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INFODEMIOLOGY: ANALYSIS OF INFORMATION ON ORGAN DONATION AND TRANSPLANTATION

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ABSTRACT
The aim of this cross-sectional descriptive infodemiological study was to identify web pages containing information on donation and transplantation of organs and analyze them according to Quality Technical Criteria. A search was conducted on the search engine Google®. In the advanced search, the option "pages in Portuguese" and the country "Brazil" were selected. The keywords used were "organ donation and transplantation". The search resulted in 130,000 pages. The first 200 Uniform Resource Locators were selected. Of those, 19 were excluded. The 181 remaining pages were individually analyzed as for the presence of Quality Technical Criteria. The results revealed that most of the evaluated sites omitted important data for reliability reasons such as authorship, source, reference and date of publication. Considering that the Internet presents itself as a means of dissemination and diffusion of knowledge in the healthcare field, this result is indicative of attention. The Internet is a fundamental tool to search for information on healthcare. Nevertheless, caution is needed as not all subjects regarding healthcare come from reliable sources. Efforts should be made to ensure the accuracy of information on healthcare obtained in the virtual environment.

Keywords: Organ transplantation. Tissue and Organ Procurement. Internet. Consumer health information.

INTRODUCTION

The Internet stands out as an invaluable communication source. The worldwide network has been capable of gathering an ever-increasing amount of users every day thanks to reduced costs, real-time information, convenience, and growing accessibility[1].

At present, 85% of American adults make use of the Internet in order to carry out a wide array of tasks, such as search for information, read emails, make online purchases, download documents and games, access social networks, among others. Data reveal that 80% out of this universe of users searched for healthcare and medicine-related information in 2010[2]. Additionally, nearly 10% of Internet users that searched for medical information state that they were more informed after searching for virtual information[2].

Internet has increasingly become an influential source of healthcare-based information to the general public, being considered as the major researchable medical library in the world. Healthcare-based information influence treatment decisions of 70% of American users who search for this type of knowledge[3].

Brazil lacks data regarding the search of Internet users for healthcare-related information. Nevertheless, Brazilians have considerably increased their Internet time, a feature that brings about a new economic and social perspective in the country. According to the Study Center on Information and Communication Technologies (CETIC, as per its acronym in Portuguese), Brazil had approximately 41.4 million Internet users in June 2012[4].

CETIC[4] also shows that every month nearly one million people are granted access to the Internet in Brazil, a figure that turns the worldwide network into a relevant and attractive tool in search for information in a wide variety of contexts. Whenever one searches for a specific issue on the Internet, whose intrinsic characteristic is to be a free environment, a broad scope of information is rapidly made available, which motivates a deeper and often effective search for knowledge[5].

On the other hand, negative aspects, such as lack of credibility of found information, or irrelevant information, advertisement and the commercialization of products related or not to the searched issue may cause the educational purpose of the Internet to head toward superficiality[5].

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Some nations of the European Community, for instance, have created regulatory norms as a way of ensuring the credibility of healthcare-related information on the Internet. Launched in 1995, the non-governmental organization Health On the Net Foundation (HON)[6], an organ that officially certifies healthcare-related websites and whose purpose is to promote quality and transparency of information, elaborated a "Code of Conduct" (HON code) to medical and healthcare-based information websites. The code is responsible for establishing a basic ethical standard for healthcare-based information to be exposed on Internet websites.

Internet websites that comply with HON's guidelines[6] are accredited and receive an identification seal that guarantees the credibility of the information found in that website. Such aspect is able to help users trust the veracity of the accessed information.

In Brazil, there is no legislation that controls the quality of healthcare-based contents made available to the general audience in scientific websites. This trait reveals a huge gap to be filled by research, so that the quality of such information can be assessed[7].

Aiming to improve the quality of healthcare-based information made available on the Internet in Brazil, the Virtual Healthcare Library (VHL) developed the Healthcare Information Locator (HIL), a database that contains a catalogue of healthcare-related information sources available on the Internet. These websites are selected in compliance with quality criteria. The HIL methodology[8] follows international norms and formats, working as a filter and containing selection criteria for healthcare-based information available on the web.

