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

Silvia Cavalieri*, Maddalena Marchiò**,
Marina Bondi**, Giuseppe Biagini**

* *"Sapienza" University of Rome*
** *University of Modena and Reggio Emilia*

ABSTRACT

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

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

1. Introduction

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

DOI: 10.25951/2958.

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

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

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

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

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

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

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

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

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

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

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

2. Methods and materials

Our approach to the study of caregivers' health literacy can be described as a 'textography' (Alexander 2000) or a 'textual ethnography' (Swales 1998) of health literacy events. By 'textual ethnography' we mean an ethnography that concerns the mediating role of (written) texts in social events, such as healthcare encounters. What makes our approach different from more

conventional ethnographies of literacy is that we rely not only on the observation of the social context in which a linguistic event takes place, but also on the analysis of the texts involved in a healthcare encounter in order to gain a complete understanding of it. To reach this goal, our investigation consisted of two main steps: 1) the administration of a questionnaire assessing the perception of caregivers on the current communicative situation and the informativeness of written materials on the KD (Oppenheim 1992) aimed at highlighting strengths and weaknesses of the communicative practices adopted by the health institution in the implementation of the treatment; 2) an analysis of the KD informative materials provided by the centers and indicated by caregivers involved in the administration of the questionnaire. The analysis was performed adopting the Evaluative Linguistic Framework (ELF) (Cleheran et al. 2005).

2.1 The questionnaire

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

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

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

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

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

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

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

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

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

2.2 ELF assessment

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

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

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

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

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

2.2.1 Organization or structure of the text (generic structure)

As for the organization or structure of the text, Clerehan et al. (2005: 336), adopting Swales's approach (1990), argue that different kinds of text generally have a specific genre consisting of a series of sections or 'moves'

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

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

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

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

2.2.3 Technicality of vocabulary used in the text

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

2.2.4 Purpose of the text (metadiscourse)

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

2.2.5 Role relationships expressed in the text

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

2.2.6 The use of headings

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

2.2.7 Density of information in the text (lexical density)

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

2.2.8 Validity of factual content

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

2.2.9 Visual aspects of text

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

2.3 Textual materials for the analysis

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

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

As is possible to see in the pictures, the first booklet starting from the left was produced by the medical nutrition company "Nutricia", which offers specialized products (food and therapeutic preparations) for the

management of the diet, whereas the second and the third were written by the dieticians of the Bellaria Hospital (Bologna) and the Policlinico Hospital (Modena). In general, the booklets consist of an average of 30 pages and all present a combination of text and images that range from pictures of food, scales and other instruments to tables with data.

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

3. Results

3.1 Results of the questionnaires

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

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

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

was considered particularly useful for explaining the KD to other people involved in the life of the child under treatment.

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

3.2 Results of the ELF assessment

3.2.1 Organization or structure of the text

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

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

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

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

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

Ordering of information was often consistent among the documents.

Table 2. Generic structure of the KD booklets

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

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

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

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

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

3.2.3 Technicality of the vocabulary

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

3.2.4 Purpose of the text (metadiscourse)

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

3.2.5 Role relationships expressed in the text

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

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

3.2.6 The use of headings

All the three booklets used headings to focus the reader's attention upon the content. Headings were generally considered adequate and appropriate,

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

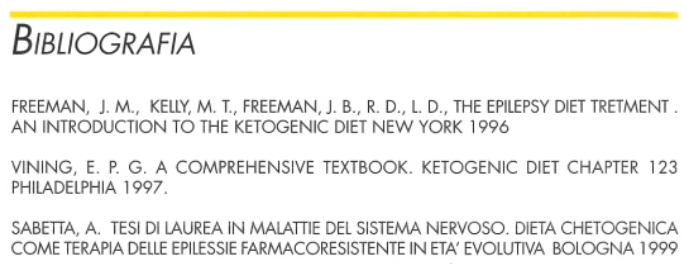
3.2.7 Density of information in the text (lexical density)

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

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

3.2.8 Factual content

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



BIBLIOGRAFIA

FREEMAN, J. M., KELLY, M. T., FREEMAN, J. B., R. D., L. D., THE EPILEPSY DIET TRETMENT . AN INTRODUCTION TO THE KETOGENIC DIET NEW YORK 1996

VINING, E. P. G. A COMPREHENSIVE TEXTBOOK. KETOGENIC DIET CHAPTER 123 PHILADELPHIA 1997.

