Medicine and health websites in face of *Health on the Net Foundation* – HON ethical principles

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Abstract

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This study analyses a sample of 80 national and international websites that carry information about cerebrovascular diseases and myocardial infarct, classifying them as to their conformity to each of the eight principles for health sites set by the *Health on the Net Foundation*-HON: 1. Of authority; 2. Of complementarity; 3. Of privacy; 4. Of attribution; 5. Of justification; 6. Of property transparency; 7. Of patronage transparency; 8. Of advertising editorial honesty and editorial policy. The study concludes that the analyzed websites do not conform to these eight Principles, considering also that to confront sites with the ethical principles stimulates the respectful coexistence of information technology and the health field.

Key words: Ethical. Internet. Health in informatics. Brain vascular disease. Myocardial infarction

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To study medicine and health websites contents, and to confront them with *Health on the Net Foundation* – HON ethical principles is to seek in ethics a path for a respectful and balanced coexistence between information technology and the health sector.

The use of computers cause substantial change in health professionals' acting, among them physicians, who started to have easier access to patients' data, their diseases, and personal lives. This change occurred also in relation to these, who began to count on faster resource to diagnosis their disease, more efficient storage systems of their own information and the possibility to have them analyzed by physicians at distance and, thus, could rely on more opinions about their diagnostics and treatment [1,2].

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In this scenario, new issues present to health sector professional, and ethics is the instrument that enables harmony of interests in the relation between technology, patient, and the professional.

Ethics

There are many ways to read ethical theories produces since the Greeks. One of them is to distinguish in ethics history two originary moments: Its internalization and objectivism. The first, since Antiquity, follows ethics constant subjectivization. In this phase, longer, ethics encompasses just human universe: universality restricts to just one species of beings. The second, recent, follows the inverse path: it is ethics objectivism, whose origin will not be anymore internalization of reason, but the objectivism, for example, the linguistic communication or relationship among people [3].

The word ethics has its etymological origin in two similar Greek words: *ethos* and *éthos. Ethos* mean tradition, and it refers to uses and traditions of a group. *Éthos* mean dwelling, household. It is someone usual dwelling; the country where one lives. Etymology of the word ethics, either *éthos* or *ethos,* converges toward the meaning of human behavior. However, ethics real objective goes beyond the etymological sense. Ethics seeks principles that guides conscience in choosing the good, concentrating its attention in human will, considering that the *human acr* is produced by Man's will. This is the true object of ethics [4].

Informatics in the health sector

Informatics in health or medical informatics is defined by Shortliffe and Blois[5] as a realm of fast scientific development that deals with storage, recovery, and use of biomedical information, data, and knowledge for problems resolution, and decision-making.

Sigulem [6] considers that medical informatics is a science that, as exemplified by other disciplines, such as molecular biology or neuroscience, has roots in history and in ideas of information theory. It is characterized by its objective (medicine) and methods (those of information management). Medical informatics evokes other disciplines like mathematics, statistics, linguistic, cognition science, and philosophy
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Health sector has own and specific needs, among them to deal with massive volume of information that needs to be stored, divided with several professionals, and recovered in different moments, been fundamental in decision-making.

Ethics in informatics in the health sector

Health sector has new ethical question, challenges, and conflict with arrival of informatics, which promoted changes in medical practice.

Goodman and Miller [7] consider that ethical issues in medicine, nursing, human research, psychology, social service, and correlated areas have been much discussed already, and the main ones are well known. However, ethical issues in health informatics are less familiar, and informatics presents, currently, as one of the most important and interesting ethical discussion in all profession within health sector.

Use of computerized system, as exemplified of other tools used in health sector, requires training, experience, education, and the same idea of standards and protocol that guide conventional professional exercise is applied to medical practice using informatics [7].