In addition to providing orientation on several different issues, the facilitated access to the Internet, especially through search engines, allows for infinite responses to a wide array of questions. The problem, though, is that a virtual search may cause untrained people to get to inconsistent or conflicting information, thus representing risks to the user's health status[3].

It is worth highlighting that some websites, in spite of displaying accurate, high-quality information, do not bring dates, references, sources, or show outdated information. Such lack of precise information may lead to doubts and conflicts. The association of this fact with the information resulting from non-scientific readings or texts that display concepts diverging from those accepted by researchers and scientists may generate the dissemination of mistaken ideas that may cause users to face physical, moral and financial damages[9].

The lack of correct information or the misinformation of the population concerning a so relevant process, such as the donation and transplantation of organs in Brazil, delay the consolidation of the transplant and contribute to the decrease of organ procurement processes and also the unsatisfactory quality of achieved organs[10].

Despite the scientific and technological advances that corroborate toward the striking increase in the procurement and transplantation of organs, the numbers are yet not satisfactory in face of the available demand. Some research identify an insufficient and often erroneous knowledge on this issue in Brazil[10].

As the Internet currently stands out as the most used information search engine and encompasses a large portion of the knowledge acquired by avid users, who constantly come back to it, one should question the credibility of the information regarding the donation and transplantation of organs made available in the virtual environment.

In this context, the present study is grounded on the purpose of assessing Brazilian websites that provide contents regarding the donation and transplantation of organs on the Internet. The aim of this research was to identify webpages containing information on the donation and transplantation of organs, as well as analyze them under quality criteria.

METHODOLOGY

The source of this cross-sectional, descriptive infodemiological study was Internet webpages that provide information on organ donation and transplantation in Brazil.

The term "infodemiology" is defined by Eysenbach[11] as a science that studies the determinants and frequency of distribution of healthcare-based information in the different means of communication, especially the Internet.

This science derives from the epidemiology and is popularly known as the discipline that studies the "epidemiology of information" on the Internet. It can make use of both descriptive and analytical intervention methods toward the implementation of the study[12].

Descriptive infodemiological studies do not explain how the quality indicators of the website are inter-related; they only analyze the frequency of healthcare-based information and its quality by assessing healthcare-based information in accordance with previously set quality criteria, such as technical website production and content aspects[12]. Such aspect identify how the information based on evidences is distinguished from the ones that do not display any scientific veracity; besides, they point out webpages in which publicity, frauds and conflicting data are shown[13-14].

Under such emphasis, this research initially aims to subsidize the planning of information to be disseminated regarding the donation and transplantation of organs via the Internet. Google® search tool was chosen because it covers a whole array of issues and owns indexation programs that navigate through and store all found information.

The search was carried out on April 15th, 2011, at 10.00 a.m., at the Google® search tool (http://www.google.com.br). The option "pages in Portuguese" and the country "Brazil" were selected in the "Advanced research" mode, so that the achieved results could bring only national information. Keywords, such as "organ donation and transplantation" were typed in Portuguese. The search resulted in 130,000 pages. The first 200 URLs (Uniform Resource Locator) were selected and inserted into a Microsoft Excel® sheet, so that the information could be alphabetically ordained and disposed, aiming to facilitate the Quality Technical Criteria (QTC) analysis[14].

After being typed in a specific slot, the search mechanisms enable information to be quickly accessed from the term that needs to be found. Whenever a search is carried out, programs scan the whole web and store pertaining information in their databases. This information is interpreted by a mathematical algorithm in such a way that a list of websites ranked by relevance status is finally presented to the user[15].

Such precise algorithms that formulate the page indexation ranking allow for the top websites to occupy privileged positions and be shown on the first ranks of the list of found results[15].

Nevertheless, this information collection process carried out by search mechanisms is quite limited and sometimes does not produce satisfactory results, as different users express their informational need in distinct ways, which may lead to an inaccuracy of what is being searched due to the capacity words have to embody different meanings, causing desired URLs not to be listed in top positions, not to be found in the list, to be insufficiently optimized, or to be misplaced in the ranking, being ultimately found down the list[16].