SABETTA, A. TESI DI LAUREA IN MALATTIE DEL SISTEMA NERVOSO. DIETA CHETOGENICA COME TERAPIA DELLE EPILESSIE FARMACORESISTENTE IN ETA' EVOLUTIVA BOLOGNA 1999

Figure 2. Reference list in the BO booklet

3.2.9 Visual aspects of text

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

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

2

BUON COMPLEANNO

COSA OFFRIRE AGLI AMICI

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

A SCUOLA

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

Assaggi e scambi di merendine non sono permessi!

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

QUANDO C' E' LA BABY-SITTER

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

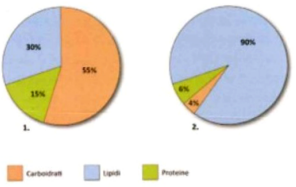
IN VIAGGIO

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

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

3

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



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

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

PIRAMIDE CHETOGENICA

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

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

4. Concluding remarks

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

APPENDIX 1

QUESTIONARIO SUI MATERIALI INFORMATIVI SULLA DIETA CHETOGENICA

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

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

PRIMA PARTE – INFORMAZIONI GENERALI

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

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

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

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

4. Sesso del figlio/a che segue la dieta chetogenica:
– Maschile
– Femminile

5. Presso quale centro è seguito suo/a figlio/a per quanto riguarda la dieta?
– Pavia
– Roma
– Bologna
– Firenze
– Modena

6. In questo momento suo/a figlio/a sta seguendo la dieta chetogenica?
– Sì → da quanto tempo la segue? _____
– No, l'ha seguita in passato → per quanto tempo l'ha seguita? _____

7. Chi si occupa maggiormente della preparazione e gestione della dieta?
– Madre
– Padre
– Entrambi in egual misura
– _____

8. Ha accesso a internet?
– Sì, quotidianamente
– Sì, almeno una volta a settimana
– Sì, ogni tanto
– No

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

1. Dove avete trovato le informazioni preliminari che vi hanno fatto avvicinare alla dieta chetogenica? (scegliere una o più opzioni)
– Siti web
– Social Media
– Strutture ospedaliere/personale sanitario
– Passaparola
– Materiale informativo cartaceo/brochures
– Altro (specificare)

2. Dove avete trovato le informazioni utili alla scelta del Centro che vi avrebbe seguito nell'adottare la dieta chetogenica? (scegliere una o più opzioni)
– Siti web
– Social Media
– Strutture ospedaliere/personale sanitario

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

3. Che materiali vi sono stati forniti dal Centro che vi segue attualmente nell'adottare della dieta chetogenica? (scegliere una o più opzioni)
– Materiali informativi cartacei prodotti dal centro stesso
– Materiali informativi cartacei prodotti da case farmaceutiche
– Sito web
– App di elaborazione ricette
– Video
– Altro (specificare)

TERZA PARTE – COME VALUTATE LE INFORMAZIONI OTTENUTE SULLA DIETA CHETOGENICA

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

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

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

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

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

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

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

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

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

REFERENCES

Sources

Booklet 1

Nutricia (Advanced Medical Nutrition). *La Dieta Chetogenica – manuale informativo per le famiglie*, a cura di A. Tagliabue e C. Trentani.

Booklet 2

Azienda U.S.L. città di Bologna, Servizio di Dietologia e Nutrizione Clinica dell'Ospedale „Bellaria". *La Dieta Chetogenica - Manuale di aiuto alle famiglie*, a cura di L. Andrini e E. Fantoni.

Booklet 3

Azienda Ospedaliero-Universitaria di Modena. *Trattamento dietetico dell'epilessia – La Dieta Chetogenica – Manuale informativo*, a cura di M. Marchiò.

Special studies

Alexander, K.
2000 "Writing up/writing down: Literate practices in a mental boarding home", *Literacy and Numeracy Studies* 10 (1-2), 23-38.

Askehave, I. – K.K. Zethsen
2003 "Communication barriers in public discourse: The patient package insert", *Document Design* 4 (1), 22-41.

Bautista, RE. et al.
2009 "The association between health literacy and outcomes of care among epilepsy patients", *Seizure* 18 (6), 400-404.

Bautista, R.E. – D. Shapovalov – A.R. Shoraka
2015 "Factors associated with increased felt stigma among individuals with epilepsy", *Seizure* 30, 106-112.