Regulating instruments – websites in health

The Health on the Net Foundation – HON, established in Switzerland in 1995, is a non-profit non-governmental organization, with the objective to render medical and health information, committed in keeping a responsible self-regulation for internet providers[8]. It created a conduct code (HON*code*) for medicine and health sites with eight principles:

Authority
All medical or health guidance stated in the site will be given only by trained and qualified professionals, except if expressed declared that certain guidance is been given by individual or organization non qualified in medical area;

Complementarity
Available information in the site was designed to support, and not to replace the existing relationship between patients or visitors and their physicians;

Privacy
The confidential character of data on patients and visitors to a medical or health site will be respected – including their personal identity. Those responsible for the site promise to honor or excel minimum legal requirements on medical and health information privacy in force in the country or in the state where site and site copies are located;

Attributions

Whenever is the case, information in the site will be supported by clear reference to consulted sources and, whenever possible, with HTML links to them. The date in which each medical page was updated for the last time will be displayed clearly (at the top of page, for example);

Justifications

Any statement made about benefits or performance of a treatment, commercial product or specific service will be supported with adequate and balanced evidence indicated in principle 4;

Property transparency

The site visual programmers will seek to make information available in the most possible clear away, as well as contact addresses for visitors who want additional information or help. Webmaster will display clearly his email address in all pages of the site

Patronage transparency

Support provided to the site will be indentified clearly, including commercial and non-commercial organizations that have contributed to the site with financing, services, or material resource help; and

Advertising honesty and editorial policy

If advertising is one of the income sources of the site, this shall be indicated clearly.. Site owners shall supply a brief description of adopted dissemination policy. Advertisements and other promotional materials will be presented to visitor in a way and content that facilitate differentiating them from the original material produced by site management.

The *American Medical Association* (AMA) has as mission to promote and improve public health in the United States of America, uniting medical professionals in national scope, and acting in major public health issues. In order to attend such objective in a computerized society, AMA created also guidelines for medical and health information in internet, the *Guidelines for AMA* Websites, which present four principles. The development of these guidelines started in 1999, and it was approved in February 2000, and it aimed at providing quality standards for content, advertising, patronage, privacy, and electronic commerce[9].

Healthcare Coalition is a non-profit organization, without political connection, created in 1997, and has as goal to develop and promote ethical principles for health in internet, considering the online fast expansion in the area. The organization seeks to integrate medical care, industry, professionals, public agencies, patients, and consumers [10]. *Healthcare Coalition* created the *e-Health Ethics Initiative,* which in May 4, 2000, in Washington, DC, USA, promulgated an international code of ethics for sites and health services in internet, the *e-Health Code of Ethics*, which presents eight principles[10].

Additionally to these instrument should be mentioned the Discern, created to judge the quality of health information targeted to consumer who seeks treatment alternatives, aims at publication that bring information about treatments and proposes 15 recommendations for good quality information [11]. In addition, it is important to report the Brazilian initiative, from the State of Sao Paulo Regional Council of Medicine (Cremesp), which, in search of excellence in the exercise of medicine and access of quality health to all citizens, issued Resolution 97/01, in March 9, 2001, releasing the Ethics Manual for medicine and health sites stating seven principles [12].

Internet in health

Internet has allowed that physicians and other health professionals access repeatedly medical information in volume without precedence. Such access has the potential to accelerate the change of physician-patient relationship from that medical authority stand administering advises and treatments (sometimes with questionable understanding, and adhesion to recommendations by patient) toward a new stand of decisions sharing among patient and physician [13].

Health information, due to its importance, should base in good quality documentation, and in complete and strict bibliography. However, internet also does product advertising, disseminates medical hoaxes, and the most sophisticated pseudoscientific article. This makes difficult for users to determine which information is useful and reliable, how it can be evaluated, criticized, or verified, when it should be ignored, rejected or deleted, when it should be read, printed, or transferred [14].

Internet use to search for information about health became so disseminate that, while large laboratories take advantage to get more information about their patients, and to announce new treatments, medical associations warn on the stimulus that the net may bring to self-medication practice [15].