In this sense, the present research chose the first 200 URLs found as selection criteria. As the results of a similar Google search may differ from user to user, the analysis of such large number of pages leads us to believe that a great amount of webpages may be present among the search results of distinct users.

As an exclusion criteria, we decided not to include images, videos, advertisement and polls (i.e., Yahoo® replies, Twitter®), as well as technical problems in the access or search, websites advertising on congresses, symposiums, conferences, campaigns, and/or courses. In case of duplicated pages, only one was selected.

Selected websites were individually assessed concerning the presence of QTCs by means of the instrument proposed by Silva, Castro and Cymrot[14], which is composed of questions that only allow for dichotomic answers, in order to facilitate their applicability (Figure 1).

Based on these questions, the technical aspects of the websites regarding authorship, conflicts of interest, means of reviewing the page, date, clinical evidence of the information, dissemination of the institution responsible for the information, availability of internal search tools, telephone numbers and address, page update, dissemination of references used in the text, dissemination of sponsors, commercialization of products, and advertisement of products related to the content could be analyzed (Figure 1).

1. Is the author's name informed in the text?
( ) Yes ( ) No
1.1. Are the author's credentials (technical background) to write about the issue presented?
( ) Yes ( ) No
1.2. Is the author of the text connected to any institution related to the issue?
( ) Yes ( ) No
2. Is the institution responsible for the website informed?
( ) Yes ( ) No
2.1. Does the webpage state "conflicts of interest"?
( ) Yes ( ) No
3. Does the webpage inform the date on which the information was made available?
( ) Yes ( ) No
3.1. Does the webpage update information?
( ) Yes ( ) No
4. Does the webpage quote the references used toward producing the information?
( ) Yes ( ) No
5. Does the webpage present the degrees of clinical evidence for available information?
( ) Yes ( ) No
6. Does the webpage inform whether or not the available texts were produced after a process of editorial review or peer review?
( ) Yes ( ) No
7. Does the webpage inform the existence of any sponsor?
( ) Yes ( ) No
8. Does the webpage offer links to the references quoted in the text?
( ) Yes ( ) No
9. Does the webpage provide an internal content search tool?
( ) Yes ( ) No
10. Does the webpage advertise contact numbers and email addresses?
( ) Yes ( ) No
11. Does the webpage advertise products related to its content?
( ) Yes ( ) No
11.1. Is the webpage used to commercialize any product?

Figure 1: Instrument used to assess the presence of Quality Technical Criteria in webpages.
Source: Silva EV, Castro LLC, Cymrot R, 2008.

RESULTS AND DISCUSSION

Following the application of the instrument, the authors proceeded to the data analysis process. From the 200 selected websites, one was excluded for being a video, five due to technical problems at the time of the analysis, and 13 as a result of being websites aimed to advertise congresses, symposiums, conferences, campaigns, and/or courses. Hence, a total of 181 websites were individually assessed concerning the presence of QTCs (Table 1).

Table 1 - Frequency distribution of quality technical criteria on assessed webpages. São Carlos, 2012.

Technical quality criteria	N = 181	%
Disclosure of the institution responsible for the website	142	78.5
Availability of internal search tools	126	69.6
Disclosure of telephone numbers and addresses	106	58.6
Disclosure of webpage update	89	49.2
Disclosure of references used in the text	76	42.0
Disclosure of sponsors	58	32.0
Commercialization of products	50	27.6
Disclosure of degrees of clinical evidence of the information	46	25.4
Disclosure of the text's authorship	41	22.7
Disclosure of advertisement of products related to the content	40	22.1
Disclosure of the date the information was made available	28	15.5
Disclosure of the links of references quoted in the text	27	14.9
Disclosure of the author's credentials	13	7.2
Disclosure of the institution represented by the author	12	6.6
Disclosure of conflicts of interest	4	2.2
Disclosure of the webpage's review process	4	2.2

The analysis of the questions regarding the update and/or dates on which the information on the donation and transplantation of organs was uploaded to the website showed that 15.5% mentioned the date on which the text had been written and posted, and 49.2% brought updated information on the issue. This means, then, that a total amount of 35.3% of the webpages was not updated.

