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Penile cancer information on the internet: a needle in a haystack

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Introduction

Primary cancer of the penis is an uncommon disease, with an overall incidence of around 1/100,000 males in industrialised countries(1). In contrast, in the developing world, such as South America, South East Asia and parts of Africa, the incidence is significantly higher and can account for 1-2% of malignant disease in men. The highest incidence rate of penile cancer in the world is reported in Brazil.(2)

Penile cancer is often associated with a delayed diagnosis, with the most common reason for patients' delayed presentation identified as the feeling of embarrassment over symptoms localised in a sexual body area. Psychological factors such as denial may also be involved, as well as insufficient awareness or knowledge about the disease(3). Subsequently, patients often present with locally advanced tumours and a high risk of invasive disease. Given the potentially significant embarrassment associated with the diagnosis of penile cancer, men may utilise the information available on the internet prior to seeking medical attention.(4) Thus, high quality, readily accessible and accurate information on penile cancer is an important part of encouraging men to engage with medical services.

Over 80% of patients and health care professionals use the internet to seek medical information, seeing it as a reliable, accessible and trustworthy source.(5) After patients are diagnosed with serious medical conditions, it is accepted that they will explore the internet for answers(4, 6). Although the internet is a powerful tool, much of the information fails to meet a generally accepted standard for medical information

– namely the World Health Organisation Health on the Net (HON) standards(7), which are a reasonable measure of the commitment of medical websites to provide quality information regarding cancer, among other diseases, and its treatment.

We aim to assess the quality of information about penile cancer on the internet and to compare the quality of internet information from developed countries such as Australia, France, Germany and Spain with Brazil, a country with significantly higher rates of penile cancer.

Methods

We searched English, French, Spanish, German and Portuguese internet websites in February 2018 using previously published methods(8). Briefly, using the Google search engine(9) in February 2018 we performed internet searches and assessed 600 websites using 'penile cancer' in English, and equivalent terms in French ('cancer du pénis), Spanish ('cáncer de pene'), German (peniskrebs'), and Portuguese ('câncer peniano'). The first 150 websites yielded by each search were identified and sequentially screened for quality as defined by the Health on the Net (HON) Foundation using the HONcode toolbar function. The HON toolbar connects in real-time to the HON server to verify the certification status of health/medical websites. Websites that have HON certification have been assessed by an independent regulator to contain reliable and credible information relating to health.(7) The HON function has been validated in several studies, and is deemed to be a high calibre tool(10).

On the basis of the observation that patients rarely access more than the first page of search results, the first 150 websites yielded by each search were screened.(5) An analysis of the first 150 websites in English, French, Spanish, German and Portuguese was undertaken to determine the Web site sponsors and each was characterised according to a previous study of quality of Web sites on the internet(8, 11). The sites were deemed to be sponsored by (1) lawyers, (2) non-profit organisations, (3) government organisations and/or educational institutions, (4) commercial, (5) urologist and their professional organisations, (6) other health

professionals or (7) other. Sponsorship was determined independently by two examiners.

A secondary analysis of the first 150 websites for all 4 languages, the websites were divided into three groups of first 50, middle 50 and last 50 websites. The number of accredited sites in each language was then analysed and compared using a Chi-squared test or Fisher exact test when the cell counts were <5. All statistical tests were performed using SAS University Edition (SAS Institute, Inc, Carry, NC) and statistical significance was defined as $p<0.05$. This was to determine where accredited websites were appearing preferentially.

Results

Based on the assumption that the first 50 websites were most likely to be viewed, followed by the second 50 websites and third 50 websites, the 150 websites analysed were divided into 3 groups of 50. Overall, there was a significantly higher percentage of HON accredited sites appearing in the first 50 websites than the middle or last 50 websites (table 1). 20.80% of the first 50 websites were HON accredited and the percentage of HON accredited websites decreased in the middle and last 50 websites ($p=<0.001$). When the websites were separated into language groups this trend was again observed (figure 1). This trend was statistically significant in all languages ($p=<0.05$) with the exception of Spanish where there were more HON accredited websites in the last 50 websites compared to the middle 50 (table 1).

Of the 750 websites analysed, 10.4% were HON accredited. French language websites had the most HON accredited websites, followed by English, Portuguese, Spanish and German (table 1). There were significantly more HON accredited websites in English and French compared with Portuguese ($p=0.009$ and $p= 0.0007$) (table 2).

Overall, 44.7% of all websites were commercially sponsored. 27.1% were sponsored by Government or Educational organisations and 11.6% were sponsored by not-for-profit organisations (figure 2). 0.04% of all websites were sponsored by a health organisation. The proportion of websites sponsored by other groups was 7.2% overall but within each language group there was large variation in the breakdown of

groups. Both English and Portuguese had only 0.67% of websites sponsored by other groups while both Spanish and German had 16%. English language websites were more likely to be sponsored by a Government or Educational organisation, with 45.3% being sponsored by one of these groups while 36% were sponsored by a commercial group.