Discussion about ethics in internet use still is new and it involves multidisciplinary perspectives for several applications of the net in health sector, such as online medicine and therapy practice, the online search, the electronic medical commerce, and medical websites [1,2,16]. Unheard possibilities provided by the net should be considered as determinant factors for all that use internet for issues related to health to gather in order to create a reliable environment, which ensures high quality of information and services. Thus, seeking to protect privacy will be possible to expand even more the value of internet for health information consumers and providers[17].

Justification

Internet use in searching health related information is increasing. Available medicine and health sites may promote and provide benefits, but causing also damages and losses to users who search for information.

HON created the behavior code (HON*code*), with eight principles to guide and regulate use of medical and health sites. Thus, one justifies the undertaking of a work to evaluate this eight principles that are respect in analyzed 80 national and international sites, in which there is higher or lower levels of compliance, allowing to measure reliability level that user may have in relation to information state in them, according to HON.

Objectives

Main

The objective of this study is to analyze a sample of national and international sites with information about two specific diseases: the cerebrovascular and myocardial infarct, checking if they conform or not with the eight principles of HON code of conduct.

Secondary

To rank the eight principle of HON code of conduct, considering the percentage of compliance by analyzed sites; to compare analyzed national and international sites regarding compliance to HON eight principles of HON code of conduct; to verify which ones comply most to HON eight principles.

Materials and method

160 sites (national and international) of medicine and health that presented information about cerebrovascular diseases, and myocardial infarct were surveyed in internet, through search engines sites *www.google.com*, *www.google.com.br*, *www.yahoo.com,* and *www. yahoo.com.br*.

The terms or key words cerebrovascular diseases and myocardial infarct represent the two major causes of death in Brazil, in the state of Sao Paulo, municipality of Sao Paulo, according to SUS Data Department– Datasus [18] (Table 1). In Table 1, the terms and key-words used for searching were *myocardial infarction*, cerebrovascular diseases, and *brain vascular disease*.

Table 1 – Mortality coefficient for selected causes (per 100,000 inhabitants) [18]

Death cause	1996	1997	1998	1999	2000	2001	2002
Aids	29.8	20.7	16.5	14.8	13.2	11.9	11.4
Breast cancer	18.6	20.1	19.9	20.1	18.5	19.3	18.8
Uterine cervix cancer	5.1	5.1	5.3	5.4	5.9	6.1	5.2
Acute myocardial infarct	66.6	66.2	63.8	62.0	60.4	57.2	56.0
Cerebrovascular diseases	61.8	61.9	60.3	62.2	56.0	54.1	54.5
Diabetes Mellitus	20.9	23.2	21.3	24.2	23.9	22.0	21.2
Transportation accidents	25.2	23.7	17.4	17.9	8.2	15.4	9.5
Aggressions	55.3	54.7	59.3	66.7	58.5	57.1	50.2

In Table 2 sites were analyzed regarding analytical category.

Table 2 – Used Sites

Sites	Analytical categories
www.google.com.br	20 *sites* – "cerebrovascular diseases" 20 *sites* – "myocardial infarct"
www.yahoo.com.br	20 *sites* – "cerebrovascular diseases" 20 *sites* – "myocardial infarct"
www.google.com	20 *sites* – – "myocardial infarction" 20 *sites* – "brain vascular disease"
www.yahoo.com	20 *sites* – "myocardial infarction" 20 *sites* – "brain vascular disease"

Results

After analysis of the 160 sites, results are presented in tables 3 and 4 and in Graphic 1.

