

Quality of Health Information on Acute Myocardial Infarction and Stroke in the World Wide Web



ARTIGO ORIGINAL

Qualidade da Informação em Saúde sobre Enfarte Agudo do Miocárdio e Acidente Vascular Cerebral na Internet

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ABSTRACT

Introduction: The quality of health information in the Internet may be low. This is a concerning issue in cardiovascular diseases which warrant patient self-management. We aimed to assess the quality of Portuguese websites as a source of health information on acute myocardial infarction and stroke.

Material and Methods: We used the search terms 'enfarte miocardio' and 'acidente vascular cerebral' (Portuguese terms for myocardial infarction and stroke) on Google[®], on April 5th and 7th 2011, respectively, using Internet Explorer[®]. The first 200 URL retrieved in each search were independently visited and Portuguese websites in Portuguese language were selected. We analysed and classified 121 websites for structural characteristics, information coverage and accuracy of the web pages with items defined a priori, trustworthiness in general according to the Health on the Net Foundation and regarding treatments using the DISCERN instrument (48 websites).

Results: Websites were most frequently commercial (49.5%), not exclusively dedicated to acute myocardial infarction/ stroke (94.2%), and with information on medical facts (59.5%), using images, video or animation (60.3%). Websites' trustworthiness was low. None of the websites displayed the Health on the Net Foundation seal. Acute myocardial infarction/ stroke websites differed in information coverage but the accuracy of the information was acceptable, although often incomplete.

Conclusion: The quality of information on acute myocardial infarction/ stroke in Portuguese websites was acceptable. Trustworthiness was low, impairing users' capability of identifying potentially more reliable content.

Keywords: Myocardial Infarction; Stroke; Internet; Health Education.

RESUMO

Introdução: A informação sobre saúde disponível na Internet é de qualidade variável e frequentemente baixa. Esta questão é fundamental em doenças como as cardiovasculares em que a auto-gestão desempenha um papel importante. O objetivo deste estudo foi avaliar a qualidade dos *sites* portugueses como fonte de informação sobre enfarte agudo do miocárdio e acidente vascular cerebral.

Material e Métodos: Utilizamos as expressões de pesquisa 'enfarte miocardio' e 'acidente vascular cerebral' no motor de busca Google[®] nos dias 5 e 7 de Abril de 2011, respetivamente, usando o Internet Explorer[®]. Os primeiros 200 URL que resultaram da pesquisa foram visitados de forma independente e foram selecionados *sites* de Portugal em língua portuguesa. Classificámos 121 *sites* de acordo com características estruturais, cobertura e validade da informação de acordo com itens previamente definidos, medidas de confiabilidade em geral de acordo com a Health on the Net Foundation e em relação aos tratamentos, utilizando o instrumento DISCERN (48 sites).

Resultados: Os *sites* eram maioritariamente comerciais (49,5%), com parte do *site* dedicado a enfarte agudo do miocárdio/ acidente vascular cerebral (94,2%), com informações exclusivamente sobre factos médicos (59,5%) e apresentavam imagens, vídeos e animações para além do texto (60,3%). A confiabilidade dos *sites* foi baixa. Nenhum dos *sites* exibiu o selo da Health on the Net Foundation. Os *sites* de enfarte agudo do miocárdio/ acidente vascular cerebral diferiram na cobertura da informação. A validade da informação foi aceitável embora frequentemente incompleta.

Conclusão: A qualidade da informação sobre enfarte agudo do miocárdio/ acidente vascular cerebral nos *sites* portugueses foi aceitável. A confiabilidade foi baixa o que pode comprometer a capacidade dos utilizadores em identificar conteúdos potencialmente mais credíveis.

Palavras-chave: Enfarte do Miocárdio; Acidente Vascular Cerebral; Internet, Educação para a Saúde.

INTRODUCTION

Health promotion, namely through health education, aims to enable and empower individuals to have control over their health determinants and consequently lead to an improvement in health status.^{1,2}

The Internet is a particularly powerful channel to disseminate health information in a very efficient way, reaching a large number of people in a short period of time with low costs. In developed countries, a large proportion of people suffering from chronic diseases seek health information in the web.³

The quality of health information on the internet is variable and often low.⁴ This is a particularly concerning issue in cardiovascular diseases, which require patient self-management in chronic phases and the ability to reach appropriate medical care within a narrow therapeutic time window in acute events. Acute myocardial infarction (AMI) and stroke are important acute manifestations of cardiovascular diseases, responsible for a high proportion of death and disability. Little is known about AMI and stroke information presented on the web. One of the few studies

