Access to health information on the internet: a public health issue?

Felipe Azevedo Moretti[1], Vanessa Elias de Oliveira[2], Edina Mariko Koga da Silva[3]

[1] Undergraduate Degree in Physiotherapy; MBA in Economy and Health Management, Universidade Federal de São Paulo (UNIFESP); Student, Postgraduate Course, Internal Medicine and Therapeutics Program, UNIFESP; Responsible for the Project Cochrane Consumidores do Brasil, São Paulo, SP, Brazil
[2] MSc and PhD in Political Sciences, Universidade de São Paulo (USP); MSc in Public Health, Faculdade de Ciências Médicas da Santa Casa de São Paulo; Professor of Political Sciences and Public Politics, Universidade Federal do ABC, São Paulo, SP, Brazil
[3] MSc and PhD in Pediatrics, UNIFESP; Deputy Coordinator of the Internal Medicine and Therapeutics Program, UNIFESP, São Paulo, SP, Brazil

Summary

Objective: To progress in the understanding of the user profile and of search trends for health information on the internet. **Methods:** Analyses were performed based on 1,828 individuals who completed an electronic questionnaire available on a very popular health website. At the same time, through the "elite survey" method, 20 specialists were interviewed, aiming at assessing quality control strategies regarding health information disseminated online. **Results:** A predominance of female users who research information for themselves ($\approx$ 90%), who consider the internet one of their main sources of health information (86%), and who spend from 5 to 35 hours online every week (62%) was verified. High reliability is assigned to information from specialists (76%), and low reliability to television, radio, or blogs (14%). **Conclusion:** It can be concluded that the internet is proving to be a major source of health information for the population, and that website certification is a strategy to be contemplated to improve the quality of information and to promote public health.

Keywords: Health communication; internet; public health; information search behavior.

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Correspondence to:
Felipe Azevedo Moretti
Rua Pedro de Toledo, 598
Vila Clementino
CEP: 04039-001
São Paulo, SP, Brazil
Phone/Fax: +55 (11) 5575-2970
+ 55 (11) 5085-0248
felipe.moretti@unifesp.br

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INTRODUCTION

Research indicates that by 2001, approximately 52 million Americans had already searched the internet for medical information, and that the internet is the main source of health information for 70% of U.S. adults[1,2].

In Brazil, it is estimated that over 10 million users access health websites on a regular basis[3]. The commercial use of the internet in the country began in 1995 and, as in other countries, there was a rapid growth in the subsequent years. Between September, 2000 and September, 2002, the number of internet users in Brazil grew by more than 50%[4]. At the time, there were 7.68 million active users in households. Taking into accounting the number of individuals accessing the internet at work, at cyber cafés, or at friends' houses, the total number could reach 22.1 million[5]. These numbers have increased significantly over the last few years. In 2009, 67.9 million people aged over 10 years old reported to have used the internet, which represents an increase of 12 million (21.5%) over 2008 – according to the Brazilian Institute of Geography and Statistics (Instituto Brasileiro de Geografia e Estatística – IBGE)[6]. Soares also points out that the Brazilian citizen is the world leader on average time spent on the internet[5].

Researches show that the creation of the internet has significantly promoted access to information and has also collaborated with mass production of content from several sources[7]. In the healthcare field, interaction through the internet – which enables the exchange of experiences between patients with similar problems, and makes discussion between experts and patients easier – was identified as a powerful strategy to manage several clinical conditions[8], providing improvements in users' quality of life by promoting greater autonomy, pro-activity, and self-confidence among participants. There are other benefits, such as improvement in social interaction and learning, reduction of hopelessness, better coping with life situations, more knowledge about the disease, emotional relief, and clinical improvement[9-11].

However, as any means of communication, the internet presents its recalcitrances, its singularities, and its biases, thus it is necessary to use this instrument for obtaining information carefully. As Biruel[7] stated: "The internet can represent a great risk in the healthcare field, as both healthcare professionals and consumers may not be aware of the rules regarding the identification of quality standards."

Several experts point out that the majority of information about diseases and treatments available on the internet is scientifically inadequate or incomplete[12–14]. Facing this reality, authors suggest that health websites should use compliance certification seals granted through criteria established by specialized organizations.

This is one form of ensuring a quality standard for information disseminated on the web.

In addition, studies show a trend of health websites growing in number faster than the overall use of the internet[4].

