

ETHIC – Evaluation Tool of Health Information for Consumers. Development, features and validation.

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Abstract

Introduction: Good information is a fundamental component of the therapeutic process and Health Information issues are of strategic importance, mostly in social and cultural contexts characterized by low literacy levels, as the Italian one.

Aim: ETHIC (Evaluation Tool of Health Information for Consumers) is an instrument developed for the quality assessment of health information materials from a linguistic, textual and documentary point of view. Our aim is to provide bio-medical librarians and health information professionals with a tool that could be helpful in directing consumers toward the best information available and in supporting healthcare professionals in the development of health information materials.

Methods: ETHIC allows to assess printed health information resources (booklets, depliants etc.) and consists of a checklist and an instruction manual. ETHIC has been drawn up according to the present literature and it's inspired to presently available tools and to publications and guidelines on plain language writing. Furthermore, ETHIC embeds instruments for the evaluation of text readability, lexical understandability and for the assessment of non-textual elements such as tables. The checklist consists of 24 items and the scoring system allows to compare each other different information materials. The instruction manual shows how to perform the evaluation, explains how to assign the correct score to each single item and contains practical examples which can guide through the evaluation process. ETHIC will undergo to a validation procedure to prove its efficacy and effectiveness.

Discussion: ETHIC could represent an effective tool for bio-medical librarians and health information professionals to assess the quality of health information materials for consumers, to support healthcare professionals in drawing up good quality health information materials, to contribute in facilitating knowledge creation and also to enhance their professionals skills.

Conclusions: The validation procedure will have to confirm the accuracy of development process and tool itself.

Key words: Consumer Health Information; Patient Education; Library Services; Questionnaires; Validation studies.

Introduction

In the last years, issues like Patient Information and Health Literacy have become increasingly important. Not only patients, but also the general public are interested in Health information. A recent research of the CENSIS –Forum per la Ricerca Biomedica (Forum for Biomedical Research) (1) found that, when faced with a health problem, 73.2% of Italians consider more important to understand what is happening, rather than finding immediately the most effective remedy. A clear majority of the sample (58.7%, with 64.1% and 61.5% among high school graduates and college graduates, respectively) also declared that, in relation to health, the most important thing is to get as much information as possible. In particular, for some kind of patients (including cancer patients) researching and obtaining information are particularly important aims and numerous studies and surveys confirm that answering to information needs has to be considered “the first medicine” and improves the doctor-patient relationship in more than 90% of the cases (2).

In recent years the world of (health) information has been revolutionized by the spread of internet access. As well known, on the one hand internet offers to an ever growing segment of the population the possibility to obtain large amounts of information materials, while, on the other hand, it presents problems of not secondary importance, among which is the issue of the validity/quality of the information retrieved (3).

Not secondary it's also another issue: the low Literacy (4-5) / Health Literacy level of the population, a factor that negatively affects access to health information and that increasing evidence relates to poorer health outcomes (6) and, as a consequence, to health inequalities (health divide). It's in this kind of context that the Joint Commission (7) emphasizes «the fundamental right and need for patients to receive information – both orally and written – about their care in a way in which they can understand this information», highlighting that «effective communication is a cornerstone of patient safety».

This need for information and the importance of health information/communication issues are confirmed by the literature and are also highlighted in the National Cancer Plan 2010-2012 published by the Italian Ministry of Health where, under the heading “Communication”, it points out that «in recent years, as well as the growth of well-being demand, there has been a substantial growth in the demand for information on health and diseases. [...] In order to promote behaviours and lifestyles healthy and able to prevent cancer, but also to change attitudes and beliefs detrimental to the care, health systems need to actively involve citizens in the protection of their own health. The public administration does not have a passive role in health management: communication increasingly establishes itself as a business tool for the health system» (8).

In this context, it becomes crucial for the health services to implement activities that can help patients, family members and citizens to obtain the required information, ensuring the quality of this information and guiding patients and citizens towards high-quality information, i.e. scientifically correct, up-to-date, written in an understandable language and customized on the needs of the user (9) (“every reader his document”) (10). An information that can help patients to make correct health choices and to take control of their own health and well-being (11).