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assessing the quality of stroke education materials available on the web found high readability scores but poor reliability.⁵

Although Portuguese literacy levels have increased tremendously in the last few decades, they are still lower than the European average, and it is estimated that 5% of adults and youth are still unable to read or write.⁶ Literacy is an important determinant of access to healthcare and health information. Individuals with lower levels of education are more vulnerable to chronic disease and complications, and have limited access and ability to interpret and evaluate the quality of health information, including what is available online.⁷ A growing number of families in Portugal (54%) have private access to the internet⁸ and a third of the adults with internet access use it to find health-related information.⁹ The users perceive the Internet as a more important source of health information than healthcare professionals,¹⁰ but studies on the quality of that information in Portuguese websites are lacking.

We aimed to assess the quality of Portuguese websites as a source of health information on AMI and stroke for consumers, namely by the characterization of their structure, and assessment of the trustworthiness, coverage and accuracy of the information on AMI and stroke.

MATERIAL AND METHODS

Search and selection

The search terms 'enfarte miocardio' and 'acidente vascular cerebral' were used on Google® search engine (www.google.pt) on April 5th and April 7th 2011, respectively, using the Internet Explorer® browser. The first 200 URLs (Uniform Resource Locator)¹¹ retrieved in each search were independently visited and Portuguese websites in Portuguese language were selected. Exclusion criteria were applied regarding the correct functioning, purpose and format of the websites (Fig. 1). Websites were considered to have data on AMI or stroke if at least one page of the website provided information on at least one topic from a list defined *a priori* by two researchers. The search was not limited in date, file format or domain.

We visited only the websites of the first 200 hits identified in the above described searches; we did not assess external pages linked from these websites. To ensure that all webpages were visited we used well-defined and known navigation criteria,¹²⁻¹⁴ based on a hierarchical strategy (Fig. 2). In the absence of these functionalities, we browsed all the pages of the website looking for each specific information based on an up-to-3-click search.^{13,14}