Bigi, S. – M.G. Rossi
2015 "ICTs for the medical profession: An application in chronic care." Paper presented at ALAPP 2015, 5th International Conference on Applied Linguistics and Professional Practice *"Language, discourse and action in professional practice"*, University of Milan, 6-8 November 2015.

Bruce, B.C. – A. Rubin
1988 "Readability formulas: Matching tool and task". In: A. Davison – G.M. Green (eds.) *Linguistic Complexity and Text Comprehension: Readability Issues Reconsidered*. Hillsdale, NJ: Lawrence Erlbaum, 5-22.

Candlin, C.
2000a "Reinventing the patient/client: New challenges to healthcare communication." Paper presented at the Cardiff Lecture, Health Communication Research Centre, Cardiff University.

2000b "New dynamics in the nurse-patient relationship?" In: S. Sarangi – M. Coulthard (eds.) *Discourse and Social Life.* London: Pearson Education, 230-245.

Candlin, C.N. – S. Candlin
2003 "Health care communication: A problematic site or applied linguistics research", *Annual Review of Applied Linguistics* 23, 134-154.

Clerehan, R. – R. Buchbinder – J. Moodie
2005 "A linguistic framework for assessing the quality of written patient information: Its use in assessing methotrexate information for rheumatoid arthritis", *Health Education Research* 20 (3), 334-344.

Clerehan, R. – D. Hirsch – R. Buchbinder
2009 "Medication information leaflets for patients: The further validation of an analytic linguistic framework", *Communication & Medicine* 6 (2), 117-127.

Coupland, J. – A. Williams
2002 "Conflicting discourses, shifting ideologies: Pharmaceutical, alternative and feminist emancipatory texts on the menopause", *Discourse & Society* 13 (4), 419-445.

Dixon-Woods, M.
2001 "Writing wrongs? An analysis of published discourses about the use of patient information leaflets", *Social Science & Medicine* 52 (9), 1417-1432.

Dray, S. – U. Papen
2004 "Literacy and health: Towards a methodology for investigating patients' participation in healthcare", *Journal of Applied Linguistics* 1 (3), 311-332.

Elliott, J.O. – C. Charyton – L. Long
2007 "A health literacy assessment of the National Epilepsy Foundation Web Site", *Epilepsy & Behavior* 11 (4), 525-532.

Elliott, J. – B. Shneker
2008 "Patient, caregiver, and health care practitioner knowledge of, beliefs about, and attitudes toward epilepsy", *Epilepsy & Behavior* 12 (4), 547-556.

Eysenbach, G. – C. Kohler
2002 "How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews", *BMJ* 324 (7337), 573-577.

Filippone, J.D. et al.
2013 "The intersection of knowledge transfer and health literacy in reducing readmission rates for heart failure", *Journal of Cardiac Failure* 19 (8), S88.

Finlay, I.G. – S. Sarangi
2006 "Medical discourse, communication skills and terminally ill patients". In: K. Brown (ed.) *The Encyclopaedia of Language & Linguistics* (2nd edn.). Vol. 7. London: Elsevier, 665-674.

Green, J. – D. Bloome
1997 "A situated perspective on ethnography and ethnographers of and in education". In: J. Flood – S. Heath – D. Lapp (eds.) *Handbook of Research on Teaching Literacy through the Communicative and Visual Arts.* New York: Macmillan, 181-202.
Grime, J. et al.
2007 "The role and value of written information for patients about individual medicines: a systematic review", *Health Expectations* 10 (3), 286-298.
Halliday, M.A.K.
1985 *Spoken and Written Language*. Victoria: Deakin University.
1994 *An Introduction to Functional Grammar* (2nd edn.). London: Edward Arnold.
Hartley, J.
1994 *Designing Instructional Text*(3rdedn.). London: Kogan Page.
Heinemann, U. et al.
2006 "Eleven novel mechanisms underlying drug resistance in temporal lobe epilepsy", *Advances in Neurology* 97, 85-95.
Hyland, K.
2005 *Metadiscourse: Exploring Interaction in Writing.* London: Continuum.
Kalichman, S.C. et al.
2000 "Health literacy and health-related knowledge among persons living with HIV/AIDS", *American Journal of Preventive Medicine* 18 (4), 325-331.
Loblaw D.A. – A. Bezjak – T. Bunston
1999 "Development and testing of a visit-specific patient satisfaction questionnaire: The Princess Margaret Hospital Satisfaction with Doctor Questionnaire", *Journal of Clinical Oncology* 17 (6), 1931-1938.
Lupton, D.
1992 "Discourse Analysis: A new methodology for understanding the ideologies of health and illness", *Australian Journal of Public Health* 16 (2), 145-150.
1999 "Archetypes of infection: People with HIV/AIDS in the Australian press in the mid 1990s", *Sociology of Health and Illness* 21 (1), 37-53.
Mancuso, C.A. – M. Rincon
2006 "Impact of health literacy on longitudinal asthma outcomes", *Journal of General Internal Medicine* 21 (8), 813-817.
Molina, L.
2001 "Readability of education materials and informed consent forms for women seeking surgical sterilization", *International Journal of Gynecology & Obstetrics* 73 (2), 177-178.
Nicholas, D. et al.
2001 "Digital health information and health outcomes", *Journal of Information Science* 27 (4), 265-276.

