# Quality of internet information available to patients on websites in Portuguese

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# SUMMARY

Objective: Patients and their relatives often look for information about their diseases on the internet. Diabetes mellitus (DM), systemic arterial hypertension (SAH), and acute myocardial infarction (AMI) are the most prevalent in Brazil, thus, information on these pathologies is extremely searched for on the internet. For this reason, this study attempted to evaluate the quality of information available in Portuguese on the Web regarding these disorders. Methods: The first 20 websites in Portuguese for each disease through the Google® search algorithm were selected. The Discern Questionnaire (DQ) and Health on the Net (HON) were used as tools in order to evaluate the quality of information. To assess adequacy, international and Brazilian guidelines for different co-morbidities were used. Results: When evaluating the information content available, 45%, 95%, and 85% of pages had the definition of DM, SAH, and AMI, respectively. Only 25% of the websites regarding the three co-morbidities had specific information on diagnosis and treatment. Only 15%, 20%, and 10% of the websites had HON certification, respectively. Using the DQ approach, scores higher than 50% were obtained in 70% of the DM websites, in 65% of SAH websites, and in 55% of the AMI websites. Conclusion: The available information in Portuguese on the internet regarding the three pathologies selected (DM, SAH, and AMI) is quite often inadequate and insufficient.

Uniterms: Internet; quality; medical information; Portuguese.

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Study conducted at the Faculdade de Medicina do ABC, Santo André, SP, Brazil

Submitted on: 01/11/2012 Approved on: 06/30/2012

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Conflict of interest: None.

# INTRODUCTION

Since the 1980s the health scenario in Brazil has been changed. Differently from the infectious and parasitic diseases (IPD), nowadays there is a prevalence of chronic non-communicable diseases (CNCDs)<sup>1,2</sup>. Among some of the prevalent illnesses in population, systemic arterial hypertension (SAH), with a prevalence rate of 37%<sup>3</sup> in the population aged over 35 years; diabetes mellitus (DM), which is present in 9.7%<sup>4</sup>; and acute myocardial infarction (AMI), responsible for 46.11%<sup>5</sup> of deaths caused by cardiovascular disorders, are the most important diseases considered in this study.

In recent years, the Internet has significantly increased opportunities for obtaining information in the medical field. It is quite different from traditional means of communication, since it offers a large and varied amount of specific information on a given topic, rather than approaching general issues<sup>6</sup>.

It is well-known that a great part of the population seeks information on their health status, along with treatments suggested by physicians on the Internet. Notwithstanding, there is still no research on the Brazilian reality concerning Internet-based seeking of health-information. In the United States, a study by Cyber Dialogue/ Internet Health Day showed that 52% of users had searched for information on diseases; one third of users had searched for information related to diet and nutrition, pharmaceutical products, and physical shape; and approximately 15% of users had searched for information on children's health status.

The analysis of the quality of information is still extremely controversial. The Health on the Net Foundation (HON)<sup>7</sup>, a Switzerland-based non-governmental

organization founded in 1995, evaluates health care websites through a code of conduct focusing on their credibility. Websites following such code are allowed to exhibit HON's logotype<sup>8</sup>. Another form of evaluation is the Discern Questionnaire (DQ), a project founded in 1996-1997 by The British Library and the National Health Services (NHS) Executive Research & Development Program, and published in the Journal of Epidemiology and Community Health. This approach provides users with a brief and reliable way of evaluating the quality of written information on treatment options for a given health problem<sup>9</sup>. The DQ is used by many authors, such as Collin Currie, regarding available information on schizophrenia<sup>10</sup>, or Moon Young Chang, regarding rhinitis<sup>11</sup>.

Following the tendency of searching information on the Internet, the most prevalent diseases in Brazil were used to analyze the information quality on websites in Portuguese. The present study reports the quality of information available in Portuguese concerning SAH, DM, and AMI on the Internet.

#### **METHODS**

SAH, DM, and AMI were searched using key words such as: "hypertension", "diabetes mellitus", and "infarction", respectively, on Google's search website. The first 20 sites were selected for each pathology on October 17, 2010.