As reported in a recent publication of the Patient Information Forum, in fact, «without appropriate guidance and support, there are concerns that information will not only fail to have the desired impacts, it could also serve to widen existing health inequalities» (11).

Bio-medical librarians and health information professionals have a strategic role in this situation, because they are part of the health services and, at the same time, they can represent an easy point of access to high-quality health information for patients and citizens. The IFLA (International Federation of Library Associations and Institutions) itself has issued specific guidelines (12) about the offer of library services dealing with the delivery of health information and the organization of recreational activities for patients and their relatives.

All these elements confirm that, in relation to health, not only clinical practice, but also good information is a fundamental component of the therapeutic process. Furthermore Health

Information issues are of strategic importance mostly in social and cultural contexts characterized by low literacy levels, as the Italian one.

Aim

Starting from this background, the aim of our project is to provide bio-medical librarians and health information professionals with a tool that could be helpful in:

- directing consumers toward the best information available;
- supporting healthcare professionals in the development of health information materials.

Our purpose is to set up a tool suitable for the Italian reality, as objective as possible, able to evaluate different types of resources and eligible for validation, i.e. a tool that can demonstrate efficacy and effectiveness on the basis of a solid evidence.

Methods

Development

ETHIC has been drawn up according to the present literature on Health Information evaluation. Furthermore, it's inspired to publications and guidelines on plain language writing and to presently available tools, such as SAM (Suitability Assessment of Materials) (13), DISCERN (14) (and its Italian version DISCERNere) (15) and others.

The development process started from these resources, but it has taken into account several problems related to the evaluation of health information materials, in particular four different kind of problems:

- problems related to *languages and cultures*: there are many tools for the evaluation of health information (DISCERN, SAM, EQUIP (16) and so on), but they have been developed for the assessment of information written in other-than-Italian languages (especially in English) and relating to other cultures (especially anglo-american culture). This implies that they aren't easily adjustable to the Italian reality in which their effectiveness should be carefully verified.
- Problems related to the *suitability* of these tools: some tools are effective only on some kinds of consumer Health Information (such as DISCERN, which can be used for the quality assessment of information about treatment choices) (14).
- Problems related to the *lack of evidence*: there isn't a strong evidence supporting the predominance of one in particular of these tools.
- Problems related to *partial subjectivity*: some tools contain items which impose the execution of too subjective evaluations. For example, different people could give very different answers to an item/question like "Does the document use everyday language?". What really is "everyday language"?

Features

ETHIC (Evaluation Tool of Health Information for Consumers) is an instrument developed for the quality assessment of health information materials from a linguistic, textual and documentary point of view. ETHIC does not provide an evaluation of the Health Information content from a clinical point of view.

ETHIC is meant to be used by medical librarians and health information professionals. This tool could have different applications such as: checking the quality of Health Information created by different institutions, performing actions in order to improve quality of information, evaluating documents to implement database and open archives on health information etc.

In particular, ETHIC (Version 1.0) allows to assess printed health information resources (booklets, dépliants etc.) and it's composed of a checklist and an instruction manual.

The checklist consists of 24 items grouped into five sections: Transparency, Suitability, Documentary Features, Linguistic and Textual Features, Graphical Features.

The checklist includes an evaluation of:

- text readability (through the GULPEASE index, a readability formula specifically calibrated for the Italian language) (17);
- lexical understandability, in relation to the amount of words belonging to the Italian Basic Lexicon (in Italian: *Vocaboario di Base*, i.e. a set of words which can be easily understood by the largest part of the population) (18).

The decision to integrate the readability assessment (a widespread practice in other countries such as the USA) with a systematic evaluation of the use of common words is justified by the intention to ensure a more effective and complete linguistic evaluation of each document (a key aspect of the texts comprehension).

An evaluation of the merely linguistic aspects (readability and use of common words) is provided in other literature tools (e.g. SAM), but ETHIC explicitly offers the possibility to analyse Italian language specific values.

