Evaluation of medical information quality

Hodnocení kvality medicínských informací

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Abstract

The internet has become a significant source of health-related information in the last ten years. Quality of health-related information is often diverse and uncertain and on the internet environment it should be evaluated by a specific method. This could be viewed as an important part of health literacy skills of the 21st century. For this purpose the indicators of medical information quality are defined based on the dimension of reliability of information quality. The dimensions are derived from three-dimensional scheme by Anton Vedder and it can be applicable in the Czech internet environment. The indicators are: origin, sponsorship, purpose and intent, currency and date, citation and links, accuracy and completeness, clarity and truthfulness. These indicators were selected from established tools for evaluation of medical information quality that are used abroad, like HONCode, MedlinePlus or DISCERN. The indicators are set into the draft of methodics with the instructions for the evaluation of medical information quality on Czech websites. The methodics could be applicable not only in the Czech Republic, but also in other countries, if a socio-political context is similar to Czech. The methodics is divided into two parts: one for non-expert sources in common online environment designed for laymen and one extended version designed for experts. The version designed for expert is a little bit modified and except these indicators also includes criteria for critical evaluation of research papers and reviews. These criteria relate to questions of correct interpretation and collection of information in summaries, and questions on researched subjects, observation and intervention (whether it was done correctly or not), results (e.g. statistical test, effect size) and data interpretation in experimental papers. Both methodics for laymen and experts improves critical thinking and supports better decision making in issues related to health.

Keywords: *quality of information, medical information, evidence-based medicine, evaluation, health literacy, methodics*

Introduction

According to Czech Statistical Office 2013 survey, 55 % of internet users searched for health-related information on the Czech websites (Czech Statistical Office, 2013). That's a significant increase in comparison with the year 2006, when the number was 23 %. These numbers go along with the increasing access to the internet of Czech households, from 27 % in 2006 to 67 % in 2013 (Veřejná databáze ČSÚ, 2014).

Internet as a medium is different from traditional media. It is easy for everyone to create and disseminate information whether in specific domain or not, with or without particular knowledge. Information are presented in various ways and in different purpose, by and to people of diverse knowledge. This trend affect also health domain, where the quality of information is often questionable and low.

The State of Knowledge in Foreign Environment

In the foreign environment, the issue of medical information quality is being discussed since mid of 1990's. In 1998 Gagliardi and Jadad (1998) indentified 47 rating instruments and described 14 of them. Although the authors mentioned that judging the applicability and credibility of information "*may present a greater challenge than just searching for information,*" in the conclusion they were sceptical whether the instruments measure what they claim to measure, and whether they are actually better then more harmful. The same authors updated their study four years later and they were again asking similiar sceptical questions about the necessity of the evaluation of medical information quality, whether it is achievable, when there is no gold standard for it, and whether it has impact on the consumer behavior and consequently on their health (Gagliardi & Jadad, 2002).

Many instruments for evaluation of medical information quality exist currently as they started to appear in the mid 1990's. In review study in 2001 thirteen leading initiatives developing ethical standards and standards of health information quality on the internet were analyzed and compared (Risk & Dzenowagis, 2001). The criteria of quality had common principles in following aspects: honesty, privacy, confidentiality, accuracy, currency, provenance, consent, disclosure, and accountability. The instruments and methods were classified into three main categories: 1. codes of conduct, 2. third-party certification and 3. tool-based evaluation. The first group is based on ethical behavior principles and the criteria of quality are based on self-certification of the web sites; if the web site comply the standards, it can display the logo of the instruments on their pages. The second group is based on compliance of standards of some company and the complying site must pay fees. Tool-based evaluation are usually questionnaires designed for citizens that can be applied to a given site and after the evaluation the "quality score" is yielded.