Despite the relevance that the internet has gained in terms of access to health information, Soares[5] points out that there are few studies about the Brazilian reality in terms of internet use for health purposes. In this regard, specific research or interventions, including by the public sector, are important for better understanding the use of the internet for health purposes, its advantages and its risks. Accordingly, it is worth questioning the role of the state and the society in the regulation of how health information is available on the web.

METHODS

In order to better understand the user profile and search trends for health care information on the internet, the authors opted for a cross-sectional study. An electronic questionnaire was prepared for data collection, with questions regarding the performance of searches for health care information, level of trust in the information retrieved, number of hours spent on the internet, and users' socio-economic profile, among others. This questionnaire was made available in a very popular Brazilian health website (4 million accesses/month), Minha Vida. Users were invited to collaborate with this research.

Data were collected between January and February, 2011. The project was approved by the Ethics and Research Committee of the Hospital São Paulo – Universidade Federal de São Paulo (UNIFESP) – under number 0434/10, and the participants of the study agreed with the informed consent.

The input and data analysis were made using Microsoft Excel®. Data obtained was analyzed through descriptive statistics, aiming to characterize a sample and identify stand-out patterns of conduct.

Another stage of the research included a qualitative study, with semi-structured interviews with experts in health communication, who were selected based on the relevance of these agents in the area at stake, pursuant to the "elite survey" method. The objective was to capture the privileged view of principal agents in the area of health communication, who were identified by reputation criteria and recognition of their ability to impact their field. An elite survey does not have a sampling nature; its main objective is not statistical, and it is extremely useful to understand the evaluations of experienced agents in the study area[15].

Interviews sought to review the strategies of quality control of health information disseminated on the internet.

Twenty experts from different entities were interviewed, among them: FioCruz, Associação Paulista de Saúde Pública, Conselho Regional de Medicina do Estado de São Paulo, Secretaria Municipal de Saúde de São Paulo, Biblioteca Virtual de Saúde, Associação Médica Brasileira, Centro Cochrane do Brasil, Universidade Federal de São Paulo, and Public Health Faculty of the Universidade de São Paulo. The number of interviews conducted proved sufficient to understand the "meanings, symbolic and classification systems, codes, practices, values, actions, ideas, and feelings". These interviews occurred between October, 2011 and February, 2012.

- The questions at this stage aimed to collect information on the following aspects:
- Importance of certification of health websites in Brazil.
- Strategic importance (assigning a score from 0 to 10) of the following institutions regarding certification (Brazilian Ministry of Health; State Health Departments; Universities; Medical Associations and Patient Associations).
- Alternative actions to ensure quality of health information on the internet
- Potential strategic actions to qualify health information disseminated on the internet

Results

The sample of 1,828 individuals that collaborated with the research showed an user profile seeking information about their own health (90% of the sample) or the health of their family members (79%); there was a predominance of females (89%), and of individuals who use the internet heavily: 62% of interviewees spend 5 to 35 hours on the internet per week, 12% spend more than 35 hours a week, and 42% more than 2 hours a day. For health-specific searches, 51% do so more than once a week, 59% from two to ten times a month, and 26% over ten times per month (Table 1).

The states with the largest number of people who collaborated with the study were: São Paulo (766 individuals = 46% of the sample), Minas Gerais (183 individuals = 10%), Rio de Janeiro (142 individuals = 8%), Rio Grande do Sul (102 = 6%), Bahia (92 individual = 5%), and Paraná (90 individual = 5%).

Of the 1,828 individuals, 80% answered "yes" to the question: "Do you use the internet as one of your main sources of health information?"

When broadening the question to "What are your main sources of health information?" – more than one answer possible –, the internet shows a frequency of 86%, against 74% for opinion of physicians or specialists, 50% for information from television or radio, and 39% for health books (Graphic 1).

To assess the level of trust in different sources of information, a question listing 11 different sources, to which four levels of reliability were assigned, was included in the questionnaire. The interviewee was requested to assign a level of reliability to each one of the information means.

Data related to highly reliable sources, as assigned by interviewees, was separated and presented in Table 2.

When analyzing the answers to which low or very low levels of reliability were assigned, the result was almost mirrored, i.e., the information means that presented a low percentage of "highly reliable" answers were the ones that presented the higher indexes of low or very low reliability. In this regard, the sources that presented higher indexes of low or very low reliability were non-specialized magazines or newspapers (such as Veja, Isto É, and Época), electronic search engines (such as Google, Yahoo, and Bing), health blogs, and television or radio.