Inclusion criteria were presence of at least of one of the following topics on the website retrieved on the Google search: definition, physiopathology, clinical presentation, diagnosis, treatment, prevention or complications; and website written in Portuguese (Table 1).

**Table 1** – Results obtained after comparison of websites with the guidelines, and application of the DQ and the HON Code\* verification

AMI      SAH      DM        Complete diagnosis      35%      20%      25%        Incomplete diagnosis      5%      10%      35%        Complete treatment      30%      20%      35%        Adequate definition      85%      80%      45%        Epidemiology      65%      45%      55%        Clinical picture      85%      60%      75%        HON      10%      20%      15%        DQ 0-20      0%      0%      0%        DQ 21-40      45%      35%      35%        DQ 41-60      50%      55%      65%        DQ 61-80      5%      10%      5%				
Incomplete diagnosis    5%    10%    35%      Complete treatment    30%    20%    35%      Adequate definition    85%    80%    45%      Epidemiology    65%    45%    55%      Clinical picture    85%    60%    75%      HON    10%    20%    15%      DQ 0-20    0%    0%    0%      DQ 21-40    45%    35%    35%      DQ 41-60    50%    55%    65%		AMI	SAH	DM
Complete treatment    30%    20%    35%      Adequate definition    85%    80%    45%      Epidemiology    65%    45%    55%      Clinical picture    85%    60%    75%      HON    10%    20%    15%      DQ 0-20    0%    0%    0%      DQ 21-40    45%    35%    35%      DQ 41-60    50%    55%    65%	Complete diagnosis	35%	20%	25%
Adequate definition    85%    80%    45%      Epidemiology    65%    45%    55%      Clinical picture    85%    60%    75%      HON    10%    20%    15%      DQ 0-20    0%    0%    0%      DQ 21-40    45%    35%    35%      DQ 41-60    50%    55%    65%	Incomplete diagnosis	5%	10%	35%
Epidemiology    65%    45%    55%      Clinical picture    85%    60%    75%      HON    10%    20%    15%      DQ 0-20    0%    0%    0%      DQ 21-40    45%    35%    35%      DQ 41-60    50%    55%    65%	Complete treatment	30%	20%	35%
Clinical picture    85%    60%    75%      HON    10%    20%    15%      DQ 0-20    0%    0%    0%      DQ 21-40    45%    35%    35%      DQ 41-60    50%    55%    65%	Adequate definition	85%	80%	45%
HON  10%  20%  15%    DQ 0-20  0%  0%  0%    DQ 21-40  45%  35%  35%    DQ 41-60  50%  55%  65%	Epidemiology	65%	45%	55%
DQ 0-20  0%  0%    DQ 21-40  45%  35%  35%    DQ 41-60  50%  55%  65%	Clinical picture	85%	60%	75%
DQ 21-40    45%    35%    35%      DQ 41-60    50%    55%    65%	HON	10%	20%	15%
DQ 41-60 50% 55% 65%	DQ 0-20	0%	0%	0%
	DQ 21-40	45%	35%	35%
DQ 61-80 5% 10% 5%	DQ 41-60	50%	55%	65%
	DQ 61-80	5%	10%	5%

DQ, Discern Questionnaire; HON, Health on the Net Foundation; AMI, acute myocardial infarction; SAH, systemic arterial hypertension; DM, diabetes mellitus. \*Results of DQ are described in accordance with the percentage of websites presenting scores from 0 to 20 (very low), from 21 to 40 (low), from 41 to 60 (intermediate) and from 61 to 80 points (high).

Exclusion criteria were websites written in languages other than Portuguese, duplicate, or non-specific for the diseases selected; websites for questions such as "Yahoo questions/answers"; and links to previously analyzed websites, or those presenting technical problems for access.

The sites were evaluated in accordance with the following criteria: approval by the HON Code, application of the DQ<sup>12</sup>, and comparison of the information present on the website with specific consensus for each disease proposed by Brazilian or American subspecialty or specialty societies.