A recent study brought a review literature about the indicators of medical information quality (Fahy, Hardikar, Fox, & Mackay, 2014). The indicators were divided on "core" and "proxy." Core indicators like accuracy, completeness and currency of information measure quality of information directly and are understood as gold standard. However, their application is limited by expert input and therefore it would be impossible to evaluate them on each web site. For

indirect measurement indicators like readability, design and disclosures were identified, which are more objective and easily applicable but may not evaluate the quality of information in reliable way. Authors also made a critical reflection of the three most widely used tools for evaluation of medical information quality: the HON Code, the JAMA benchmarks and the DISCERN tool. HON code is the oldest evaluation tool from 1995 translated into more than thirty languages. It works as codes of conduct with eight indicators: authoritative, complementarity, privacy, attribution, justifiability, transparency, financial disclosure and advertising policy. HON Code concentrates more on ethics of information presented and not on the content (e.g. the indicator of accuracy of information is missing). The JAMA benchmarks include authorship, attribution (sources and references), disclosure (ownership, sponsorship, advertising policies, conflict of interest) and currency (date of post or date of update) (Silberg, Lundberg, & Musacchio, 1997). The third tool presented was the DISCERN. It is a questionnaire tool consisting of 16 items designated for patients in order to evaluate the reliability of the publication and the quality of information on treatment choices. Thanks to this questionnaire patients can judge their treatment choices in more critical way. The questions also includes short comments so that consumers may evaluate the quality of information more comprehensibly. But the DISCERN tool also has its limitations because of its usage by patients who may rate web sites differently (Rao, Mohapatra, Mishra, & Joshi, 2012).

Amount of manuscripts have been published and they investigated the quality of medical information in many different medical disciplines. Researchers used various tools and ways for evaluation in the manuscript. They used the tools introduced above or other tools, they applied some test on readability, they defined their own definitions and methods of assessing information quality, or they combined the ways of evaluation. These studies often show that the quality of information is poor. For example in one study the quality of vascular surgery web sites was evaluated and it was found out that the reliability and readability was of a low quality (Grewal, Williams, Alagaratnam, Neffendorf, & Soobrah, 2012). There are many ways to assess readability score of the content (Shedlosky-Shoemaker, Sturm, Saleem, & Kelly, 2009) and in this study authors used The Flesch Reading Ease Score and Gunning Fog Index. The former is designed to calculate the comprehension level of the text and the latter calculates the sentence length and hard words. Then number of years of school education that are required for the reader are estimated based on the GFI results. To assess reliability, accessibility and usability the online instrument LIDA tool was applied. These tools showed that readability, usability and reliability were poor. Authors stated limitations of the study. The FRES and GFI measuring the difficulty to read the text may actually not reflect reading level accurately. The LIDA tool is a long questionnaire with many criteria quality that is prone to subjective use and may lead to bias. The study brings some important implications that the way we evaluate the quality and the tool which is used for evaluation has an impact on results of the evaluation and results of these studies.

Another recent study showing poor information quality investigated information on allergic rhinitis, rhinitis, and sinusitis (Chang, Kim, & Rhee, 2015). The JAMA benchmarks, DISCERN tool and ARIA 2008 update, which analyzes AR-related websites content, were used for evaluation. Researchers pointed out the requirement that the medical information quality should improve internationaly. They also mentioned that it is difficult to compare results of studies on medical information quality because they are using different tools and instruments

for evaluation and therefore there is a necessity of creating international standards for quality criteria.

A recent systematic review analyzed studies evaluating web sites of pharmacies and web sites offering prescription drugs (Orizio, Merla, Schulz, & Gelatti, 2013). Authors investigated criteria of presentation of information and also quality of information and came to conclusion that online pharmacies are a significant phenomenon requiring regulation of the law at the international level and requiring strengthening of health literacy among individual persons for the purpose of appropriate health decisions in the internet environment.

The information can even cause harm if it is untrue (Crocco, Villasis-Keever, & Jadad, 2002a; Crocco, Villasis-Keever, & Jadad, 2002b).