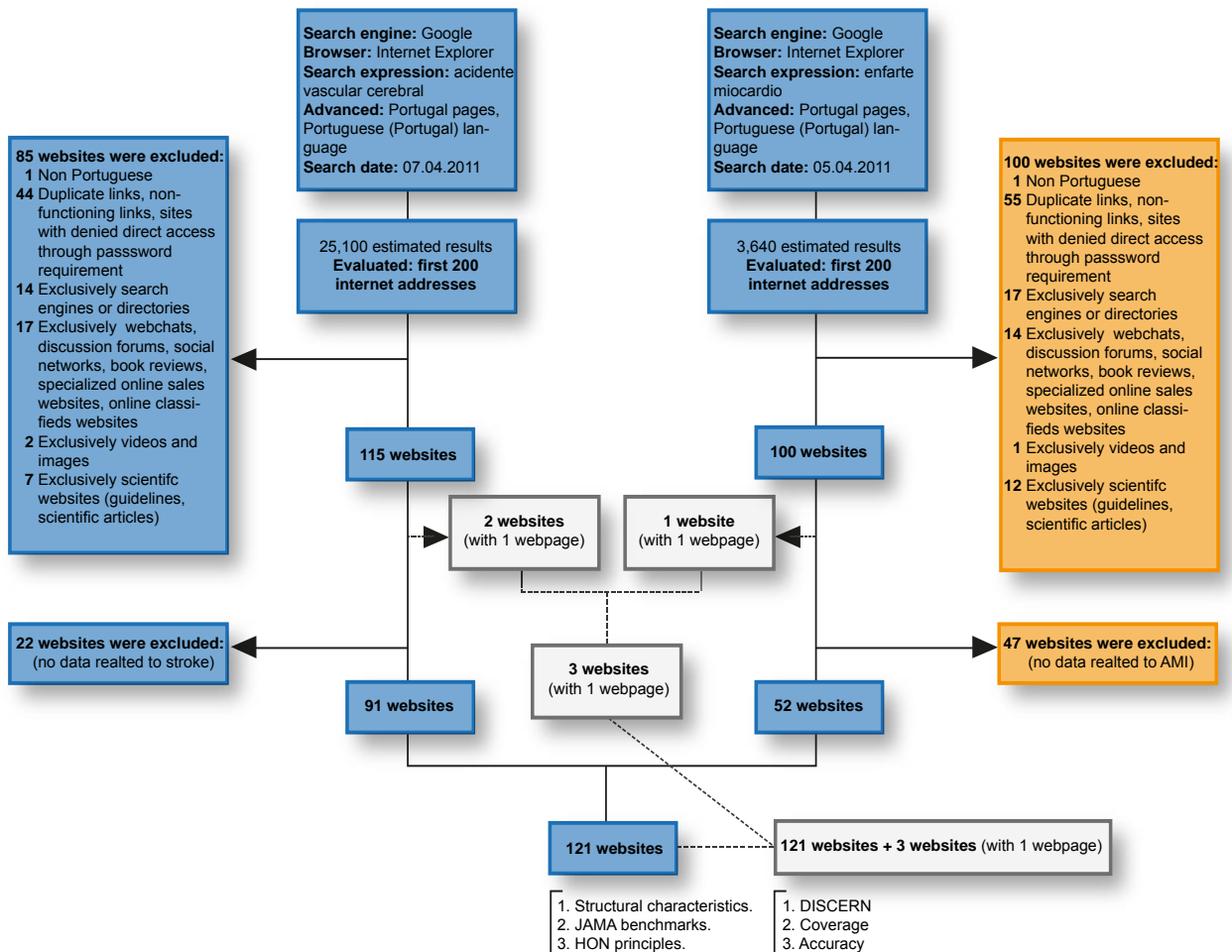


Figure 1 - Data selection flow chart, including the number of websites excluded and the reasons for their exclusion

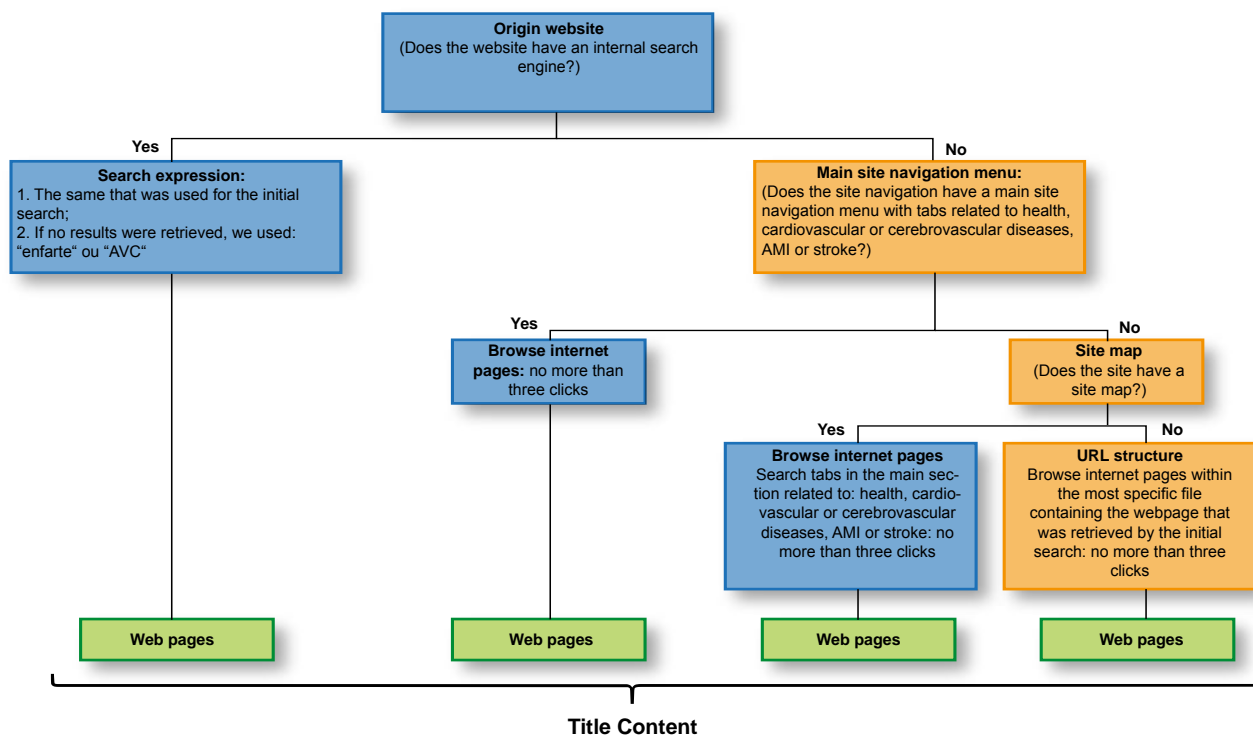


Figure 2 – Navigation diagram. AMI – acute myocardial infarction; URL - Uniform Resource Locator

After excluding non-eligible websites, we selected 93 websites on stroke and 53 websites on AMI (Appendix 1). Twenty-two of the websites were common to both Google searches, and were analysed only once for assessment of overall characteristics. In the particular case of DISCERN, there were 25 stroke websites and 31 AMI websites with information on treatments (8 were common to both diseases and counted only once in the overall analysis).