The principles of the HON Code<sup>7,8</sup> are the most traditional, reliable, and comprehensive for evaluating healthcare and medicine information available on the internet. The aim of consultation was to validate the code certification regarding the research of sites and Brazilian professionals. The study aimed to check the HON certification on the selected Brazilian websites. DQ (Table 2) consists of 16 subjective questions, which are individually classified on a scale of five scores, where n=1 does not meet the criterion, and n=5 completely meets the criterion. The questionnaire focuses on the quality of the transmitted information. The grades were separately attributed by two authors and compared to the evaluation by a third party, in case of noticeable

discrepancy, and this third party was responsible for selecting the score. The results of the DQ are presented in series according to the scores from 0 to 20 (very low), 21 to 40 (low), 41 to 60 (intermediate), and 61 to 80 points (high).

In order to assess the technical adequacy of the text present on each website, the most recent consensus statements approved by Brazilian and/or International Medical Society regarding the respective subspecialties correspondent to the illnesses researched were used. The selected consensus statements were on diabetes<sup>13,14</sup>, hypertension<sup>15</sup>, and acute myocardial infarction<sup>16,17</sup>. Only total agreement between the information present on the website and that from the respective consensus statements resulted in the content being considered adequate.

# RESULTS

The criteria "definition" and "clinical picture" were discussed in over 60% of websites, while only 45% of the websites on DM presented an adequate definition of the pathology. Regarding epidemiology, the frequency of adequate information was 65%, 45%, and 55% for AMI, SAH, and DM, respectively. Analyzing the treatment and diagnosis, this index did not exceed 35% on the websites evaluated for the three pathologies. Regarding

Table 2 - DQ (translated by the authors) and the results obtained for each disease analyzed\*

Questions	SAH	AMI	DM
Are the objectives clear?	5	4.2	3.9
Have the objectives been reached?	4.5	4.25	3.7
Is it relevant?	4.85	3.75	3.9
Is it clear which information sources were used for making the website?	2	4.4	2.9
Is it clear when information used for making the website was produced?	2.2	2.45	3.2
Is it balanced and with no biases?	4.3	2.5	3.1
Are there any details on additional information sources?	1.75	2.6	2.9
Is there any reference to doubtful areas?	4.8	2.05	2.2
Is it described on this website how each treatment works?	2.25	2.7	2.36
Are the benefits of each treatment described on this website?	1.55	2.2	2.36
Are the risks of each treatment described?	3	1.65	1.89
Is it described what would happen if no treatment were performed?	3.2	2.15	3.05
Is it described how each treatment selection would affect the quality of life?	1.65	1.9	2.47
Is it clear that there is more than one possible therapeutic selection?	2.55	2.25	3.2
Is there support for decision-making?	1	2	2.7
Based on the responses to all questions above, classify this website according to its quality for selecting therapeutic alternatives.	1.55	3.4	2.6
Average	2.884375	2.778125	2.901875

DQ, Discern Questionnaire; SAH, systemic arterial hypertension; AMI, acute myocardial infarction; DM, diabetes mellitus. \*Each question was evaluated on a scale from 1 to 5 points (see "Methods").

information on the complete treatment, the results were 30%, 20%, and 35% for AMI, SAH, and DM, respectively (Table 1).

Regarding HON certification, it was present in less than 20% of the websites consulted (Table 1). As to the DQ (Table 1), the great majority of sites presented average scores of 2.88, 2.78, and 2.9 for SAH, AMI, and DM, respectively.

On Table 2, it is possible to observe that websites regarding SAH, AMI, and DM have achieved their goal of providing readers with information (second question of the DQ). By verifying the source of content (fourth question of the DQ) presented for AMI, an average of 4.4 was obtained; the two other pathologies received an average below 3. SAH websites presented stability and no biases (sixth question of the DQ), with an average of 4.3, differently from AMI and DM-related websites, which presented averages of 2.5 and 3.2, respectively.

# DISCUSSION

This study aimed to evaluate the quality of information on health care available on the Internet. Thus, three prevalent diseases in the Brazilian population were selected, as well as the Google search engine, a search tool widely used by the Brazilian community. The quality of information available was found to be unsatisfactory, reflecting a tendency previously found in the medical literature of other countries.