Oppenheim, A.N.
1992 *Questionnaire design. Interviewing and Attitude measurement*. London: Pinter.
Payne, S. et al.
2000 "Written information given to patients and families by palliative care units: A national survey", *The Lancet* 355 (9217), 1792.
Pollock, K. et al.
2011 "Exploring patients' experience of receiving information about cancer: A comparison of interview and questionnaire methods of data collection", *Health* 15 (2), 153-172.
Raynor, D.K. et al.
2007 "A systematic review of quantitative and qualitative research on the role and effectiveness of written information available to patients about individual medicines", *Health Technol Assess* 11 (iii), 1-160.
Sanson-Fisher, R.W. – Paul, C.L. – S. Redman
1997 "The development of a checklist of content and design characteristics for printed health education materials", *Health Promotion Journal of Australia* 7 (3), 153-159.
Sarangi, S.
2007 "Other-orientation in patient-centered healthcare communication: Unveiled ideology or discoursal ecology", *Discourse, Ideology and Specialized Communication* 33,39-71.
Schillinger, D. – K. Grumbach – J. Piette
2002 "Association of health literacy with diabetes outcomes", *Journal of the American Medical Association* 288 (4), 475-482.
Schriver, K.A.
1997 *Dynamics in Document Design: Creating Text for Readers*. New York: Wiley.
Seale, C.
2001 "Sporting cancer: Struggle language in news reports of people with cancer", *Sociology of Health and Illness* 23 (3), 308-29.
Smart, J.M. – D. Burling
2001 "Radiology and the Internet: A systematic review of patient information resources", *Clinical Radiology* 56 (11), 867-870.
Swales, J.M.
1990 *Genre Analysis: English in Academic and Research Settings*. Cambridge: Cambridge University Press.
1998 *Other floors, Other Voices: ATextography of a Small University Building*. New York: Routledge.
Turnbull, J.
2015 "Knowledge dissemination online: The case of health information". In: M. Bondi – S. Cacchiani – D. Mazzi (eds.) *Discourse In and Through the Media. Recontextualizing and Reconceptualizing Expert Discourse*. Newcastle upon Tyne: Cambridge Scholars Publishing, 290-314.

Voghera, M.
2001 "Teorie linguistiche e dati di parlato". In: F. Albano Leoni et al. (eds.) *Dati empirici e teorie linguistiche, Atti del XXXIII Congresso Internazionale di Studi della Società di linguistica italiana (SLI)*. Roma: Bulzoni, 75-95.

Wall, G.
2001 "Moral constructions of motherhood in breastfeeding discourse", *Gender and Society* 15 (4), 592-610.

Wright, P.
1999 "Writing and information design of healthcare materials". In: C. Candlin – K. Hyland (eds.) *Writing: Texts, Processes and Practices*. London: Longman, 85-98.

Address: Silvia Cavalieri, MEMOTEF Department, "Sapienza" University of Rome, Via Castro Laurenziano 9, 00161 Roma, Italy.
ORCID code: orcid.org/0000-0001-7010-1489.

Address: Maddalena Marchiò, Department of Biomedical, Metabolic and Neural Sciences, University of Modena and Reggio Emilia, Via Campi 287, 41125 Modena, Italy.
ORCID code: orcid.org/0000-0003-2675-687X.

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

Address: Giuseppe Biagini, Department of Biomedical, Metabolic and Neural Sciences, University of Modena and Reggio Emilia, Via Campi 287, 41125 Modena, Italy.
ORCID code: orcid.org/0000-0002-7130-2511.