Three of the websites (2 on stroke and 1 on AMI) had only one page and were included exclusively in the analysis of coverage and accuracy since they did not have sufficient data to assess structural characteristics and trustworthiness (Fig. 1).

Data collection and variable definition

We analysed and classified websites according to affiliation, specificity, content type, content presentation and number of webpages with links to each site assessed, provided by Google® search engine (link tool). Affiliation was later classified as commercial or not commercial. The number of linking pages was categorized as 0, 1-20 and > 20 linking pages, based on the sample distribution.

In order to assess the trustworthiness of websites information we used the Health on the Net (HON) code of conduct, and presence or absence of the HON seal. The HON Foundation was created in 1995 and is a non-profit, non-governmental organization¹⁵ which defined a code of conduct for online health information providers, based on 8 principles (authority, complementarity, privacy, attribution, justifiability, transparency, financial disclosure and advertising policy) with the well-defined objective

of protecting citizens from ambiguous, confounding or unreliable information. Only websites that meet the eight principles are approved for the HON seal.¹⁶ In case of absence of the HON seal, we assessed if the website complied with the 8 HON principles, using the HONcode Site Evaluation Form.¹⁷ This form consists of 15 questions, related differently to each of the eight principles, that allow us to identify if the website respects elementary ethical and quality standards, according to HON. Each principle was assessed dichotomously (met or not).

To assess the trustworthiness of the information on treatment choices for health problems we used the DISCERN instrument,¹⁸ a valid and reliable 16-point questionnaire with the purpose of helping patients and health professionals judge the quality of written information about treatment choices.¹⁹⁻²¹ This tool was only used if websites had information on treatments ($n = 48$ websites). The DISCERN questions assess the reliability of the publication and focus on specific details of the information about treatment choices (Appendix 2). According to the recommendations, each question is scored in a scale from 1 to 5 and the overall score is a subjective final rating, also ranging from 1 to 5, done by the user based on previous assessment of individual questions. Higher scores represent higher trustworthiness.

Coverage of the information on AMI and stroke was assessed as the proportion of areas of knowledge defined *a priori* available in a website. Accuracy was operationalized as the extent to which the information provided was concordant with the best evidence or with generally accepted medical practice, expressed in one or more

items per knowledge area. Concordance was measured as the proportion of incorrect, incomplete or unspecific and correct items assessed in each defined area. Two health professionals (AB and AA) defined a list of areas considered for assessment of coverage (Appendix 3) and accuracy (Appendix 4), according to established criteria: (a) information should be recognized by the authors as providing a general understanding about AMI and stroke; (b) information should be objective, based on well documented scientific evidence or reported in generally accepted medical literature. For this purpose we used UpToDate[®],²² a clinical decision support system to provide clinicians with accurate information, based on current evidence, in a quick and easy way. If specific information items were not available in UpToDate[®] we used other medical sources ranging from specific guidelines (preferred primarily because they present clear and updated medical knowledge), namely the European Society of Cardiology[®],²³ American College of Cardiology²⁴ and American Heart Association^{®25} guidelines, to recognized health information sources and organizations, specifically general internal medicine²⁶ and cardiology²⁷ textbooks, and the World Health Organization.²⁸

We assessed structural characteristics, trustworthiness, and coverage and accuracy of the 121 websites identified. DISCERN and assessment of coverage and accuracy were also applied to the 3 websites with only one webpage (Fig. 1).

In a subsample of 8 websites, data were independently collected by two researchers (AB and DP), both of them health professionals. Disagreements were solved by consensus with involvement of a third researcher (AA) if necessary. In general, there were few disagreements (83 of 218 items) and this approach was used to finely tune the criteria of classification, which were then applied for assessment of the whole sample by one of the researchers (AB).

Statistical analysis

Data are described as counts and proportions for categorical variables and median and range for the score in each DISCERN question. We used Pearson's chi-square test to compare proportions according to classes of categorical variables. A probability < 0.05 was accepted as statistically significant.

In the analysis of website's accuracy, formal characteristics and trustworthiness measures, data was analysed for all websites together since there were no differences between stroke and AMI websites.