The study population showed a high degree of interest in many different health topics. High interest was expressed, for example, by at least 50% of the individuals in all subjects researched (quality of life, prevention of health problems, food and diet, causes and symptoms of health problems, medical diagnosis, medical and drug therapies, alternative therapies, and child health). The same trend is observed when studying the degree of interest in certain health conditions, such as anxiety, cancer, and obesity.

Online activities related to health mentioned more frequently by the population in the study were: reading of journal articles, search for self-diagnosis, video viewing, blog reading, search for quality of life and diet, search for supplementary information after medical advices, search for information after feeling any symptom, and search for alternative therapies.

Regarding actions after an online search, the most frequent are: talk to friends/family members about the information obtained (70%), lifestyle change (65%), talk to a physician (48%), and schedule a medical appointment (30%).

Conversely, the actions more frequently mentioned as not taken by users are: online purchase of health products or services (51% do not), search for online health professionals or services (45% do not), viewing of online advertisements (35% do not).

When contacting communication experts, most of the interviewees placed a great emphasis on the relevance of public sector initiatives to qualify health information available on the Web, especially in Brazil and Latin America.

Table 1 – Basic details of the 1,828 interviewees

Data	n	%
Education		
High School degree	483	26%
College degree	459	25%
Incomplete secondary education	362	20%
Post-graduation course fully or partially completed	391	21%
Elementary school fully or partially completed	133	7%
English knowledge		
Basic level	737	40%
None	676	37%
Intermediate level	250	14%
Advanced level or fluent	163	9%
Monthly income		
Up to R$ 510.00	79	4%
From R$ 510.00 to R$ 1,530.00	509	28%
From R$ 1,530.00 to R$ 3,060.00	564	31%
From R$ 3,060.00 to R$ 5,100.00	361	20%
From R$ 5,100.00 to R$ 10,200.00	222	12%
Over R$ 10,200.00	93	5%
Frequency of SUS (Unified Health System) use		
Never	687	38%
Little	540	30%
Sometimes (moderately)	278	15%
Often – it is my main service provider	295	16%
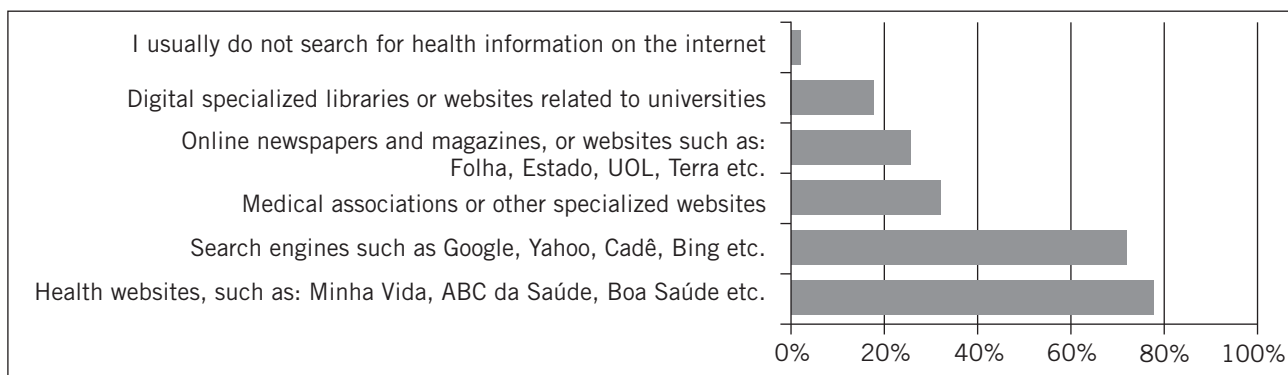
Graphic 1 – Sources searched for health information.

The certification of health websites was deemed a good strategy by communication experts. The average grade (from 0 to 10) assigned to the importance of health websites certification was 8.2, and the Brazilian Ministry of Health was the most mentioned among the entities that should undertake such task.

Some aspects pointed out during interviews are noteworthy. Firstly, the need to establish a legal framework to regulate health information available on the internet, without interfering in the individual freedom of expression, emerged as a subject to be debated and contemplated. This point can be captured in the statements below:

Table 2 – Percentage of individuals who assigned a high level of reliability to several sources

Source of information	Highly reliable
Physicians', healthcare professionals', or specialists' opinion	76%
Books on health	55%
Journal articles	52%
Medical associations or other specialized websites	51%
Health websites, such as: Minha Vida, ABC da Saúde, Boa Saúde etc.	47%
Digital specialized libraries or websites related to universities	45%
Online newspapers and magazines, or websites such as: Folha, Estado, UOL, Terra etc.	20%
Television or radio	18%
Non-specialized magazines or newspapers, such as: Veja, Isto é, Época etc.	16%
Websites derived from electronic search engines as Google, Yahoo etc.	12%
Blogs on health	10%

"Health professional councils should work together to establish a legal regulatory framework."