A study aimed to assess Internet-based information on leishmaniasis[17] showed that a large amount of websites (76.5%) was not updated regarding new knowledge produced at that time. Such discrepancy may be due to the fact that the

issue of the transplantation and donation of organs has been more disseminated lately as a result of the campaigns carried out by the Ministry of Health and also the need healthcare professionals have to be updated on this field.

As for the authorship of the websites, only 22.7% of them displayed such information; from these, only 7.2% presented the credentials of the author and 6.6% showed the connection of the author to healthcare institutions related to the donation and transplantation of organs.

Another research that assessed information on malaria made available on Brazilian websites referred that 38.2% of pages displayed information on the author[18]. Such index, higher than those found in the present study, may be explained by the fact that malaria stands out as a specific matter that is quite emphasized in the public health field.

Another relevant aspect was that among the 181 assessed websites, only 32% revealed the existence of sponsors not necessarily related to the healthcare area. A percentage of 69.6% of webpages presented an internal content search tool, thus facilitating access to other available information related to the healthcare area, and 58.6% of the pages also made available contact telephone numbers and addresses of the author/institution responsible for the text, which does not guarantee the authenticity of data and responses.

As for the advertisement, dissemination and commercialization of products and services, 22.1% of the websites displayed references concerning healthcare products/services specifically related to the donation and transplantation of organs, with a highlight to private hospitals and healthcare insurance plans. Moreover, 27.6% of pages corresponded to websites that were used as a location to commercialize products and/or services. This disturbing aspect should be taken into account, as it may generate conflicts of interest between the person/institution responsible for the website and the product/service.

Within such context, HON[6] established eight principles, including the clarity of information regarding the authorship of the website, ways to contact the author for further information, and the transparency of the sponsorship. This last aspect was highlighted by the identification of commercial and non-commercial organizations that had provided the website with financial/material resources or services. It also recommends that commercial advertisements be presented in such a way that they differ from the content produced by the institution that administers the webpage.

As for the institution responsible for the website, it was mentioned in 78.5% of cases, yet in only 2.2% of them it was mentioned that there was no conflict of interest; in other words, 97.8% of the webpages did not display any mention in this regard. It is known that the healthcare area presents reports of conflicts of interest regarding a wide array of produced information. Such conflicts imply ethical problems related to sponsors, pharmaceutical industries, educational institutions, hospitals, or researchers[19]. For this reason, if any website information wants to have credibility, the page necessarily has to mention conflicts of interest.

Credibility of information is also related to the references employed by the author and/or institution in the elaboration of the text inserted into the website. In the present study, 42% of the webpages quoted the bibliography or the source from where the information would have been located, but only 14.9% offered links to these pages. Additionally, 25.4% presented different degrees of clinical evidence to the information and only 2.2% informed that the text had been produced by means of editorial or peer review originated in scientific articles published in databases' indexed magazines.

Although the assessed websites were largely directed to lay populations, it is crucial that the information generated within the healthcare context be grounded on the scientific knowledge produced in the area[14]. For this reason, the degree of clinical evidence should be displayed, regardless the necessarily popular, accessible aspect of its language. After the advent of the Internet, information gets to the population in quite a fast, dynamic way, thus contributing to the socialization and the use of pedagogical resources as mediators of the search and exchange of knowledge[20].

In face of the above-mentioned research, the Internet stands out as a healthcare-based information search tool; as such, its broadness encompasses a vast scope of information that can be either trustworthy or misleading. In this sense, the production of tools that guarantee the accuracy of the information available in the virtual world stands out as an extremely important step.

CONCLUSION

The Internet is a source of very relevant information in the global context, including the healthcare area. Nonetheless, new forms of managing the quality and the accuracy of the information to be accessed by users should be created.