RESULTS

The majority of the websites were commercially oriented and not exclusively related to stroke or AMI. More than half had information about medical facts exclusively and presented images, video or animation beyond text. Almost 50% had more than 20 linking pages. Almost three quarters of the stroke (79.1%; 82.4%) and AMI (73.1%; 82.7%) websites met the justifiability and transparency principles,

respectively, defined by HON. However, only 4 stroke websites and 2 AMI websites met the attribution principle. None of the stroke or AMI websites displayed the HON seal (Table 1).

The trustworthiness of the information on treatment choices was low, with more than half of the websites scoring 1 in the DISCERN overall question (Table 2).

Our results showed significant differences in coverage between stroke and AMI websites. AMI websites presented more often information on definition (54.7% vs 14.0%, $p < 0.001$), symptoms (73.6% vs 54.8%, $p = 0.030$), diagnosis (37.7% vs 9.7%, $p < 0.001$) and prevention (69.8% vs 57.0%, $p = 0.125$). On the other hand, stroke websites most frequently presented information on pathophysiology, warning signs and prognostic complications, although these differences were small and non-significant (Fig. 3).

Regarding specific information within these domains, the need to call the emergency telephone number when experiencing warning signs and death mentioned as a prognostic complication were more commonly found in stroke websites (43.0% vs 24.5%, $p = 0.026$; and 63.4% vs 56.6%, $p = 0.415$ respectively). Overall, less than 20% of the websites called attention upon recurrence, with more AMI websites mentioning this complication (8.6% vs 13.2%, $p = 0.378$). The importance of undergoing regular physical activity was mentioned more often in AMI than stroke websites (54.7% vs 36.6%, $p = 0.003$) (Fig. 3).

Almost all the information in areas of knowledge defined a priori was correct or incomplete, with few inaccuracies. Stroke websites had less than 20% of inaccurate information on treatment, in comparison with none of the AMI websites (9.5% vs 0% $p < 0.001$). In contrast, incomplete or unspecific information on disease definition was found significantly more often in stroke than AMI websites (69.2% vs 20.7% $p = 0.002$). Information in all other areas of knowledge was correct in over 60% of items (Fig. 4).

DISCUSSION

Portuguese websites with information on AMI and stroke had low trustworthiness according to the HON principles and the DISCERN instrument. They varied largely in coverage of specific knowledge areas, with AMI websites presenting more often information on definition, symptoms, diagnosis and prevention, and stroke websites on pathophysiology, warning signs and prognostic complications. There were few inaccuracies.

The high number of commercially oriented websites, the number of websites presenting medical facts, and with part of the site dedicated to AMI/stroke are consistent with previous results.²⁹⁻³¹ However, these findings may vary according to the study aims, search strategies, the number and unit of observations and other methodological criteria.^{32,33}

None of the websites displayed the HON seal, which is free of charge. Acquiring the seal implies that webmasters are aware of its existence and are concerned with the importance of providing trustworthy information. None of the

Table 1 - Structural characteristics and trustworthiness of assessed websites

	Stroke, <i>n</i> (%) <i>n</i> = 91	AMI, <i>n</i> (%) <i>n</i> = 52	Total, <i>n</i> (%) <i>n</i> = 121
Number of sites			
Affiliation			
Commercial	52 (57.1)	21 (40.4)	60 (49.5)
Health related	13 (25.0)	8 (38.1)	17 (28.3)
Non-commercial	26 (28.6)	23 (44.2)	44 (36.4)
Non-profit organisation	11 (42.3)	11 (47.8)	18 (40.9)
University or research centre	1 (3.8)	0	1 (2.3)
Public hospital or public entities providing care	1 (3.8)	1 (4.3)	2 (4.5)
Private hospital or private entities providing care with Government partnership	1 (3.8)	1 (4.3)	2 (4.5)
Government entity	4 (15.4)	5 (21.7)	8 (18.2)
Private/Personal	8 (30.8)	5 (21.7)	13 (29.5)
Not perceptible	13 (14.3)	8 (15.4)	17 (14.1)
Specificity			
Exclusively related to AMI/stroke	5 (5.5)	2 (3.8)	7 (5.8)
Part of the site dedicated to AMI/stroke	86 (94.5)	50 (96.2)	114 (94.2)
Content type			
Medical facts	53 (58.2)	34 (65.4)	72 (59.5)
Medical facts and human interest stories or experiences	38 (41.8)	18 (34.6)	49 (40.5)
Content presentation			
Text only	1 (1.1)	0	1 (0.8)
Images	22 (24.2)	16 (30.8)	33 (27.3)
Images and video/animation	56 (61.5)	32 (61.5)	73 (60.3)
Images and video/animation and audio	12 (13.2)	4 (7.7)	14 (11.6)
Number of linking pages			
0	10 (11.0)	12 (23.1)	20 (16.5)
1-20	36 (39.6)	17 (32.7)	45 (37.2)
> 20	45 (49.4)	23 (44.2)	56 (46.3)
Respect for HON principles			
1.Authority	6 (6.6)	6 (11.5)	11 (9.1)
2.Complementarity	6 (6.6)	6 (11.5)	8 (6.6)
3.Privacy	17 (18.7)	8 (15.4)	21 (17.4)
4.Attribution	4 (4.4)	2 (3.8)	6 (5.0)
5.Justifiability	72 (79.1)	38 (73.1)	96 (79.3)
6.Transparency	75 (82.4)	43 (82.7)	99 (81.8)
7.Financial disclosure	23 (25.3)	18 (34.6)	41 (33.9)
8.Advertising policy	15 (16.5)	11 (21.2)	26 (21.5)

