Jan Kochanowski University Press

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

Cecilia Lazzeretti and Franca Poppi
University of Modena and Reggio Emilia

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

---

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.

REFERENCES

Sources

Angelman Syndrome Foundation
        https://www.angelman.org/, accessed August 2019
Child Neurology Foundation
        https://www.childneurologyfoundation.org/, accessed August 2019
Epilepsy Foundation
        https://www.epilepsy.com, accessed August 2019
National Autistic Society
        https://www.autism.org.uk/, accessed August 2019
International Rett Syndrome Foundation
        https://www.rettsyndrome.org, accessed August 2019
United Leukodystrophy Foundation
        https://ulf.org, accessed August 2019

Special studies

American Psychological Association
    2010   *Publication Manual of the American Psychological Association.*
            Washington, DC: American Psychological Association.
Antonovsky, A.
    1987   *Unraveling the Mystery of Health. How People Manage Stress and Stay*
            Well. San Francisco: Jossey-Bass.

Baker, P.
    2006   *Using Corpora in Discourse Analysis*. London: Continuum.

Bucholtz, M.
    1999   " 'Why be normal?': Language and identity practices in a community of nerd girls", *Language in Society* 28, 203-223.

Bucholtz, M. – K. Hall
    2005   "Identity and interaction: A sociocultural linguistic approach", *Discourse Studies* 7, 585-614.

Case, S.
    2000   "Refocusing on the parents: What are the social issues of concern for parents of disabled children?", *Disability and Society* 15 (2), 271-292.

Cavalieri, S.
    2019   "The dissemination of dietary treatments for refractory epilepsy: A preliminary analysis of web-based discourse on the ketogenic diet". In: M. Bondi – S. Cacchiani – S. Cavalieri (eds.) *Communicating Specialized Knowledge. Old Genres and New Media*. Newcastle upon Tyne: Cambridge Scholars Publishing, 52-68.

Collier, R.
    2012a   "Person-first language: Laudable cause, horrible prose", *CMAJ: Canadian Medical Association Journal* 184 (18), 939-940.
    2012b   "Person-first language: Noble intent but to what effect?", *CMAJ: Canadian Medical Association Journal* 184 (18), 1977-1978.

Dunn, D.S. – E.E. Andrews
    2015   "Person-first and identity-first language: Developing psychologists' cultural competence using disability language", *American Psychologist* 70 (3), 255-264.

Dyer, J.
    2007   "Language and identity". In: C. Llamas – l. Mullany – P. Stockwell (eds.) *The Routledge Companion to Sociolinguistics*. New York: Routledge, 101-108.

Eysenbach, G.
    2008   "Medicine 2.0: Social networking, collaboration, participation, apomediation, and openness", *Journal of Medical Internet Research* 10 (3): e22, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2626430/, accessed August 2019

Gabrielatos, C.
    2018   "Keyness analysis: Nature, metrics and techniques". In: C. Taylor – A. Marchi (eds.) *Corpus Approaches to Discourse: A Critical Review*. Abingdon; New York: Routledge, 225-258.

Gernsbacher, M.A.
    2017   "Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma", *Journal of Child Psychology and Psychiatry* 58 (7), 859-861.

Granello, D.H. – T. Gibbs
    2016   "The power of language and labels: 'The mentally ill' versus 'people with mental illnesses'", *Journal of Counseling and Development* 94 (1), 31-40.

Graungaard, A.H. – L. Skov
    2007   "Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled", *Child Care Health and Development* 33 (3), 296-307.

Gundersen T.
    2011   "'One wants to know what a chromosome is': The Internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder", *Sociology of Health and Illness* 33 (1), 81-95.

Hanks, W.F.
    1999   "Indexicality", *Journal of Linguistic Anthropology* 9 (12), 124-126.

Hansen, J.G. – J. Liu
    1997   "Social identity and language: Theoretical and methodological issues", *TESOL Quarterly* 31, 567-576.

