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Discursive Representations of Controversial Issues
in Medicine and Health

La rappresentazione discorsiva di questioni controverse
in ambito medico e sanitario

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Exploring Health Literacy: Web-based Genres in Disseminating Specialized Knowledge to Caregivers The Case of Paediatric Neurological Disorders

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ABSTRACT

This paper aims at analyzing the discursive practices used in web-based informative materials in the specific context of a chronic disease, i.e. neurological disorders resulting in epilepsy, for liaising with caregivers of paediatric patients. The study centres on a corpus of webpages gathered from the websites of the major foundations dealing with paediatric neurological syndromes. From a methodological perspective, the study makes recourse to existing studies on the discursive practices that in the literature on knowledge dissemination are identified as being used to facilitate the layman's access to specialized scientific knowledge. The overall results show that knowledge dissemination strategies used in the webpages under investigation offer cognitive tools to parents as caregivers in order to make them informed about their children's disease. These webpages enhance caregiver health literacy and achieve the goal of caregiver empowerment, giving her/his greater control over decisions affecting her/his child's health.

Keywords: caregivers; expert-to-lay communication; health literacy; specialized knowledge dissemination; web-based genres.

* Research for this study was conducted jointly by the two authors. More specifically, Giuliana Diani is responsible for sections 1, 1.1 and 4; Silvia Cavalieri is responsible for sections 2 and 3.

1. INTRODUCTION

Disseminating expert knowledge to the general public has become a popular area of research in academic and professional discourse (i.e. Garzone 2006; Keramas and Christiansen 2013; Bongo and Caliendo 2014; Gotti 2014; Bhatia, Chiavetta, and Sciarrino 2015; Bondi, Chiacchiani, and Mazzi 2015; Salvi and Bowker 2015; Garzone *et al.* 2017; Engberg *et al.* 2018; Bondi, Cacchiani, and Cavalieri 2019). The growth of specialization has created the need to make knowledge accessible also to non-experts, adopting communicative tools that can reach an ever growing, globalized audience.

The study of specialized knowledge dissemination between experts and non-experts has been approached in terms of expert discourse vs. ‘popularization’. A definition of this concept is provided by Calsamiglia and van Dijk (2004, 370):

Popularization is a vast class of various types of communicative events or genres that involve the transformation of specialized knowledge into ‘everyday’ or ‘lay’ knowledge [...]. This means that popularization discourse needs to be formulated in such a way that non-specialized readers are able to construct lay versions of specialized knowledge and integrate these with their existing knowledge.

The way specialists communicate their knowledge to lay people has been widely discussed often in terms of “translating” (Gotti 2013, 13) specialized knowledge into more comprehensible language. As Gotti (*ibid.*, 13) remarks, the popularization process is a kind of redrafting that does not alter the disciplinary content as much as its language. In the process, information is transferred linguistically in a very similar way to intra-linguistic translation. This idea supports Garzone’s (2014, 76) view that popularization “like translation involves a form of re-writing through which discourse presenting the complexities of science and technology is re-elaborated in order to make it accessible to the layman”. This view reinforces the approach to popularization developed by Calsamiglia and van Dijk (2004, 372) that it includes 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. The drafting of popularizing texts is therefore seen as an instance of the linguistic, textual and discursive re-elaboration of specialized knowledge in a way that is comprehensible and relevant for new recipients, in terms of both information-giving and argumenta-

tive as well as promotional reasons. As Gotti (2014) observes, this is particularly evident in health communication, in which information about treatments and therapies from the scientific research community is adapted and disseminated to the lay public.

In this regard, health communication is similar to popularization. However, as Turnbull (2015, 248) points out, a main difference exists between the two, in terms of purposes. While popularization aims to transfer information to broaden the reader's general knowledge, health communication aims not only to inform but also to give practical advice and support to patients, enabling them to understand better their illness and manage their situation. Central to this dual purpose is the relation between health communication addressing the lay public and health literacy – the area covered by this study.

This paper, which is part of a wider research project¹, aims at investigating web-based health informative materials used in the specific context of a chronic disease, i.e. neurological disorders resulting in epilepsy, for liaising with caregivers of paediatric patients. To this purpose, we shall analyze the discursive strategies used in medical discourse to bridge the knowledge asymmetry between expert and layman, in the dissemination of health information.

The paper begins with a brief overview of recent literature on health literacy and expert-to-lay communication (section 1.1). This is followed by a description of the corpus used for the analysis and the methodologies adopted (section 2). Section 3 discusses the results and some concluding remarks are provided in section 4.