AMI – acute myocardial infarction; HON – Health on the Net

Table 2 - Trustworthiness of the information on treatment choices

	Stroke, n (%)	AMI, n (%)	Total, n (%)
Number of sites	n = 25	n = 31	n = 48
DISCERN: overall score			
1	14 (56.0)	17 (54.8)	26 (54.2)
2	4 (16.0)	8 (25.8)	11 (22.9)
3	5 (20.0)	3 (9.7)	6 (12.5)
4	2 (8.0)	3 (9.7)	5 (10.4)
5	0	0	0

AMI – acute myocardial infarction

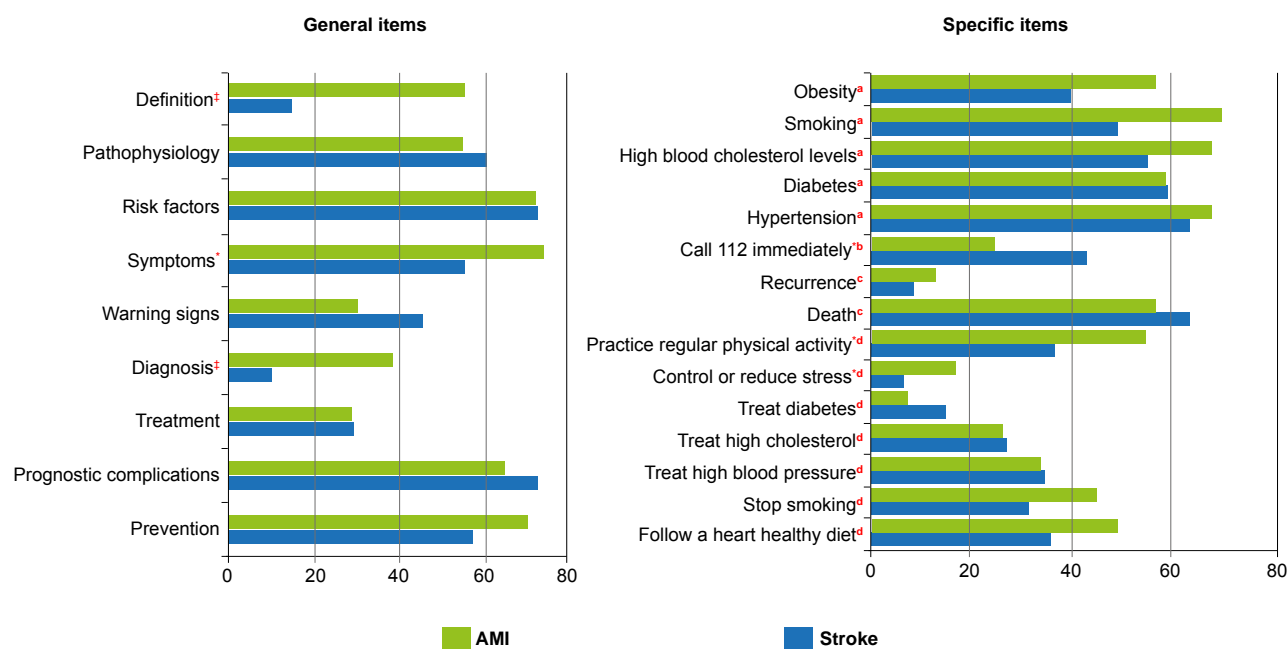


Figure 3 – Websites' coverage of specific areas of knowledge defined a priori. * $p < 0.05$; † $p < 0.001$; ^arisk factors; ^bwarning signs; ^cprognostic complications; ^dprevention strategies. AMI – acute myocardial infarction