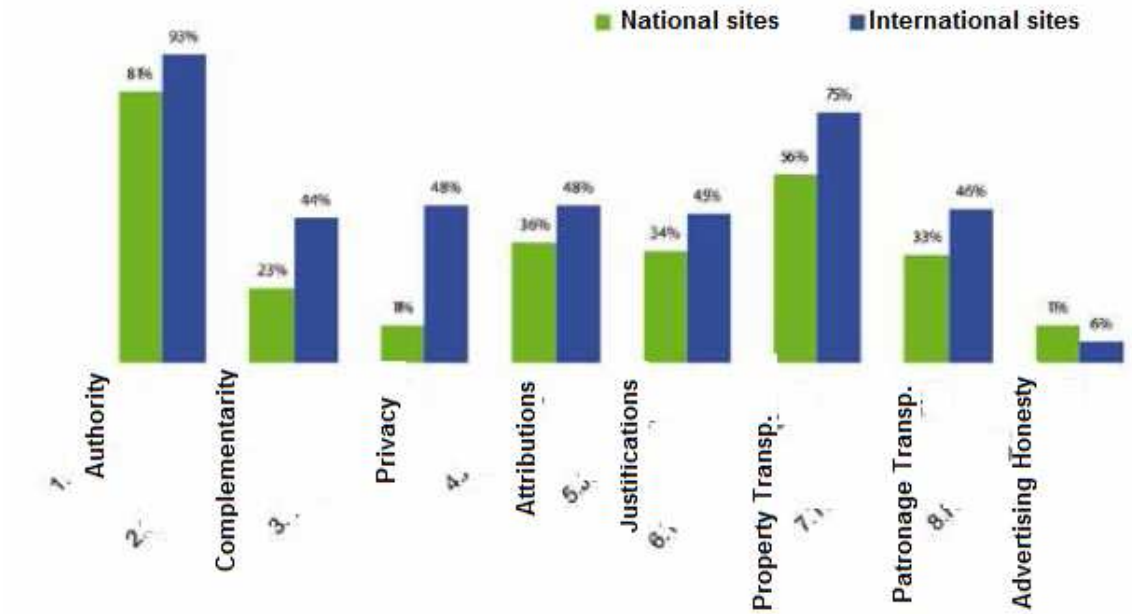
Surveyed sites were analyzed based in each of HON eight principles, getting evaluation *Yes* or *No* (complies of does not comply with principle). Descriptive statistical analysis was used, considering that its basic objective is to synthesize a series of values of the same nature, organizing and describing in three ways: tables, graphics, and descriptive measures [19].

Table 3 – Results

Surveyed sites according to the eight principles of HON*code of the* Health on the Net Foundation – HON																
Sites/analytical categories	**1**		**2**		**3**		**4**		**5**		**6**		**7**		**8**	
	Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
www.google.com.br "cerebrovascular diseases"	14	6	3	17	1	19	7	13	6	14	9	11	7	13	1	19
www.yahoo.com.br "cerebrovascular diseases"	16	4	3	17	0	20	9	11	8	12	9	11	9	11	2	18
www.google.com cerebrovascular diseases	17	3	4	16	9	11	6	14	5	15	13	7	9	11	1	19
www.yahoo.com „ myocardial infarction„	19	1	7	13	9	11	7	13	7	13	15	5	8	12	0	20
www.google.com.br „myocardial infarction„	18	2	6	14	5	15	6	14	6	14	14	6	5	15	4	16
www.yahoo.com.br „myocardial infarction„	17	3	6	14	3	17	7	13	7	13	13	7	5	15	2	18
www.google.com „myocardial infarction„	20	0	12	8	11	9	16	4	15	5	18	2	13	7	3	17
www.yahoo.com „myocardial infarction„	18	2	12	8	9	11	9	11	9	11	14	6	7	13	1	19
Total	**139**	**21**	**53**	**107**	**47**	**113**	**67**	**93**	**63**	**97**	**105**	**55**	**63**	**97**	**14**	**146**
	87%	**13%**	**33%**	**67%**	**29%**	**71%**	**42%**	**58%**	**39%**	**61%**	**66%**	**34%**	**39%**	**61%**	**9%**	**91%**

Table 4 – Sites compliance to HONcode principles

Yes	87	66	42	39	39	33	29	9
No	13	34	58	61	61	67	71	91
Rank	1	2	3	4	4	5	6	7



Graphic 1 – Comparative of HONcode principles in 160 sites (international and national)

Discussion

The use of informatics in health sector generated initiatives in Brazil and in the world, which resulted in the establishment of *regulating instruments*, previously described and presented. The concern with ethics motivated their establishment, made that some got the title of *codes of ethics.*

This title remits to the fact that throughout time, the professional codes of ethics have been used in the practice of medicine, and in other health areas. However, despite of it, it is illusion to believe that issuance of a code assures an ethical relation between professionals and patients, in as much as ethics is not normative or imposition.