The State of Knowledge in the Czech environment

The ability of patients to use and understand health information in order to make appropriate health decisions falls under the field of health literacy (Holčík, 2009) and a need of improving information literacy of the Czech patients came to light (Vyčítalová, 2012). The mention of the importance of medical information quality in the Czech literature comes back to 1999 (Potomková, 1999), when the author cited an important study of leading person Gunther Eysenbach and his coauthor Thomas Diepgen (Eysenbach & Diepgen, 1998). The importance of the topic is still highlighted (Menoušek, 2011).

In the Czech environment it is Pavel Kasal with his colleagues who is interested in the topic. In the 2001 publication (Kasal, 2001) the issue of quality of information was divided in three main subtopics – quality of retrieval, evaluation of web documents quality and evaluation of clinical information quality. The quality of retrieval included success of retrieval (precision and recall), sort by relevance, currency of the document, quality of retrieve services (number of indexed documents, currency, user aspect). Evaluation of web documents quality included availability of the source, publication of web documents standards, PICS metadata standard, technical aspects of the web document, visit rate, number of citations, reviews (external – by users, internal – by experts) and credibility of content. Also the HONCode Principles were introduced. Evaluation of clinical information quality should be realized from the perspective of evidence-based medicine and some useful web sites are introduced.

We assume that these criteria of health information quality brought valuable state of knowledge of that time but it is not suitable for systematic evaluation neither for experts nor for consumers. Moreover, from our point of view, the quality of retrieval is not related to quality of medical information, it is just an aspect of information retrieval.

The concerns about credibility of alternative medicine web sites were raised (Kubů & Kasal, 2003; Kasal, 2004) and strategies for solutions were proposed like creating a web portal that would bring objective and trustful information from alternative medicine domain and these information would be generated from collecting casuistics of patients with alternative therapies experiences. No such portal has been created yet. Another paper dealt with evaluation of hospital web sites quality, which was part of a national health register and which set thirty-two quality criteria concerning quality of presentation, well designed navigation,

helpful function of user, signs of credibility of the content and communication with hospital (Kasal, 2009).

Despite many ways to assess readability score of the content in English, there are not standard and validated methods and tools to measure readability score in Czech language for medical texts.

Recently a study describing semi-automatic evaluation of web sites quality with the use of databases of controlled medical vocabularies was published, where guidelines were used as a standard of quality (Rak, 2010).

Theoretical framework

The theoretical framework for our own methodics is adapted from Anton Vedder's three dimensional scheme of quality of information. The dimensions are reliability, functionality and significance, and in this paper it is worked only with the reliability of the information. It deals with the internal quality of information. The other two dimensions deals with relevance and use of information.

From Vedder's point of view reliability of information includes "content criteria" (evidence, logical and subject-matter criteria), which belong to experts, but which is here also evaluated by laymen, and "pedigree criteria", which relates to authoritativeness of the source or intermediary of the information (Vedder, 2008). In this paper pedigree criteria is changed to criteria of form, which could be understood as superior to pedigree criteria.

Indicators and methodics

We define indicators of medical information quality and propose a draft of methodics for evaluation of information. Both is based on already established evaluating tools functioning abroad (HONcode: Principles - Quality and trustworthy health information, 1997; The DISCERN Instrument, 1997; MedlinePlus: Trusted health information to you, 2012; SPRY foundation, 2001), on a review study by Risk and Dzenowagis (2001) analyzing individual tools and indicators, and on the criteria found in book written by Cullen (2006). The methodics is applicable in the Czech internet environment.

Definitions of indicators

Origin – the originator of the information should be health professional or the whole organization consisting of team of professionals. Health professionals are educated in medicine and other health sciences and information spread by them are considered to be reliable.

Sponsorship – owner, provider, sponsor or partner may have commercial interests instead of health interests. It is important to try to find who is the sponsor and whether the information doesn't talk in favor of the funder.

Purpose and intent – the primary intent of the website should be to educate people instead of selling products or offering health services to them. The information must be objective and

independent. This indicator is related to sponsorship, because the non-visible owner or sponsor of the website could present information in objective and independent way, but talking again in favor of a sponsor, which could be commercial.