"We need a public forum for discussion, with exchange of information and strategies conducted by the Ministry of Health."

"Monitoring and control of several websites."

"Creation of working groups to discuss the issue in several health institutions."

"Promotion of strategic discussions, such as on Twitter and Facebook."

Another aspect highlighted was the possibility of acknowledged and relevant institutions in the field of public health to take over health websites, ensuring the quality of the information provided:

"Medical schools should patronize health websites, so their content would be certified."

"Requirement of a technician in charge with education corresponding to the information discussed."

Finally, another point raised was the need to increase awareness of the issue in society, through processes of social education (e.g., through highly popular TV programs), in order for citizens to become more critical of information easily accessed via the internet:

"Certifying websites is not enough, it is necessary to make users understand this problematic situation better, with more TV programs and lectures on the subject."

"User education/empowerment and free exchange of information on the subject."

DISCUSSION

The ease of insertion of several sources of information on varied subjects made the internet a great outreach and search tool in the healthcare field. Searches vary from diseases and their treatments to prevention of pathologies, promotion of wellness, nutrition, hygiene, and services[7].

However, a better understanding of the metrics or patterns of search for healthcare information on the internet is critical, considering that the user of this tool may be exposed to a great amount of dubious and inconsistent information[16]. While there is the ease of finding all sorts of information, conversely, there is the difficulty of obtaining reliable information, as the amount of data makes it difficult to locate a reliable source[17].

A research carried out by Google in Brazil[18] to understand the use of the Web for health purposes has shown that the internet is an important channel for research on diseases and treatments. The study was performed with 603 Brazilian adults that had searched the internet for diseases, medications, and health questions in general during the previous three months. The study stated that the sample profile was representative of the universe of internet users in Brazil. In this research, the main topic researched by interviewers was medical treatment (60%), followed by general information about diseases (52%), causes and symptoms (48%), information about medications (40%), potential treatment consequences (39%), search for specialists (39%), and diagnosis of diseases (28%). Searches related to nutrition and diet, fitness, and child health were also mentioned with high prevalence.

Of the more frequent online activities, the reading of articles was reported by 78% of the 603 interviewees, 35% said they read blogs, and 30% often saw or clicked on ads, made self-diagnostic tests, watches videos, and posted comments in blogs.

Many of the data presented in the Google study are close to or match the findings of the present research.

Also on the Google study, 85% of the sample said they used search engines such as Yahoo, Cadê, and Google to search for issues related to healthcare and medications; the use of simple search engines is the main online source of information. Among traditional (offline) sources, the most used are healthcare professionals (57%), magazines (53%), books (42%), television (40%), package inserts (33%), and newspapers (28%).

Simple search engines also appear as the most useful source of information about healthcare issues, preferred by 42% of the sample, followed by healthcare professionals (14%). Additionally, 72% of the sample indicated search engines as the first source of information about healthcare, followed by experts, with 44%, and websites or wellness magazines, with 31%.

Interviewees affirmed to spend, on average, six hours per day on the internet. Over 70% of the interviewees intend to increase the use of online search engines to learn about healthier lifestyles, and to search regarding diseases and/or treatment options for their own benefit or for the benefit of third parties (family and friends).

Additionally, 69% affirm that the internet has a very positive or positive impact on the relationship with their physicians. After an online research, 16% of the sample asked the physician to prescribe a specific medication, and 10% asked the physician to change their prescriptions – of this total, 52% said that the physicians met their prescription requests. This data evidences not only that the access to healthcare information was extended with the democratization of internet access, but also – and as a result of it – that there was a change in the doctor-patient relationship. Physicians now have to deal with the patients' knowledge, which, until now, was something held only by healthcare professionals.

Aspden & Katz[19] note that the great majority of the users believe in the information value of the internet, considering it "highly important" for healthcare. Part of the users is suspicious about certain information; however, the majority of them tend to believe in the content disseminated online. Pursuant to the authors, few people report having read reckless or very commercial information about healthcare on the internet. And those that have read allegedly misleading information are usually more critical, pursuant to the research. This data can be disturbing, considering that a good amount of information disseminated on the web is poor in quality, mistaken, or with major conflict of interest. Misuse of content related to healthcare may, among other things, result in lethal consequences to internet users.