websites of our sample received the maximum overall score on DISCERN and these results are consistent with previous studies in other fields³⁰⁻³² suggesting that poor quality of written information on treatment choices is not exclusively a problem with AMI and stroke websites. Some of the questions that scored lower were related to information on treatment risks and support for shared decision making. This is a concerning issue, particularly in cardiovascular diseases which are chronic conditions that largely require patient self-management, intersected by acute events for which effective treatment options have a narrow therapeutic time window and thus can only be offered if patients act adequately in response to warning signs.

Our results showed differences in coverage of the information between AMI and stroke websites on specific knowledge areas assessed. Stroke websites presented

more often information on pathophysiology and used this information in an attempt to define stroke, disregarding the clinical nature of the stroke definition and often misleading towards the consideration of ischemic thrombotic strokes only. Furthermore, stroke websites presented more often information on warning signs, and we found significant differences specifically for the information that people should call the emergency telephone number in presence of warning signs. In fact, the time elapsed from the onset of symptoms is a predictor of worse outcomes, both for AMI and stroke, and AMI websites should not neglect this information.^{34,35} Stroke websites more often pointed death as a prognostic complication. Both stroke and AMI websites seldom reported recurrence as an outcome. This can be particularly alarming since, if individuals are not aware of this complication, they may not be able to identify a recurrent

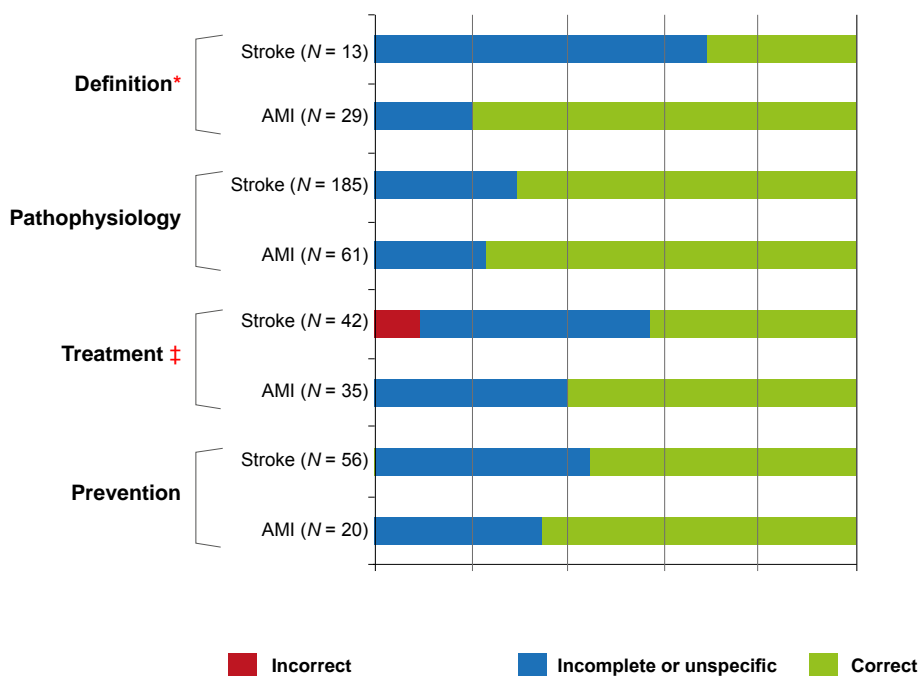


Figure 4 – Assessment of sites' accuracy as the proportion of items with incorrect, incomplete or unspecific, and correct information. * $p < 0.05$. AMI – acute myocardial infarction; ‡ $p < 0.001$

episode and, most importantly, they will not understand the purpose of secondary prevention strategies.

The fact that AMI websites presented information on prevention strategies more often than stroke websites may be explained by stroke being perceived as having a worse outcome, with more associated disability, leading to lower investment in secondary prevention. Websites providing information on stroke should inform individuals that stroke patients, as in AMI, are eligible to primary, secondary and tertiary prevention.