Currency and date – the information shouldn't be older than ten years. The information older than two years must an expert receive critically in the context of dynamics of discipline evolving. Evidence-based medicine is the core of medical practice and information should keep up with the most recent evidence. The limitation of the indicator is its application for retrospective studies and historical analyses in the field of health disciplines (e.g. history of medicine).

Citation and links – the reliability of the information is underlined if it is provided by citations and links to expert sources. It shows the author's skill to work with expert sources and it also enables the user to assess the objectivity of the facts with the subsequent verification of the truthfulness.

Accuracy and completeness – information should be formulated accurately and completely. It must include every important aspect of the topic discussing.

Clarity – the way of formulation, sentence construction and usage of technical terms should reflect a target group of information receivers. Information for laymen and general public should be easily understandable, clear and readable, and should not content technical terms. Indicator can be evaluated subjectively, or **objectively by cloze test, Nestlerová-Průcha**-Pluskal method, degree of difficulty of the text by Mistrik, and others. The limitation of the indicator is a dimness of the definition of the indicator in many sources and also a subjectivity in its evaluation.

Truthfulness – medical information must not be false in order not to cause harm when it is used. According to Vedder a reliable information is not necessary truthful, people at certain times were justified to trust some information, which appeared to be wrong later. Truthful medical information is variable depending on time, place and circumstances, for which it is considered to be right. For this paper truthfulness is related to evidence-based medicine and it should correspond with the latest scientific knowledge. Due to possible epistemological and philosophical consequences, it is just an operational definition.
In the methodics for laymen the indicator of truthfulness is implemented implicitly. It is supposed that highly reliable information is approaching to truth as it is disseminated by health professionals. In the methodics for experts the evaluation of truthfulness would be practically realized by creating literature search in order to try to find as much evidence as possible.
It should be stated that the truthfulness of the information cannot be determined conclusively, it can only be approximate.

Methodics for other than expert sources in common online environment

Criteria of form

1. Origin
- Is the originator of the information expert in the field?
  - Is the author signed by the material?
  - Is there on the website author's profile stating his education and specialization? (If signed, the name may be clickable and link to his profile.)
  - If the education is stated with the name of school, can you find out more information about the school?
  - In what organization or where does the author work? What subject pays him or her?
- Is the author an original source of the information or intermediary? (If original source, it is necessary that he or she is educated and specialized in the field that is a subject-matter. If intermediary, the specialization is not necessary, but he or she should cite and interpret the information properly.)
- Is the originator of the information health organization?
  - Is it consisted of team of health professionals?
  - **Can you explore section "About" (usually at the top or in the footer of the page)** and read more? Are there names and profiles of authors stated?

2. Sponsorship
- Is a sponsor, owner or provider of the website retrievable or deducible?
    - While evaluating sponsorship, different situations can occur: website is sponsored by commercial subject, the information may talk in favor of sponsor, but it may or may not be true; the website is sponsored by non-commercial subject, but the information also may or may not be true.
  - **Can you explore section "About"? (Usually at the top or in the footer of the page.)**
  - Is there any logo of a company or organization shown? Either directly stating its sponsorship or not.
  - Are there any partners stated?
- Is there a contact stated?

3. Purpose and intent
- Is it retrievable, in what purposes and intents did the website develop and in what intents runs now?
  - Is the intent of the website to educate and provide objective facts? (The intent of the website is not to sell products or to offer services.)
    - Different situations can occur: the intent of the website is to sell products or offer services, but the information may be true though.

4. Currency and date
- Is there a date stated by the information?
- Isn't it older than 10 years?
- Is there a date of actualization of the website or information source? (Usually in the page footer.)

