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

Annalisa Sezzi and Marina Bondi
University of Modena and Reggio Emilia

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).
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 Cavallari (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 […]” (Stratiform – 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

---

1 PI. 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. *Generalization* 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.


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;

---

\(^2\) 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);

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.

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 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

<table>
<thead>
<tr>
<th>TYPES OF EXPLANATIONS</th>
<th>Matthew’s Friends</th>
<th>Charlie’s Foundation</th>
<th>Chi-Square</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=157</td>
<td>N=50</td>
<td></td>
</tr>
<tr>
<td>Feature</td>
<td>N</td>
<td>Percent</td>
<td>N</td>
</tr>
<tr>
<td>– denomination designation</td>
<td>65</td>
<td>41.40%</td>
<td>23</td>
</tr>
<tr>
<td>– definition</td>
<td>22</td>
<td>14.01%</td>
<td>7</td>
</tr>
<tr>
<td>– reformulation or paraphrase</td>
<td>30</td>
<td>19.11%</td>
<td>8</td>
</tr>
<tr>
<td>– exemplification</td>
<td>39</td>
<td>24.84%</td>
<td>11</td>
</tr>
<tr>
<td>– generalization</td>
<td>0</td>
<td>0.00%</td>
<td>0</td>
</tr>
<tr>
<td>– analogy</td>
<td>1</td>
<td>0.64%</td>
<td>2</td>
</tr>
<tr>
<td>Frequency per thousands words (ptw)</td>
<td><strong>6.75</strong></td>
<td><strong>4.29</strong></td>
<td></td>
</tr>
</tbody>
</table>
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 mitochondrial disorders paralleling mitochondria 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>
<thead>
<tr>
<th>QUESTIONS</th>
<th>Matthew’s Friends</th>
<th>Charlie’s Foundation</th>
<th>Chi-Squ</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=28</td>
<td>Percent</td>
<td>N=46</td>
</tr>
<tr>
<td>– <em>wh</em>-questions</td>
<td>18</td>
<td>64.29%</td>
<td>28</td>
</tr>
<tr>
<td>– <em>yes/no</em> questions</td>
<td>10</td>
<td>35.71%</td>
<td>18</td>
</tr>
<tr>
<td>Frequency per thousand words (ptw)</td>
<td>0.76</td>
<td>6.21</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>STYLES OF CITATIONS</th>
<th>Matthew’s Friends</th>
<th>Charlie’s Foundation</th>
<th>Chi-Square</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=205</td>
<td>N=33</td>
<td></td>
</tr>
<tr>
<td>Feature</td>
<td>N</td>
<td>Percent</td>
<td>N</td>
</tr>
<tr>
<td>– direct citation</td>
<td>14</td>
<td>6.83%</td>
<td>2</td>
</tr>
<tr>
<td>– indirect citation</td>
<td>70</td>
<td>34.15%</td>
<td>14</td>
</tr>
<tr>
<td>– integrated citation</td>
<td>1</td>
<td>0.49%</td>
<td>2</td>
</tr>
<tr>
<td>– inserted citation</td>
<td>1</td>
<td>0.49%</td>
<td>5</td>
</tr>
<tr>
<td>– NRSA(p)</td>
<td>119</td>
<td>58.05%</td>
<td>10</td>
</tr>
<tr>
<td>Frequency per thousand words (ptw)</td>
<td>5.60</td>
<td>4.46</td>
<td></td>
</tr>
</tbody>
</table>

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/content/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