1.1. Health literacy and expert-to-lay communication

It is well recognized that we live in an information-rich society in which daily activities are negotiated through competing and sometimes contradictory sources of information (Giddens 1991). As Jordan, Buchbinder, and Osborne (2010) rightly observe, this is particularly relevant in the healthcare setting where information seeking practices and patient actions and reactions towards information take on greater importance in

¹ This article contributes to the FAR 2015 – UNIMORE project “Exploring Health Literacy in liaising with caregivers: the case of the Ketogenic Diet”. This project aims at developing a linguistic framework for assessing best practices in informative materials for chronic paediatric patients and their caregivers.

managing their own healthcare. This process, as they point out, assumes that patients have adequate ‘health literacy’².

The term health literacy reflects the skills that are needed by patients to understand their health and effectively use the healthcare system (Cutilli 2005). Ratzan and Parker (2000, vi) define health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”. As emerged from their definition, a crucial feature of an individual’s access to and benefit of health information is his or her level of health literacy.

The issue of health literacy has become central in the debate of health knowledge dissemination among individuals living with diseases. A growing body of research has discussed the effects of patients’ inadequate health literacy on their diseases (i.e. Kalichman *et al.* 2000; Mancuso and Rincon 2006; Bautista *et al.* 2009; Lloyd, Bonner, and Dawson-Rose 2014). These studies have shown that poor health literacy creates barriers to fully understanding one’s health, illness, and treatments. Patients with low health literacy are more likely to have poor health, are less likely to understand their health problems and treatment management, and are at higher risk of hospitalization (Kondilis *et al.* 2008).

Another area of research that has received scholarly attention is related to the readability of written health communication. The literature on this field is largely based on statistical estimates of readability levels of materials used in healthcare settings and for health promotion purposes. Some studies have assessed the readability of paper or web-based materials targeted at specific diseases, such as cancer (Meade, McKinney, and Barnas 1994; Biermann *et al.* 1999; Jacobs *et al.* 2016) or diabetes (Hill-Briggs and Smith 2008). Other studies have taken a broader approach, examining a specific type of material, such as patient information leaflets (Dixon-Woods 2001) or materials used in institutional settings for emergency department discharge instructions or informed consent (Molina 2001; Slade *et al.* 2008). Although readability formulas tend to assume a direct relationship between average sentence lengths, number of words and the ability to act upon information received (Dray and Papen 2004), they do not take into account the overall organization of the text, readers’ prior knowledge and author-reader relationships.

² A recent discussion of health literacy taking an international perspective can be found in Wolf, Parker, and Ratzan 2017.

While substantial research exists on health literacy and health knowledge dissemination, many studies still tend to focus on comprehensiveness of content rather than on functional analysis of recontextualizing procedures making information relevant to the specific reader. Only few researchers have examined this issue in patients with diseases (Múnoz-Miquel 2012; Luzón 2015; Turnbull 2015, 2016; Mazzi 2016; Mattiello 2019), and to the best of our knowledge, no research has explored it in caregivers. This becomes crucial when addressing written communication to them, who need to be able to mediate health practices to patients, and paediatric patients in particular.

The role of caregivers has always been considered only in face-to-face communication (Iedema 2007), especially in multilingual contexts in which the caregiver takes the place of interpreter (see, for example, Ho 2008; Jansson and Wadensjö 2016; Dal Fovo 2017).

The paucity of linguistic studies on print materials and web-mediated genres highlights the need for further research on this issue. In the light of this, the aim of this article is to investigate the discursive practices used in web-based informative materials to make information cognitively accessible to paediatric caregivers. A straightforward access to medical issues is particularly important for paediatric caregivers since they have to make informed decisions about their children's health.

2. MATERIALS AND METHODS

The data for this study consists of a corpus 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 selected. These webpages were created by parents for parents of children affected by one of the above mentioned neurological disorders 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” [Paediatric 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).

From a methodological perspective, the study adopted a discourse analytical approach focusing on the strategies employed in health knowledge dissemination. To identify them, we made recourse to existing studies on the discursive practices that in the literature on knowl-

edge dissemination are identified as being used to facilitate the layman's access to specialized scientific knowledge. More specifically, we used a model adapted from the methodological toolkit provided by Ciapusio (2003), Gülich (2003) and Calsamiglia and van Dijk (2004). *Table 2* shows the categorization applied in this study.

Table 2. – Categorization of knowledge dissemination strategies.