These findings increase the importance that the internet has been gaining over recent years regarding online healthcare research by the population. Some of these findings are even worthy of public debates involving the civil society, the state, and experts in the area, in order to establish healthcare-promoting actions on the web, initiatives capable of maintaining the user's integrity and safety. Joint initiatives should also be prepared to resolve online conduct capable of causing harm to the population's health.

In a study in which 800 Americans (sample representing the population of the United States) were interviewed via telephone, 41% of the sample (328 individuals) had already searched for medical information on the internet – these searches were greater among women, white individuals, and among those that believed themselves to be more skilled in internet browsing. The authors also noted that individuals that access health information usually do so multiple times.

Soares[5] also mentions a study of the Health on Net Foundation, carried out in 1998, which evidenced that women represent the majority of health searches on the internet.

Great part (73%) of the 328 Americans mentioned in the study of Aspden & Katz[19] stated that they had discussed the information found on the internet with other people and/or with their physicians. Women, wealthier individuals, and those with greater internet skills showed a stronger tendency to discuss the information with other people.

In the present study, the fact that 89% of the interviewees are women reaffirm the findings in the research of Aspden & Katz and Soares, that they represent the majority of online searches for health. It was also observed that the present sample showed a strong tendency of sharing searched information, in addition to searching health topics on the internet several times a month.

In the present study, simple search engines (Google, Yahoo, etc.) were also pointed out as the most useful source of information regarding health issues, even over specialists' opinion. The same phenomenon was observed when they indicated search engines as the first source of health information.

Rice & Katz[20] mentioned a study that focused on internet use by 220 physicians of New Jersey, in which three quarters of the interviewees agreed that physicians should recommend relevant websites (accurate and safe) to their patients. In this study, the authors postulate that the internet already was, in the late 1990s, the largest source of health information both for users and physicians.

A systematic review by Masters[1], who proposed to identify how and why physicians use the internet in their daily activities, analyzed 38 studies published from 1994 to 2004. Among the factors discouraging the use of internet are the excess and confusion of information.

Conversely, the demand of patients for such media is a factor that stimulates its use by physicians.

Therefore, the internet also has a significant effect on the doctor-patient relationship. An increasing number of physicians have being reporting a huge number of patients that often discuss information arising from the internet in their offices. In this review[1], the author says that 89% of physicians reported such an event.

Dart[21] analyzed the socioeconomic variable and its relationship with the use of the internet among 758 Australian individuals from three different communities (low income, average income, and college students). The internet proved to be a much more important source of health information for the college student sample. Low-income interviewees also demonstrated less access to the internet for medical information in comparison to those with average income and college students.

A cross sectional study conducted by Schwartz, et al.[22] evaluated the use of the internet for health purposes in a sample of 1,289 checked-up patients in a family health care program in Detroit, USA. The study analyzed physicians' perception on how their patients used the internet for health searches. Of the 1,289 participants, 65% reported to have access to the internet. Age, gender, race, and education were variables significantly correlated with access. Of the individuals with internet access, 74% had researched health information for themselves or family members.

Information regarding specific diseases was the most frequently searched topic by the abovementioned sample, followed by information regarding medications, nutrition, and physical exercises. Patients determined the accuracy of the websites especially based on endorsement of governmental agencies or professional organizations. Personal evaluation of the reliability of the sources and understandability of the information were also important aspects to determine accuracy.

Almost 90% of that sample tried to verify the information obtained during a search for a health topic. Most of them also claimed to discuss website information with their physicians.

In the study by Schwartz et al.[22], 92 physicians were interviewed. Physicians tended to underestimate the proportion of their patients who used the internet to search for health information. Of this sample of 92 physicians, 36% said that at least one patient per week had brought health information derived from the internet, and 63% said they suggested a specific website to their patients.

It is worth mentioning that, although the indiscriminate use of information obtained on the internet may be harmful, this phenomenon also has a beneficial side. It allows more careful decisions by users or consumers, in addition to greater autonomy and freedom of choice.

Dart, et al.[23] point out the major importance still assigned to physicians' or specialists' opinion. In the three study communities (lower class, middle class, and college students), the physician's recommendation was deemed the main source of health information. However, there was a significant difference among the three communities. The internet was the most used and/or deemed the most important source of health information among the college student population. Additionally, the lower class less frequently considered using the internet as a source of health information in the future.