The creation of an area studies or of a technology set rapidly new knowledge and possibilities that, not always, are followed by guidelines and principles necessary for ethics regulation in this area or for use of this technology. And this happens, especially, in medicine, as one may observe in the mix between medicine and medical care with e-commerce, and internet. This consortium raises questions related to the kind of conduct, from the ethical point of view, expected from physicians and internet program and systems developers in the medical area [16].

The article *Assessing the content and quality of information on the treatment of postmenopausal osteoporosis on the World Wide Web*, published in December 2006 in the *Gynecological Endocrinology*, *Journal of the International Society of Gynecological Endocrinology*, brings evaluation results of sites that present information on postmenopausal osteoporosis, noting great variety of information that, often, were incomplete. Authors consider that cooperation among scientific medical societies may be a path to qualify information in internet [20].

One may state that using internet, human beings are relating among themselves, virtually. Ethics pervades human relationships and, thus, are present in virtual human relationships that take place in internet, either in real time or not. If those responsible for information stated in medicine and health sites have this awareness in choosing item, users seeking information in internet will be safer. It is ethics pervading virtual relationships via internet.

Graphic 1 and Table 3 compare the results regarding national and international sites compliance in view of each of HONcode eight principles. In all of them, except in principle 8, *Of advertising honesty and editorial policy,* international sites achieve higher percentage of compliance – which makes them more aligned with HON*code*.

Graphic 1 shows that the greatest difference was with principle 3, *Of privacy*, item in which international site got 48% in compliance, while the national site got 11%. However, this higher compliance percentage reveals that almost half of international medical sites do not ensure confidentiality or privacy to their users, basic ethical principles when one speaks of ethics in the medical practice. The principle 8, *Of advertising honesty and editorial policy*, was the only that got greater attention from the national sites (11%), compared to international ones (6%), but it was the least complied by the analyzed sites, ranking in the last position.

Table 3, which presents compliance with HON principles by the analyzed 160 sites, shows that principle 1, *Of authority*, was the most followed, with 87%, that is, 139 positive replies. In this principle and in according to stated in the introduction of this work, HON*code* sets: *all medical or health guidance stated in the site will be given only by trained and qualified professionals.*

Despite the fact that 87% represent a good result, 13% of sites remain without professional support, which is worrisome when one considers user's vulnerability in face to health information provide by laymen. One should highlight still that, in many cases, user does not know to discern origin of information (if it comes from a legitimate medical source or not), thus, becoming even more vulnerable.

Graphic 1 shows that principle 6 was complied by 56% of the national sites and by 75% of international. When a medicine and health site does not make available a contact address, user becomes isolated in the search for information and without possibility to confirm or clarify any doubt.

Final comments

The results from this survey are similar to those gotten by a work carried out and published in the *Revista Brasileira de Otorrinolaringologia (Brazilian Otorhinolaryngology Magazine)*, in 2005
2005, which analyzed national medicine and health sites presenting information about allergic rhinitis, comparing them with the *Manual of ethics principles for medicine and health sites* by Cremesp (mentioned in the introduction). The 2005 work concluded that majority of analyzed sited did not comply to principles elaborated by Cremesp [21].

Several works in medicine and health sites arrived at similar conclusion to those of present work concerning quality of health information available in internet. It is clear authors' concern, in surveyed articles, with the quality of available health information in internet, and users' vulnerability in face of it.