5. Citation and links
- Are there any citation and links on expert sources present?

Content criteria

6. Accuracy and completeness
- Does the information refer to effect of the product (drug) or service (medical help)?
  - Is it stated how the treatment is working?
  - Are the benefits of treatment stated?
  - Are the risks of the treatment or side effects of the drug stated?
  - Is there a target patient group stated?
- Does the information refer to explanation or description of a disease or undesirable condition?
  - Are the symptoms of a disease stated?
  - Are the causations and risk factors of a disease stated?
  - Are the possible methods of treatment stated?
  - Is the risk group of patient who may suffer the disease stated?
- Does the information refer to healthy nutrition or food ingredient?
  - Are the health benefits of a food or food ingredient stated?
  - Is the possible causation of health benefit stated?
  - Are the possible health risks of a food or nutrition method stated?
  - Is the possible causation of health risk stated?
- Does the information refer to healthy lifestyle or circumstances causing health?
  - Is it stated why does the specific manner of healthy lifestyle help to achieve health?
  - Are the possible risks of specific manner of healthy lifestyle stated?
  - Are the different target groups eventually stated (in relation to age, sex, predisposition)?

7. Clarity
- Is the text clear and easily readable?
  - Is the text absence of technical terms, which laymen cannot understand?
  - Is the text formulated simply, comprehensibly and readably?
  - If the information is intermediated, is it interpreted correctly?

A draft of methodics for experts

A little modified and extended methodics is intended for experts to evaluate mainly expert sources, like reviews, interventional and observational studies. The criteria for evaluation of experimental studies were created by combination of already existing criteria found on web and in medical literature (Centre for evidence-based medicine, n.d.; Dans, Dand, & Silvestre, **2008; Greenhalgh, 2000; Mittlböck, 2008;** *Support Unit for Research Evidence (SURE),* 2013; UCL, 2011; Young & Solomon, 2009).

Methodics for expert sources in online environment

1. Origin
   - Is the originator of the information professional organization?
     ◦ Is it governmental or nongovernmental subject?
     ◦ Is it commercial or noncommercial subject?
     ◦ Is it composed of team of health professionals?
   - Is the originator an expert in the field?

2. Sponsorship
   - Is a sponsor, owner or provider of the information source who are responsible for the functioning or funders of the research retrievable or deducible?
     ◦ **Can you explore section "About"? (Usually at the top of the page or in the footer.)**
     ◦ Is there any logo of a company or organization shown? Either directly stating its sponsorship or not.
   - Is there a contact stated?

3. Currency and date
   - Is there a date stated by the information or the date of the publication?
   - Is there a date or year of actualization of the information source stated?
   - The information should not be older than two years.
     ◦ Think about the information critically if it is older than two years. Newest evidence may have come.

4. Reference and links
   - By the posts considering health or disease, effects of drugs and other health products and services, are there citation and links on expert sources of information stated?
     ◦ Can you search the full-text?

5. Purpose and intent
   - Is it retrievable, in what purposes and intents did the website develop and in what intents runs now?
     ◦ Is the intent of the website to educate and provide objective facts? (The intent of the website is not to sell products or to offer services.)

6. Completeness
- Is the information complete (contain both positive and negative effect of product or medical action and are the possible side effect stated?
- Are the limitations of the study stated?

7. Accuracy and formulation
- Is the terminology of the field used correctly?
- Is the information formulated accurately and clearly?
- Is the information formulated in the way of objective and verifiable facts, not in the way of subjective assumptions?

Continue:
A. If it is a literature review
B. If an experiment is a part

A. If it is a literature review

8A. Collection of information
- Is it described how the selection of information sources was made?
- Does it include recent information sources in the subject?
- Are the studies that support results of the paper but also disprove the results taken into account?
- Do the stated information sources have a maximum position in the hierarchy of evidence within the context of use and goals of the paper?

9A. Interpretation
- Did the study take into account type of studied subjects, the size of studied groups and the length of the experiment in the original publication?
- Haven't the interpretation for human health been created on the basis of animal models?
- Was the correlation and causality distinguished?
- Have the both positive and negative effects been taken into account?