We cannot assume that the areas of knowledge defined a priori are enough to define if a website is complete or not. Furthermore, we recognize that websites could have omitted some particular aspects on purpose, giving priority to others that are more important to transmit, in order to avoid excessive information that may confuse people. On the other hand, complementarity of the information is a reality in the internet world, and the lack of information in one particular topic could be complemented by other websites.^{4,36} Therefore, instead of trying to define specific a priori coverage areas, researchers could assess to which extent websites cover information they have proposed to.

Comparisons with other studies are difficult for several reasons. First of all, the prevalence of inaccurate information is different according to different study fields.⁴ In fact, methodological problems can influence the evaluation of information accuracy, with studies using personal and experts' opinion as gold standard reporting more often less inaccuracies than those using scientific evidence.⁴ Likewise, differences in the sampling process, selection strategies and in the unit of observation (websites or webpages) further challenge comparisons.

Although statistics from December 2011 show that Internet Explorer® has been losing popularity to Chrome, it continues to be the most popular browser used.³⁷ We used only one search tool and only one search strategy. This could represent a limitation since different search engines and queries provide different results as was shown in recent studies.^{31,32} Our AMI query was based on the most frequent expression used by Portuguese Google consumers (data provided by Google "Estatísticas de Pesquisa"³⁸) until 5th April 2011. On the contrary, our stroke query was not based on the same criterion, as the most frequent query used was an acronym (AVC), providing results that were less specific, not related to stroke. To assess the impact of this limitation, we compared our search results to the ones obtained with the query 'AVC' and the results did not vary meaningfully.

Moreover, even using the same search engine, results could be different when using different expressions or searching at different times.³⁸ The search was conducted by the same researcher, using the same computer and at the same location. The internet is a dynamic source and ranking of the results retrieved are estimated according to different elements including the IP address and machine used, results of previous searches and the number of linking pages. Commercial interests and other strategies of ranking websites could also bias results.³⁹ The results presented could be a good indicator of popularity but not necessarily of high quality.³³ In order to try to overcome these obstacles we analysed 200 results and conducted the search on a single day for each query. This methodology has been described in previous studies assessing quality of the health information in the websites, mainly in the cancer field.^{30,32,33}

The constant update of the internet information is important since its quality should be constantly assessed.⁴⁰ In order to minimize this influence, we defined a strict period of time for data collection (1 week) and we assumed that during this period presentation and content of the assessed websites' would not change meaningfully. We selected only Portuguese websites in Portuguese language. We are aware that Portuguese consumers have access to websites in other languages as well as in Portuguese from countries other than Portugal, mainly Brazil. However there are specific vocabulary, syntax and grammar features of Brazilian Portuguese that could influence the performance of the methods used for measurement. The inclusion of materials from these sources, in our view, would warrant a stratified approach, thus making that analysis an independent second study.

The fact that data selection and collection were done by a single researcher who is also a health professional is a limitation of this study. The assessment of the quality of the information is a subjective issue, even when adopting previously used structured instruments, because some of them do not include specific guidelines for application. In an attempt to minimize this problem, we randomly selected a subsample of six websites, which were reviewed, solely for data collection, by another researcher. Moreover, both researchers were health professionals. Content could be perceived differently between health professionals and consumers.⁵ Interviews with e-health consumers would be an interesting complementary approach to test the suitability of the websites information.

The number of items included in each knowledge area to assess accuracy varied between areas, thus our observation unit is the number of items and not the number of websites. Also, any attempt to weigh the items proportionally to their importance would be arbitrary. However this does not change the fact that we are giving the same weight to different things.

Other studies have been published on how Portuguese

people use the internet to obtain health information,^{10,41} but to the best of our knowledge, this is the first study assessing the quality of health information on the internet on AMI and stroke, both for presentation and content of the Portuguese websites' information. Evaluation of the internet quality content and presentation on health information remains a challenge. Strategies focused on educating people in order to improve their ability to identify trustworthy websites, which provide also accurate health information, are more effective than trying to assess all the websites providing health information.⁴

Further effort is needed to continuously assess and improve the quality of websites' health information on stroke and AMI. Educational strategies should be pursued and health professionals involved in guiding consumers to trustworthy websites and in improving users' ability to identify unreliable or incorrect information.

CONCLUSION

The quality of information on AMI/stroke in Portuguese websites was acceptable and, in general, no incorrect information was found. In contrast, trustworthiness was low, impairing users' capability of identifying potentially more reliable content. Education strategies should be implemented to improve the judgment of the quality of health information online by internet users, to enable them to make informed decisions about their health.

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CONFLICTS OF INTEREST

None stated.

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