Other usual sources of health information listed among the top four by all communities researched[23] were: television and friends and family. However, the authors report lack of data and studies able to correlate socioeconomic variables with the use of the internet for health purposes.

This data shows the close relationship established among physicians, patients, and the use of the internet for health information, which will tend to be intensified in the coming years, given continuing growth of internet use.

Despite the importance of this relationship, few studies in Brazil have proposed to analyze the profile of lay users and their mechanisms for searching health information on the internet. A better understanding of these patterns may be an important strategy to promote the public health of internet users.

In Brazil, in an attempt to qualify the health information available on the internet, initiatives such as FioCruz's must be highlighted, with its Laiss (Internet, Health, and Society Laboratory – Laboratório Internet, Saúde e Sociedade) Laboratory, which seeks to create mechanisms capable of evaluating the reliability of medical websites and the health information on the web. Also noteworthy are the actions of the Regional Medical Council of the State of São Paulo (Conselho Regional de Medicina do Estado de São Paulo – CREMESP), which issued on February 20th, 2001 a resolution (No. 97) that provides for the design, creation, maintenance, and professional activity on websites, pages, or portals about medicine and health on the internet.

The resolution requires the use of a Manual containing guidelines and criteria that should be followed by physicians and health institutions registered with the Council, and points to a problematic situation: the lack of specific laws and regulations to control the use of the internet or electronic commerce in Brazil. This problem requires an incentive for self-regulation of the industry, so that minimum quality, safety, and reliability standards may be established for health websites. The resolution also indicates that internet users, when searching for online health information, services or products, have the

right to demand from organizations and individuals responsible for the websites: [1] transparency; [2] honesty; [3] quality; [4] informed consent; [5] privacy; [6] medical ethics; and [7] responsibility and origin.

Outside of Brazil, among these initiatives, and perhaps with higher expressivity and pioneering spirit in the area, it is inevitable to highlight the work developed by the Health on the Net Foundation (HON), which since 1995 has promoted mechanisms capable of ensuring a more careful use the internet for health purposes[24]. The entity exists to ensure that health information conveyed on the web follows critical ethical standards, by developing a code of conduct (HONCode), which establishes rules to protect citizens from misleading health information. Some of these rules are: [1] the website should qualify who are the project owners and respect users' privacy; [2] sources and data obtained from third parties should be mentioned; [3] details on the financing of the website should be provided and advertisements should be clearly distinguished from the content.

Today, the HONCode is used by over 7,300 websites, amounting to more than 10 million pages and 102 countries.

There are few websites accredited by HON in Brazil. In a study of 100 websites containing information about dental cavities in children, Leite and Correia[25] have demonstrated that only 5.3% of the researched websites were accredited by HON.

HON also provides guidelines consisting of patient and information consumer advice, to guide users on how to safely take advantage of the internet when searching for health information. Some of these guidelines are: [1] governmental, hospital, and university websites, as well as those hosted by reputable institutions, are usually more reliable; [2] ask your physician for a list of reliable websites; [3] always use more than one website to compare information; [4] verify the source of the information provided; [5] check the person's qualification to provide information; [6] read the websites' privacy policy to understand how the data collected is used; [7] check whether the website has any quality certification seal; [8] always be careful, do not trust promises of miracle cures; [9] never take information or advice found on the internet as a replacement for an appointment with your healthcare provider; [10] keep in mind your national laws and regulations when ordering a procedure or product online, and always check on the credibility and security of institutions selling products on the web.

Study data demonstrate the complexity of the issue of use of health information obtained on the internet and, consequently, the public agencies' and/or non-governmental organizations' responsibility related to the safety of this information, which not only changes the doctor-patient relationship (often compelling physicians to adopt a certain type of procedure "expected" by the patient due to information obtained on the web), but also become a risk to the health of individuals, who may look for improper treatments due to "diagnoses" performed via the internet.

Conclusion

The discussion presented indicates a health issue that deserves attention not only from academia, given the insufficient scientific knowledge on the problem, but moreover, that requires critical thought, on a societal basis, of what the state's and specialized institutions' role should be in ensuring citizens' access to safe information. It is not about discussing censorship of certain websites or contents, but ensuring that those available are credible and unsuspected, ensuring safety to the patient and the user. It is, finally, a public health issue that deserves attention, involving governments and the civil society in a debate about the benefits and risks of using health information available on the internet.

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