DQ average scores found in the study (2.85/5) are similar to those found by various foreign authors who researched the quality of information available for different diseases on the Web. Currie et al., in a study on schizophrenia<sup>10</sup>, obtained an average of 3.18/5; Chilton and Collet<sup>18</sup>, in a study on rheumatoid arthritis, 1.7/5; and Moon Young Chang et al.<sup>11</sup>, in a study on allergic rhinitis, 1.92/5.

The HON logo was present in less than 20% of websites, which could reflect ignorance of this certification in the Brazilian community, and thus it is not necessarily a parameter for lack of quality.

All the information from the websites consulted in this study were compared to consensus statements from specialties and subspecialties societies; diagnosis and treatment related-data were found to be quite deficient, leading to a situation of misunderstanding regarding the most critical field, that is, the therapeutic approach of the disorder.

In recent years the world has experienced a dramatic technological transformation that has radically enhanced access to information, especially by means of the Internet. There is increasingly more information available in the healthcare field. Access to

technical-scientific information, along with the increased educational level of the population gave rise to patients who actively seek information on their illnesses. The countless search websites facilitate these individuals proactive behavior of seeking information ever more independently.

The use of medical websites has completely changed the relationship between physicians and patients. Nowadays the patient, armed with information, questions and discusses the diagnosis and many different therapeutic modalities much more. Therefore, the patient is a special consumer of health products and services, who has relevant information that should be, at least, taken into account<sup>19,20</sup>.

Eastin<sup>21</sup> stresses that medical professionals are not necessarily the authors responsible for the information available on the Web. This factor creates the possibility that information has no guarantee of credibility. For this reason, HON was created, and it is internationally well-known and applied.

Conversely, in Brazil there is the manual of ethical principles for medicine and healthcare websites <sup>22</sup>, from the Regional Council of Medicine of São Paulo (Conselho Regional de Medicina de São Paulo — Cremesp). The manual defines ethical principles and criteria of conduct on internet websites, presenting a set of concepts for applications of medicine and healthcare fields similar to those of HON, including: transparency, honesty, quality, informed consent, privacy, medical ethics and responsibility, as well as source. These criteria are not yet standard in Brazil<sup>23</sup>, and they are not adequately disseminated either, as the majority of physicians and patients do not know about them.

The general public needs to be informed that medical information on the Web is free of rules. It is necessary to carefully and judiciously evaluate the degree of reliability of the information, and both medical professionals and the general public must know that the veritable and quality information should be sought on websites with a quality certification<sup>24</sup>. Physicians play an essential role in explaining to their patients about the limits of information available on the Web, as well as indicating the most trustworthy websites regarding their disorders.

The present study has some limitations. Considering Google's present search mechanisms, different people may have access to different results for the same research. However, the authors believe that at least some of the first 20 sites found for each disease used in this study are present in the searches performed by the majority of users. Therefore, the evaluation of the adequacy of the criteria employed reflects, at least in part, the quality of information users will find on the Web.

# Conclusion

Taking into account the great importance of the diseases studied, and the role played by the Internet on patients' information and consequently on their relatives' information, the quality of information available concerning those diseases was questioned. Hence, it is concluded that this information is neither sufficient nor adequate for the patient's needs.