Furthermore, ETHIC provides the possibility to measure these values also through an automated tool (Èulogos[®] Censor) which offers the best effectiveness, precision and comparability. The automated evaluation of readability and basic lexicon presence allows to overcome not only possible differences in the use of GULPEASE readability formula among raters, but also arbitrary items such as “Does the document use everyday language?”, replacing the personal opinion of the evaluator with an objective quantification of the amount of words belonging to the Italian Basic Lexicon. This leads towards an easier and more consistent evaluation process.

The linguistic comprehension represents the key of the comprehension process of a text, but Health Information, in addition to written parts, often include tables, lists and so on. And often these elements contain a lot of useful and important information. As a matter of fact, one of the skills studied by international literacy surveys (e.g. ALL (4)) is the so called “document literacy”, defined as «the knowledge and skills required to locate and use information contained in various formats, including (...) tables and charts» (4). This is the reason why ETHIC embeds the evaluation of non-textual elements such as tables. This is performed through the PMOSE/IKIRSCH tool, an instrument published by Peter Mosenthal and Irwin Kirsch in 1998 (19), that permits to measure the understandability of these elements.

Similarly to SAM, ETHIC gives the possibility to assign 3 different scores to each single item:

- 2 points if the document entirely possesses the characteristic assessed by that particular item;
- 1 point if the document partially possesses this characteristic;
- 0 points if the document does not possess it at all.

When, because of the peculiarity of the document, it's not possible to apply one or more items to the document itself, the evaluator has the possibility to assign an N/A (“Not Applies”) to the item(s), without conditioning the final score, because this consists in a percentage calculated on the maximum score achievable according to the number of items applied to the document assessed. The scoring method itself helps to make the checklist easily adaptable to the assessment of different kinds of Health Information materials and the use of a relative score, instead of an absolute one, allows to compare each other different documents (considering the total scores, or section by section).

Each structural choice has been made in order to have a minimum degree of arbitrariness and subjectiveness, which could cause mistakes in the evaluation process. To further reduce these risks, an instruction manual has been drawn up as an integral part of the ETHIC project. The manual helps to ensure the correct use of the checklist, making it reliable and minimizing inter-rater (and intra-rater) differences. The manual explains how to perform the evaluation, how to assign the correct

score item by item and explains also when not to apply some items. Furthermore, the instruction manual:

- contains practical examples that can guide the evaluator through the evaluation process;
- explains the use of the embedded instruments mentioned before (Eulogos[®] Censor/GULPEASE readability formula and PMOSE/IKIRSCH)
- explains how to assess readability and use of common words also without the automated tool.

Validation

ETHIC will undergo to a validation procedure to prove its efficacy and effectiveness. This will make it possible to spot checklist mistakes which could be then improved taking into account the problems arising in the test period.

Essential passages of the validation procedure will be:

- a pre-test of the tool on a little sample of documents;
- assessment of “face & content validity” by a pool of experts;
- application of the tool (amended, if necessary, in comparison with version 1.0) on a large sample of documents;
- data analysis.

Discussion

ETHIC could represent an effective tool for bio-medical librarians and health information professionals not only to assess the quality of health information materials for consumers and to support healthcare professionals in drawing up good quality health information materials, but also to contribute in «facilitating knowledge creation» (20) and to enhance their professionals skills. This could also represent an opportunity for librarians and health information professionals to be considered more active agents in the Health Information process and in the Health Literacy field. Furthermore, the evaluation process promoted by ETHIC project is not only directed to the formulation of a judgment, but also to encourage:

- a virtuous linkage among different professionals which take part in the Health Information process (librarians and health information professionals included) with the acknowledgment and the enhancement of their specific expertise;
- consumers’ cooperation; as a matter of fact, quality evaluation could become an educational tool (developing abilities and consumers’ critical sense about Health Information) and could help patients/consumers to be more involved in developing and testing Health Information materials.

Conclusions

The ambitious purpose of this project is to fill a gap thanks to a reliable and authoritative tool; a tool that can cope with one of the problems described before, i.e. the lack of evidence about efficacy/effectiveness of other available tools.

For this reason, the validation procedure is of primary importance to confirm the accuracy of the development process and of the tool itself.

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