Hedov, G. – K. Wikblad – G. Anneren
    2002   "First information and support provided to parents of children with Down syndrome in Sweden: Clinical goals and parental experiences, *Acta Paediatrica* 91 (12), 1344-1349.

Hyland, K.
    2004   "Engagement and disciplinarity: The other side of evaluation". In: G. Del Lungo Camiciotti – E. Tognini Bonelli (eds.) *Academic Discourse: Linguistic Insights into Evaluation*. Bern: Peter Lang, 13-30.

Labov, W.
    1966   "The effect of social mobility on linguistic behaviour", *Social Inquiry* 36, 186-203.

Ladau, E.
    2015   "Why person-first language doesn't always put the person first", https://www.thinkinclusive.us/why-person-first-language-doesnt-always-put-the-person-first, accessed May 2019

McLaughlin, J.
    2005   "Exploring diagnostic processes: Social science perspectives", *Archives of Disease in Childhood* 90, 284-287.

Mendoza-Denton, N.
    2008   "Language and identity". In: J.K. Chambers – P. Trudgill – N. Schilling-Estes (eds.) *The Handbook of Language Variation and Change*. Oxford: Blackwell, 475-499.

Milroy, L.
    2000   "Britain and The United States: Two nations divided by the same language (and different language ideologies)", *Journal of Linguistic Anthropology* 10 (1), 56-89.

Norton, B.
    2010   "Language and identity". In: N.H. Hornberger – S.L. McKay (eds.) *Sociolinguistics and Language Education*. Bristol: Multilingual Matters, 349-369.

Oprescu F. et al.
    2013   "Online information exchanges for parents of children with a rare health condition: Key findings from an online support community", *Journal of Medical Internet Research* 15 (1): e16, https://www.ncbi.nlm.nih.gov/pubmed/23470259, accessed May 2019

Partington, A. – A. Duguid – C. Taylor
    2013   *Patterns and Meanings in Discourse. Theory and Practice in Corpus-Assisted Discourse Studies (CADS)*. Amsterdam: John Benjamins.

Peters, P. et al.
    2016   "Language, terminology and the readability of online cancer information", *Medical Humanities* 42, 36-41.

Rinn, M.R.
    2018   "Nineteenth-century depictions of disabilities and modern metadata: A consideration of material in the PT Barnum Digital Collection", *Journal of Contemporary Archival Studies* 5 (1), 1-15.

Scott, M.
    2012   *WordSmith Tools. Version 6*. Stroud: Lexical Analysis Software.

Sezzi, A. – M. Bondi
    2019   "'I am going on a ketogenic diet'. Communicating dietary requirements for pediatric patients", *Token: A Journal of English Linguistics*, this issue.

Silverstein, M.
    1976   "Shifters, linguistic categories and cultural description". In: K.H. Basso – H.A. Selby (eds.) *Meaning in Anthropology*. Albuquerque: University of New Mexico Press, 11-55.

Skotko, B.
    2005   "Mothers of children with Down syndrome reflect on their postnatal support", *Pediatrics* 115 (1), 64-77.

Tajfel, H.
    1974   "Social identity and intergroup behaviour", *Social Science Information* 13 (2), 65-93.

Tozzi, A.E. et al.
    2013   "The Internet user profile of Italian families of patients with rare diseases: A web survey", *Orphanet Journal of Rare Diseases* 8 (1), 76-89.

Trudgill, P.
    1974   *Sociolinguistics: An Introduction*. Harmondsworth: Penguin Books.

Wolff, P. – K.J. Holmes
    2011   "Linguistic relativity", *Wiley Interdisciplinary Reviews: Cognitive Science* 2 (3), 253-265.

Address: Cecilia Lazzeretti, Department of Studies on Language and Culture, University of Modena and Reggio Emilia, Largo Sant'Eufemia 19, 41121 Modena, Italy. ORCID code: orcid.org/0000-0002-0415-9129.

Address: Franca Poppi, Department of Studies on Language and Culture, University of Modena and Reggio Emilia, Largo Sant'Eufemia 19, 41121 Modena, Italy. ORCID code: orcid.org/0000-0003-0069-5300.