on such factors as communicative goal, conversational context, and relationship of the interlocutors. Not only the closing structure, but also in what way important meanings are negotiated by the two groups of interacting speakers over a small number of turns, ranging from one to four, have been investigated and have revealed informative results. The study has accounted for the findings by drawing upon not only the local context, physical, social and linguistic (Thomas 1995), of the nurse-elderly resident consultation, but also broader institutional communicative purposes specific to this specialized genre.

This preliminary study of closing sequences in nurse-elderly resident consultations in the Mobile Integrative Health Centre (MIHC) is the first step to further studies of the patterns, and discourse and pragmatics, of closings in medical interactions. The quintessential Pattern 1, as well as other frequent patterns of closings identified in the study, could also be a useful reference, and even benchmark, for future studies when evaluating communicative effectiveness of medical consultation closings, and in turn empowering medical and healthcare professionals in communicating with their patients and contributing to an improved quality of life for the elderly and other groups of patients.

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