EXPLANATORY STRATEGIES	CONCRETIZATION STRATEGIES	REFORMULATION STRATEGIES
Definition Denomination	Exemplification Scenario	Explanatory rephrasing

Starting with explanatory strategies, 'definition' is a complex strategy that may involve many linguistic realizations; in general, it provides a description of the core features of a scientific object. In order to describe this strategy, we examined the various types of definitions occurring in the sub-corpora, drawing our analysis on Copi, Cohen, and McMahon's (2016, 104) categorization of definitions.

Table 3. – Categorization of definitions (Copi, Cohen, and McMahon 2016).

A. INTENSIONAL DEFINITIONS	B. EXTENSIONAL DEFINITIONS
1. Synonymous definitions	4. Definitions by example
2. Operational definitions	5. Ostensive definitions
3. Definitions by genus and difference	6. Quasi-ostensive definitions

'Intensional' definitions provide a set of attributes shared by all the objects denoted by a term. Copi, Cohen, and McMahon distinguish three varieties of intensional definition: 'synonymous definition', in which another word, whose meaning is already understood by the receiver, is provided and it has the same meaning of the word being defined; 'operational definition', which states that a term is applied correctly to a given case if and only if the performance of specified operations in that case yields a specified result; 'definition by genus and difference' involves the relationship between 'genus', stating a general class to which the object belongs, and 'difference', i.e. how the object differs from others in the group.

On the other hand, 'extensional' definitions employ techniques that formulate their meaning by specifying the extension of a term, that is, every object that falls under the definition of the concept in question (i.e. *enumeration*). Three are the varieties of extensional definition

explained by Copi, Cohen, and McMahon: ‘definitions by example’, in which examples of the objects denoted by the term are provided; ‘ostensive definitions’, are more space-related and, instead of naming or describing the objects denoted by the term, make recourse to a gesture such as pointing a finger in the direction of the object mentioned (e.g., the word “table” means ‘this’ [pointing at it]); ‘semi-ostensive definitions’, in which the pointing or gesture is accompanied by a descriptive phrase whose meaning is assumed known.

Associated to definitions, we often find denominations which introduce the name of a scientific object. Denominations can be usually found after a marker such as *called*, *known as*. These strategies are often followed by explanatory rephrasing, consisting of a reference expression, usually a reformulation marker (e.g. *which means*, *that is*) and a treating expression (e.g. “Canavan disease is a progressive leukodystrophy which means it tends to get worse through the life of the patient”). Reformulation thus consists in the modification or change of what has been said to clarify the meaning. It is a strategy that involves rephrasing of difficult concepts that can be an obstacle to understanding. There is a relationship of semantic equivalence between the two expressions, along with a change of register or maybe just simply a change of words. In general, reformulations are used to suggest an alternative to the layperson as to relate new knowledge to old one and, as a consequence, familiar language to a more technical one.

Sharing the same purpose, also concretization strategies connect old knowledge to new knowledge by rewording abstract information in a non-abstract manner. More specifically, exemplifications provide a list of specific/concrete instances of a general scientific category often prefaced by means of a marker like *for example*, *for instance*, *such as*. On the other hand, scenario is a strategy that is used to create a possible yet imaginary situation that allows the explanation of complex notions.

In the next section, the results emerging from the analysis are presented, with special reference to the most frequent knowledge dissemination strategies found in each sub-corpus.

3. RESULTS

A recurrent knowledge dissemination strategy employed in the SYNDROMES sub-corpus is *definition* often combined with *denomination*, as shown in examples (1) and (2).

- (1) *Krabbe Disease is an autosomal recessive disorder* resulting from a deficiency in an *enzyme known as galactocerebrosidase (GALC)*. *GALC is an enzyme* that breaks down molecules *called galactolipids*, which are heavily present in the brain. [Krabbe disease Foundation_SYNDROMES]
- (2) *Canavan disease is a progressive, fatal neurological disorder* that begins in infancy in which the lack of an essential enzyme causes deterioration of *the white matter (myelin)* in the brain, thereby preventing the proper transmission of nerve signals. [Canavan disease Foundation_SYNDROMES]

In both examples, *definitions*, occurring in combination with *denominations*, are used to introduce unknown words or terms related to a specific syndrome. The majority of definitions found in the sub-corpora are *intensional definitions*, using the defining technique called ‘genus and difference’, as they give the meaning of a medical term (genus, e.g. “Krabbe disease, GALC, Canavan disease”) first stating the broad category it belongs to and then specifying necessary properties that an object needs to have in order to be counted as a referent of the term (e.g. “an autosomal recessive disorder”; “a progressive fatal neurological disorder”). The preferred pattern identified is: the referential term of the syndrome given at the beginning (“Krabbe disease”; “Canavan disease”) and its definition provided after the existential verb *be*. On the other hand, the *denominations* that follow are frequently introduced by a marker (*called, known as*) or simply by brackets signalling the introduction of a technical term.