In order to verify how the information regarding the donation and transplantation of organs have been currently made available in Brazil, once this is quite an important issue permeated by several and pertaining discussions, this research decided to employ an instrument that could identify the technical quality aspects of websites, aiming at assessing the conditions under which the information concerning this subject has been presented.

In conclusion, although such instrument did not aim to qualitatively assess contents, the majority of the evaluated websites omitted relevant data that could offer increased credibility, such as authorship, source, references, and publication date. Additionally, taking into account that the Internet has been increasingly presented as a locus for the dissemination and propagation of healthcare-based knowledge in such an unlimited, all-embracing way, the results of this study should draw our attention, as not all the webpages searched by the population display trustworthy data.

Therefore, efforts should be made toward maintaining the quality of the information, so that users who look for healthcare orientation may be provided with an accurate support.

Within this context, future research on specific healthcare areas, as well as studies that can assess the accuracy of the information available on the Internet, should be encouraged, so that the population at large can safely access them.

INFODEMIOLOGIA: ANÁLISE DAS INFORMAÇÕES SOBRE DOAÇÃO E TRANSPLANTE DE ÓRGÃOS

RESUMO

Este estudo infodemiológico descritivo transversal teve como objetivo identificar páginas na Internet que continham informações sobre doação e transplante de órgãos e analisá-las de acordo com Critérios Técnicos de Qualidade. A busca foi realizada no sítio de busca Google®. No modo “pesquisa avançada”, foi selecionada a opção “páginas em português” e país “Brasil”. Utilizou-se como palavra-chave “transplante e doação de órgãos”. Foram encontradas 130.000 páginas. As 200 primeiras *Uniform Resource Locators* foram selecionadas. Destas, 19 foram excluídas. As 181 restantes foram analisadas individualmente quanto à presença de Critérios Técnicos de Qualidade. Os resultados revelaram que a maioria dos sítios amostrados omitiu dados importantes para maior confiabilidade, como autoria, fonte, referências e data de publicação. Considerando que a internet se apresenta como meio de divulgação e difusão do conhecimento na área da saúde, este resultado é indicativo de atenção. A internet constitui-se fundamental ferramenta para busca de informações em saúde. Todavia, é preciso cautela, já que nem todos os assuntos veiculados a ela são de fontes seguras. Esforços devem ser feitos a fim de garantir a veracidade das informações sobre saúde obtidas no meio virtual.

Palavras-chave: Transplante de órgãos. Obtenção de Tecidos e Órgãos. Internet. Informação de saúde ao consumidor.

INFODEMIOLOGIA: ANÁLISIS DE LA INFORMACIÓN SOBRE LA DONACIÓN Y TRASPLANTES DE ÓRGANOS

RESUMEN

El objetivo de este estudio infodemiológico descriptivo transversal fue identificar las páginas en Internet que contenían informaciones al respecto de donación y trasplante de órganos y analizarlas de acuerdo con los Criterios Técnicos de Calidad. Se realizó una búsqueda en el sitio de búsqueda Google®. En el modo "búsqueda avanzada", se seleccionó la opción "páginas en portugués" y el país "Brasil". Se utilizaron como palabras clave "trasplante y donación de órganos". Fueron encontradas 130.000 páginas. Las 200 primeras *Uniform Resource Locators* fueron seleccionadas, de las cuales 19 fueron excluidas. Las 181 restantes fueron analizadas individualmente en cuanto a la presencia de Criterios Técnicos de Calidad. Los resultados revelaron que la mayoría de los sitios analizados omitió datos importantes para una mayor confiabilidad, como autoría, fuente, referencias y fecha de publicación. Considerando que Internet se presenta como medio de divulgación y difusión del conocimiento en el área de la salud, este resultado es indicativo de atención. Internet se constituye en una herramienta fundamental para la búsqueda de informaciones en salud, sin embargo, es necesario tener precaución, pues ni todos los temas transmitidos por ella son de fuentes seguras. Deben ser hechos esfuerzos para garantizar la veracidad de las informaciones sobre salud obtenidas en el medio virtual.

Palabras clave: Trasplante de órganos. Obtención de Tejidos y Órganos. Internet. Información de salud al consumidor.

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