The *Journal Diabetic Medicine,* for example, published the article "*Type 2 diabetes and inheritance: what information do diabetes organizations provide on the internet?*", in which its authors consider that providing people with information about the world epidemics of type 2 diabetes is fundamental. To that end, they carried out a comparative study of specialized organizations sites presenting content warning about inheritance of the disease, and the benefits of a healthy life style, with the objective to evaluate this information. The study concluded that quality of the evaluated sites, in majority of cases, was not satisfactory, and the care with life style, and attention to inheritance were not mentioned always [22].

In the study undertaken in sites in Japan, with information about mental diseases, authors concluded that, with few exceptions, the quality of information was inadequate in majority of cases, particularly those related to treatments. They considered, still, a challenge to establish standards to evaluate and enhance health information in sites[23].

For patients who consult a medical site it may represent a major means of information and clarification, and may be an interesting way to provide education on several issues in health area also.

The number of web users who seek their physician sites, as well as of other professional categories is increasing. The 2005 American census, in this regard, estimated that 117 million adults sought for health information in internet[1]. As mentioned in introduction, study from the *Millward Brown Institute* (marketing survey), carried out with 800 internet users, and concluded that three out of four internet users seek for information concerning health in the web [2]. Therefore, it is necessary much attention to this practice [24].

We understand that the professional codes of ethics are, in reality, codes of conduct for the professional, aiming at the practice of determined category. In view of this, we propose a clear distinction between ethics and normative instruments or conduct guides herein denominated regulating/codes of ethics. This, because, in order to ensure ethics in medicine and health sites does not depend on rules or norms, as, as stated, ethics is not normative. What is possible is to promote discussions, reflections, and awareness about major issues involving search of health information in internet. From then on, one may cultivate and conquer ethics in internet use in the health sector.

Conclusions

Medicine and health sites analyzed in this work do not comply with the eight principles of HON code of conduct *(HON-code).* The most complied of them was principle 1, *Of authority*. Principle 8, *Of advertising honesty and editorial policy*, ranked last position, been the least complies by analyzed sites. Compared with national sites analyzed, international sites (English language) complied more with analyzed principles.

Resumen

Los sitios web de medicina y salud frente a los principios éticos de la *Health on the Net Foundation* – HON

Este estudio analiza un muestreo de 80 sitios web nacionales e internacionales que contienen información sobre enfermedades cerebro-vasculares e infarto de miocardio clasificándolos en lo relativo a la obediencia a cada uno de los ocho principios del código de conducta para sitios web de salud delineados por la *Health on the Net Foundation*-HON: 1. De la autoridad; 2. De la complementariedad; 3. De la confidencialidad; 4. De las atribuciones; 5. De las justificaciones; 6. De la transparencia en la propiedad; 7. De la transparencia en el patrocinio; 8. De la honestidad editorial de la publicidad y de la política editorial. El estudio concluye que los sitios web analizados

no atienden a esos ocho principios considerando también que confrontar sitios web de salud con los principios éticos estimula la convivencia respetuosa entre la tecnología de la información y el área de salud.

Palabras-clave: Ética. Internet. La informática médica. La enfermedad del cerebro. Infarto de miocardio vascular.

Resumo

Os *sites* de medicina e saúde frente aos princípios éticos da *Health on the Net Foundation* – HON

Este estudo analisa uma amostra de 80 *sites* nacionais e internacionais que trazem informações sobre as doenças cerebrovasculares e infarto do miocárdio, classificando-os quanto à obediência a cada um dos oito princípios do código de conduta para *sites* de saúde delineados pela *Health on the Net Foundation*-HON: 1. Da autoridade; 2. Da complementaridade; 3. Da confidencialidade; 4. Das atribuições; 5. Das justificativas; 6. Da transparência na propriedade; 7. Da transparência no patrocínio; 8. Da honestidade editorial da publicidade e da política editorial. O estudo conclui que os *sites* analisados não atendem a esses oito princípios, considerando ainda que confrontar *sites* de saúde com os princípios éticos estimula o convívio respeitoso entre a tecnologia da informação e a área da saúde.

Palavras-chave: Ética. Internet. Informática médica. Transtornos cerebrovasculares. Infarto do miocárdio.

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