Interestingly, in some cases the *definition* of a syndrome is associated to its acronym together with the pronunciation of the name of the syndrome, enhancing caregivers’ competence. Examples (3) and (4) offer instances of this pattern:

- (3) *Pitt Hopkins Syndrome (PTHS) (pit hop-kinz sin-drohm)* is a rare genetic disorder resulting from a mutation of the TCF4 gene or a deletion in the region of the 18th chromosome where the TCF4 gene is located. [Pitt Hopkins Syndrome (PTHS) | Pediatric Brain Foundation_SYNDROMES]
- (4) *Sanfilippo Syndrome (MPS III) (sahn-fil-ee-poh sin-drohm)* is the most common disorder of mucopolysaccharide metabolism and also known as Mucopolysaccharidosis Type III (MPS III). [Sanfilippo Syndrome | Pediatric Brain Foundation_SYNDROMES]

Another frequent pattern found in the SYNDROMES sub-corpus is the incorporation of *denominations* into a *scenario*. In so doing, the writer

describes a concrete experience which can be part of caregivers' life and, at the same time, s/he is able to introduce new technical terminology. The combination of these two strategies may have a didactic purpose making easier for a layperson to remember a complex scientific notion. Example (5) provides evidence of this strategy:

- (5) *An example is a 4 month-old infant who becomes suddenly limp and stops breathing (apnea) after an alleged (stated but not proved) fall from the bed. This infant hasn't developed enough to roll yet. The baby is in a coma (unconsciousness lasting more than 6 hours). Injuries include a complicated skull fracture, bleeding around the brain (subdural hematomas), brain swelling, bleeding into the brain and bleeding into the retina (retinal hemorrhages). The infant also has rib and arm fractures. These injuries are very severe, not found after short falls and not possible in an infant not yet rolling over. [Apparent life-threatening event (ALTE) and Sudden infant death syndrome (SIDS) – Child Neurology Foundation_SYNDROMES]*

Example (5) opens up with a *scenario* describing a scene in which an infant, who could be the caregiver's baby, has problems in breathing. As can be seen, the general description of the situation, which creates a familiar background for the caregiver, is interspersed with specialized medical expressions given in brackets, such as *apnea*, *subdural hematomas*, *retinal hemorrhages*, thus trying to provide new knowledge in a known context. Interestingly, the use of brackets conveys this transition and can be considered an alert signal for the reader who is required to pay more attention to what is coming next. The purpose of this combination of strategies is didactic. The *scenario* takes the whole example and we also find a *definition* of two words "alleged" and "coma", which is provided in brackets. As regards the majority of the definitions detected in the SYNDROMES sub-corpus, they are *intensional definitions* stating the general properties of the objects described. Even in this example, the style is impersonal and retains a high degree of scientific objectivity.

Moving on to the MEDICATIONS&TREATMENTS sub-corpus, we found some similarities in the use of knowledge dissemination strategies compared to the SYNDROMES sub-corpus. Indeed, also in this case explanatory strategies seem to be preferred. However, differently from what we observed in the texts about neurological syndromes, here it is possible to highlight an association of defining procedures with concretization strategies. The typical knowledge dissemination strategy identified consists of an introductory *description* and *denomination* of the drug/treatment followed by a *scenario* recreating a hypothetical interac-

tion that may take place in a doctor-patient encounter. This is realized through a question-answer pattern, as shown in example (6):

- (6) Clobazam (*KLOH-bab-zam*) is the generic name (non-brand name) of the brand-name drug *commonly known* as ONFI in the United States and Frisium (*FRIH-zee-um*) elsewhere. Clobazam is approved for add-on treatment of seizures types associated with Lennox Gastaut Syndrome (LGS).

Each ONFI tablet is a white to off-white, oval tablet with a functional score on one side and a “2” and “0” debossed on the other side.

How does Clobazam affect my child’s brain? How Clobazam works in the brain is not fully known. It’s thought to affect neurotransmitters or substances in the brain that affect the way brain cells communicate.