B. If an experiment is a part

8B. Groups studied
- Are the characteristics of subjects described?
- Is it described how the subjects were chosen and how many were excluded?
- Has the randomization been done if the study design ordinarily requires it?
- Has the blinding been done if the study design ordinarily requires it?
- Was the sample large enough in the context of the study?
- Was the risk of selection bias reduced?

9B. Observation and intervention
- Is the methodics of a study described enough?
- Are the specifics of exposure described?
- Was the observation / intervention carried out systematically in accordance with the guidelines of the field and according to standard protocols?

- In case of instruments and devices use, are they sufficiently described (producer, type, batch), and is the limit of detection and limit of setting defined?
- Were suitable methods for measuring exposure and outcome assessment or outcome of the intervention chosen?
- As part of the assessment pharmacotherapy or impact assessment of nutritional supplements and lifestyle determinant, was it compared with placebo / standard established treatment / or otherwise defined control groups?
- Were the confounding factors in different groups defined and was the risk of their occurrence reduced?

10B. Results

- Are the methods of evaluation described (statistical tests etc.)?
- Was the appropriate method for the statistical analysis of data used?
- Is the effect size described enough? What is the rate?
  - Experimental event rate (EER), control event rate (CER), relative risk (RR), absolute risk reduction (ARR), relative risk reduction (RRR), number needed to treat (NNT).
- What is the power of the study? Was the difference between intervention and control group expressed?
- How precise was the effect size? Was the confidence interval (CI) expressed?
- Were the appropriate methods for confounding factors assessment used?
- If study design needs it, was the odds ratio calculated?

11B. Data interpretation

- Was the correlation and regression distinguished and were the assumptions about causality expressed?
- Was the null and alternative hypothesis for the statistical evaluation defined?
- Were the side effects stated?
- Was the study conducted according to original protocol?
  - Did the study not end sooner or later than it was originally planned?
  - Were the patients who withdraw/left the study or who did not comply the **treatment included into the results? Helpful term could be "intention**-to-**treat."** Was the analyze of activity performed? Were the patients analyzed in groups, in which they were divided?
- Was the data interpreted correctly?

Discussion

Both methodics have some limitations in its application. Methodics for other than expert sources are suitable in common online environment. For patients requiring detailed information (e.g., an educational course, patient websites) there are limitations in criteria of form (e.g., a course created by a private subject, websites supported by commercial subjects). It can be hard to find an origin of every information, especially when the whole course is guaranteed by a company or by one expert. In contrast with health population, criteria such as purpose and intent should respect specified needs of an individual patient or specified needs of patient's groups. On the other hand information provided by commercial subjects or supported by a sponsorship should meet currency and content criteria in every time if it is determined for patients.

The use of methodics for expert sources have more limitations. Except the similar limitations as in methodics for other than expert sources it is not suitable for every topic and it is not applicable in every health discipline or process. For seeking and processing expert information it is used expert tools (e.g., medical journals, medical databases). In expert tools there is a better control of criteria of form such as origin, sponsorship, currency or references. Content criteria should meet official national standards of the health discipline. We can see the limitations in case when the standards of health disciplines do not exist. After seeking and processing the information there are other limitations derived from process based on evidence-based practice. Results of a literature review or results of an experimental study should be interpreted in focus on an individual patient and patient's background (e.g., anamnesis, diagnosis, comorbidities, et al.). We can see the limitations of methodics for usage with raw medical data, in diagnostics and screening tests and in some type of qualitative studies. In general, methodics for expert sources are the first draft and it is necessary to develop it, to evaluate in selected field of health disciplines and to modify (e.g. for evaluating papers of alternative therapies).

Conclusion

Internet and libraries provide large amount of medical information. The amount of medical knowledge is rapidly increasing and for health professionals it is impossible to know everything from their field. The methodics here presented can help both laymen and professionals to evaluate medical information quality in order to make appropriate health decisions.

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