<table>
<thead>
<tr>
<th>SOURCES OF CITATIONS</th>
<th>Matthew’s Friends</th>
<th>Charlie’s Foundation</th>
<th>Chi-Squ</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=205</td>
<td>N=33</td>
<td></td>
</tr>
<tr>
<td>Feature</td>
<td>N</td>
<td>Percent</td>
<td>N</td>
</tr>
<tr>
<td>– Self (we)</td>
<td>5</td>
<td>2.44%</td>
<td>0</td>
</tr>
<tr>
<td>– Specified others (patients)</td>
<td>2</td>
<td>0.98%</td>
<td>0</td>
</tr>
<tr>
<td>– Unspecified others (it-passive)</td>
<td>4</td>
<td>1.95%</td>
<td>0</td>
</tr>
<tr>
<td>– Community (folk quotes)</td>
<td>15</td>
<td>7.32%</td>
<td>0</td>
</tr>
<tr>
<td>– Specified others (caregivers)</td>
<td>3</td>
<td>1.46%</td>
<td>3</td>
</tr>
<tr>
<td>– Specified others (guidelines)</td>
<td>8</td>
<td>3.90%</td>
<td>1</td>
</tr>
<tr>
<td>– Specified others (research)</td>
<td>161</td>
<td>78.54%</td>
<td>23</td>
</tr>
<tr>
<td>– Unspecified others (studies)</td>
<td>7</td>
<td>3.41%</td>
<td>6</td>
</tr>
</tbody>
</table>
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)
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)

[..] 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)

Electric vaporisers have been recommended by some families. (Matthew’s Friends)

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).

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)

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:

“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.

REFERENCES

Sources

Charlie Foundation for Ketogenic Therapies
https://charliefoundation.org/, accessed August 2019

Matthew’s Friends
https://www.matthewsfriends.org/, accessed August 2019

Special studies


Anesa, P. – A. Fage-Butler.
2015 “Popularizing biomedical information on an online health forum”, *Ibérica* 29, 105-128.
Bautista, R.E. et al.  

Bondi, M.  

Bondi, M. – D. Yu  

Briones, R.  

Cacchiani, S.  


Caliendo, G.  

Calsamiglia, H. – C. López Ferrero  

Calsamiglia, H. – T.A. van Dijk  

CANDLIN, C.N. – CANDLIN S.  

Cavalieri, S.  


Frade, C. 2015 “Attempting the easification of Patient Information Leaflets (PILs) in Brazil”. In: M. Gotti – S. Maci – M. Sala (eds.) Insights into Medical Communication. Bern: Peter Lang, 137-158.


"I am going on a ketogenic diet"

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

Hyland, K.  


Kalichman, S.C. et al.  

Lupton, D.  

Luzón, M.J.  

Maglie, R.  
2015 “‘Can you read this leaflet?’: User-friendliness of patient information leaflets in the UK and in Italy”. In: M. Gotti – S. Maci – M. Sala (eds.) Insights into Medical Communication. Bern: Peter Lang, 159-188.

2017 “Engaging with online communication-based medicine, reframing healthcare delivery to adolescents: Online healthcare delivery to adolescents”. In: G. Garzone et al. (eds.) Specialised and Professional Discourse across Media and Genres. Milano: Ledizioni, 75-91.

Mattiello, E.  

Mazzi, D.  
2018 “‘The diet is not suitable for all…’: On the British and Irish web-based discourse on the ketogenic diet”, Lingue Culture Mediazioni / Languages Cultures Mediation 5 (1), 37-56. http://www.ledonline.it/LCM-Journal/

Muñoz-Miquel, A.  
O’Donnell, M.

Scotto di Carlo, G.

Seale, C.F.

Semino, E. – M. Short

Sinclair, J.

Stratform, C.E. – J.M. Rho (eds.)

Thompson, G.

Turnbull, J.

Van Berkel, J. – M. Gerritsen

Vaughan, E. – B. Clancy
“I am going on a ketogenic diet”

Vicentini, A.

Wheless, J.W.

Wolf, M.S. – R.M. Parker – S.C. Ratzan

Address: ANNALISA SEZZI, Department of Studies on Language and Culture, University of Modena and Reggio Emilia, Largo Sant’Eufemia 19, 41121 Modena, Italy.
ORCID code: orcid.org/0000-0000-0001-7002-0718.

Address: MARINA BONDI, Department of Studies on Language and Culture, University of Modena and Reggio Emilia, Largo Sant’Eufemia 19, 41121 Modena, Italy.
ORCID code: orcid.org/0000-0002-3462-8387.