# REFERENCES

- Malta DC, Cezário AC, Moura L, Morais Neto OL, Silva Junior JB. A construção da vigilância e prevenção das doenças crônicas não transmissíveis no contexto do Sistema Único de Saúde. Epidemiol Serv Saúde. 2006:15(3):47-65
- Brasil. Ministério da Saúde. A vigilância, o controle e a prevenção das doenças crônicas não transmissíveis: DCNT no contexto do Sistema Único de Saúde Brasileiro. Epidemiologia e serviços de saúde. Rev Sistema Único de Saúde do Brasil. 2006;15(1):47-65.
- DATASUS. Taxa de prevalência de diabete melito. [cited 21 Apr 2011]. Available from: http://tabnet.datasus.gov.br/cgi/tabnet.exe?idb2009/g02.def.
- DATASUS. Taxa de prevalência de hipertensão arterial. [cited 21 Apr 2011].
  Available from: http://tabnet.datasus.gov.br/cgi/tabnet.exe?idb2009/g01.def.
- Pinto CCS, Santos CFS, Pereira ER, Silva RMCRA. A importância do conhecimento da incidência de infarto agudo do miocárdio na unidade coronariana e dos cuidados de enfermagem para uma gestão em saúde de qualidade. [cited 20 Nov 2010]. Available from: http://www.uff.br/anaissegerenf/pdf/279%20-%20a%20importancia%20do%20conhecimento%20da%20incidencia%20de%20infarto.pdf.
- Soares MC. Internet e saúde: possibilidades e limitações. Textos de la Ciber-Sociedad. 2004;(4).
- HON Code. [cited 2012 apr 15]. Available from: http://www.hon.ch/HONcode/conduct.html.
- HON Code. [cited 2012 apr 15]. Available from: http://www.hon.ch/HON-code/Pro/intro.html.
- Discern Online. [cited 17 out 2011]. Available from: http://www.discern. org.uk/.

- Currie C, Di Mambro P, Joice A, Glip RM, O.Neill M, Ralston EG, et al. Evaluating the quality of educational materials about schizophrenia. The Psychiatrist. 2002;26:96-98.
- Chang MY, Han DH, Moon IJ, Kim ST, Kim DY, Lee CH, et al. Assessment of allergic rhinitis websites s in Korea. Clin Exp Otorhinolaryngol. 2010;3(1):32-6.
- Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. J Epidemiol Community Health. 1999;53(2):105-11.
- American Diabetes Association. Standards of medical care in diabetes 2006. Diabetes Care. 2006;29(Suppl 1):S4-42.
- Diretrizes da Sociedade Brasileira de Diabetes 2009. [cited 17 out 2011].
  Available from: http://www.diabetes.org.br/attachments/diretrizes09\_final.pdf.
- 15. Diretrizes Brasileiras de Hipertensão VI. J Bras Nefrologia. 2010;32(Supl 1).
- The Joint European Society of Cardiology/American College of Cardiology Committee. Myocardial infarction redefined: a consensus document of the Joint European Society of Cardiology/American College of Cardiology Committee for the Redefinition of Myocardial Infarction. Eur Heart J. 2000;21(18):1502-13; J Am Coll Cardiol. 2000;36(3):959-69.
- III Diretriz Sobre tratamento do infarto agudo do miocárdio. Arq Bras Cardiol. 2004;83(Supl 4).
- Chilton F, Collett RA. Treatment choices, preferences and decision-making by patients with rheumatoid arthritis. Musculoskelet Care. 2008;6(1):1-14.
- 19. Giddens A. Modernidade e identidade. Rio de Janeiro: Jorge Zahar; 2002.
- Hardey M. Doctor in the house: the internet as a source of lay health knowledge and the challenge to expertise. Sociol Health Illn. 1999;21(6):820-35.
- Eastin MS. Credibility assessments of online health information: the effects of source expertise and knowledge of content. J Comput Mediated Commun. 2001.;6(4):10-26. [cited 2011 May 16]. Available from: http://onlinelibrary. wiley.com/doi/10.1111/j.1083-01.2001.tb00126.x/full.
- CREMESP. Manual de princípios éticos para sítios de medicina e saúde na Internet. [cited 20 May 2011]. Available from: http://www.saudeinformacoes.com.br/institucional\_cremesp.asp.
- Sales ALC; Toutain LB. Aspectos que norteiam a avaliação da qualidade de informação em saúde na era da sociedade digital. In: Proceedings CIN-FORM-Encontro Nacional de Ciência da Informação. VI. Salvador; 2005. Bahia. [cited 17 Out 2011]. Available from: http://www.cinform.ufba.br/ vi\_anais/docs/AnaLidiaSales.pdf.
- Hargrave, DR; Hargrave, UA; Bouffet, E. Quality of health information on the Internet in pediatric neuro-oncology. Neuro Oncol. 2006;8(2):175-82.