What if I forget? A forgotten dose should be taken right away. If it is almost time for the next one, 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. If you forget to give doses to your child often, it may be a good idea to get a special pillbox or watch with an alarm to remind you. [Clobazam Epilepsy Foundation_MEDICATIONS&TREATMENTS]

Interestingly, the example shows that the *denomination* of the medication is followed by its pronunciation; this empowers caregivers in that they will be able to talk with physicians about their children’s treatments in a correct way. The subsequent *scenario* puts it into practice and recreates a question-answer pair that may take place in a doctor-patient encounter, i.e. the caregiver asks a question and receives the information requested from the doctor. The questions are posed in the first person singular (“How does Clobazam affect my child’s brain? What if I forget?”), whereas the answers address the reader through second person singular pronoun “you” thus recreating a face-to-face interaction.

Not surprisingly, concretization strategies are also common in the GUIDELINES FOR FAMILIES sub-corpus, where caregivers are given suggestions to deal with aspects concerning the everyday life of their children. Even in this sub-corpus we often find *scenarios* involving question-answer patterns used to mimic doctor-patient encounters, as shown in example (7):

- (7) *Will we be consulted?* If *your child* does require ventilation this will be discussed with *you* by a paediatrician and an anaesthetist. They will try and discuss the ‘pros & cons’ with *you* before they proceed, but it is sometimes an emergency procedure and so they may have to explain the procedure afterwards. It is up to the individual doctors and nurses

whether *you* are able to be present during the intubation, but they will always keep *you* fully informed. [Dravet_Family_Guide_Booklet_GUIDELINES FOR FAMILIES]

Example (7) starts with an interrogative sentence using the first person plural pronoun (“Will we be consulted?”) as to initiate a dialogue. The parents are probably addressed with the pronoun “we” since what is coming next is a tough topic. This hypothesis is further corroborated by the declarative statements following the interrogative sentence, where the writer creates a direct relationship with the reader/caregiver “you” and offers suggestions to help her/him face delicate situation such as artificial ventilation of the child.

The GUIDELINES FOR FAMILIES sub-corpus also shows a high frequency of *exemplifications* serving the purpose of connecting abstract information to real-life situations that the caregiver could experience, as shown in examples (8) and (9):

- (8) Physiotherapy can help your child to achieve his/her maximum level of functional independence. It is also used to prevent and minimise recognised complications that can develop. *For example*, your child’s mobility might reduce after a seizure or as gait difficulties progress, so physiotherapy is often ongoing. [Dravet_Family_Guide_Booklet_GUIDELINES FOR FAMILIES]
- (9) Keep questions short. Ask only the most necessary questions. Structure your questions, eg you could offer options or choices. Be specific. *For example*, ask “Did you enjoy your lunch?” and “Did you enjoy maths?” rather than “How was your day?”. [Communicating – NAS_GUIDELINES FOR FAMILIES]

As the examples illustrate, *exemplifications* give specific and concrete instances of phenomena (such as “recognised complications”) or situations (such as “how to ask the right questions to children affected by Asperger syndrome”) and help caregivers think about concrete experiences of their lives. Everyday life becomes the channel to link medical knowledge to something more familiar and easier to understand.

4. CONCLUDING REMARKS

Knowledge dissemination is particularly relevant when dealing with health issues. Health literacy, in fact, should start from transferring

knowledge of health information that has to be integrated into individuals' existing knowledge and experiences so that it can be used to make informed health decisions about whether adopting or not a specific treatment. Health knowledge dissemination in the case of paediatric chronic neurological disorders not only broadens caregivers' general knowledge about their children's disease, but also has a profound and direct effect on their lives.

The study shows that knowledge dissemination strategies used in the webpages under investigation offer cognitive tools to parents in order to make them informed about their children's disease. The aim of these webpages is to build a relationship with parents as caregivers who face the difficulties of coping with their children's disease for the first time. Indeed, they tend to relate abstract knowledge to concrete experiences by making recourse to 'concretization' strategies of knowledge transfer such as *scenarios*, *hypothetical question-answer sequences* and *exemplifications*. In so doing, caregivers can compare what is described in the webpages to their own personal experience and, as a consequence, understand the abstract medical issues. Moreover, medical terms about syndromes and medications are often defined and reformulated.

The relationship between knowledge dissemination and health literacy is further carried out by a peculiar strategy consisting in providing parents with the pronunciation of syndrome and medication terms. Therefore, caregivers acquire familiarity with technical words and they can use them in a correct way when talking to experts.

In conclusion, the study highlights that the webpages of major foundations dealing with paediatric neurological disorders enhance caregiver health literacy and achieve the goal of caregiver empowerment, giving her/his greater control over decisions affecting her/his child's health.

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