Discussion

Web based resources are especially important when obtaining information from health professionals is challenging, such as when symptoms are embarrassing or stigmatised(12). This suggests that there is potential for the internet to be particularly important in men with penile cancer, a disease in which a considerable proportion of patients have a delay of more than 6 months prior to seeking medical treatment.(3) Despite increased openness about male health problems such as prostate cancer, there is still a great need for public discussion about penile disease. In a prospective study of men with newly diagnosed penile cancer, most of the men remarked that they had never head of penile carcinoma before being diagnosed with the disease themselves, and the symptoms they experienced were an impediment to seeking help.(3) In addition, the low incidence of penile cancer in developed countries may also contribute to prolonged time before diagnosis as clinicians were less familiar with the disease. Men with penile cancer represent a vulnerable group that may turn to the internet for information. As patients use information on the internet from throughout all stages of the disease, from symptom onset to long-term disease management, online tools can provide patients with a sense of empowerment but they should also specifically contribute to each stage of the healthcare process(13). Internet use can be primarily patient-driven or guided by medical teams. Clinicians involved in the care of these patients should participate in the development of informative and reliable health websites and direct patients to them. The greatest barrier on the internet is not the difficulty of finding healthcare information, but rather the difficulty of finding valid and reliable information(14).

It must also be taken into account that a website can be influenced by commercial interests, with 44.7% of overall websites across all languages found to have a commercial sponsor. Websites may be a conduit for advertising, with health

information increasingly being controlled by marketing and commercial interests, taking advantage of a significant proportion of the population searching for health information [28]. This can induce selective disclosure of evidence and the presence of biased information. In order to assist users to differentiate between websites, a broad range of organisations have developed methods and instruments for quality evaluation and classification. The HONcode is a simple means by which a clinician or patient can objectively correlate a website with high quality information. Compared with other instruments for evaluating website quality, it appears to be a straightforward, valuable tool, and fulfils its goal of identifying reliable health websites [29]. However, HONcode is not the only way to rate quality and several other tools such as the DISCERN instrument [30] and LIDA tool [31] are freely available online, also designed to help users evaluate the quality of health information on the internet.

Using the HON seal as an indicator of information quality, we found that only 10.4% of all sites analysed relating to penile cancer are HON-accredited. HON-accredited websites were overall more likely to appear in the first tertile than in the second or third tertiles. This tertile discrepancy was expected since the Google algorithm generally places the most relevant websites first. The low number of HON-accredited websites relating to penile cancer is concerning, as it suggests that patients will encounter unreliable information about penile cancer. Evidently, this makes website assessment difficult for patients and clinicians alike, potentially leading to distrust of penile cancer resources found on the internet.

Convenience, anonymity and the volume of information that can be found on the internet make it an attractive option for patients with genital malignancies, and may be especially useful in developing countries, where access to healthcare may be limited by socioeconomic factors. We found that Portuguese and Spanish language websites had significantly less HON-accreditation than English language websites despite the unequal distribution of penile cancer between the developed and developing world. This highlights the importance of education and public health measures to address the various aetiological factors which are proposed to play a role in penile cancer. These generally relate to inflammatory processes that occur in the penis and include human papilloma virus infection, phimosis, lichen sclerosis and poor penile hygiene.(15) Limited available web resources in Spanish and Portuguese

contribute to disparities in information access and disease outcomes.(16) A study of both English and Spanish-speaking internet users found that penile cancer was the 5th most commonly searched cancer in Spanish, whereas it was not in the top 10 cancers searched in English.(16) By recognising the differences in both search patterns and web resources available, content of web-based oncology resources can be developed to best target the needs of populations at higher risk of penile cancer.

Patients with cancer believe their needs to obtain information about their disease from their healthcare providers are often unmet.(17)Clinicians directing patients to reliable information has many benefits such as improving patient-doctor relationships, reinforcing consultation discussions, assisting informed decision-making, providing education before and after events, and helping patients seek appropriate consultation for sensitive topics. (18) Online health information can impact on both the decision to seek help and on communication with health professionals. Health websites must ensure they provide useful information to support patients in their decisions and health care interactions.(18)

Limitations

The HONcode is a predictive indictor for high quality websites, which has limitations. As of 2015, HONcode certification is provided as a paid service which may distort the validity of website information with HONcode criteria. Thus, a proportion of websites with objectively high-quality information may not fulfil HONcode criteria. In addition, the HONcode is a measure of quality of the website and not necessarily the medical accuracy of the content in relation to penile cancer, thus may lack relevant information about the disease on the website.

An inherent limitation of this study involves the search terms used. It cannot be guaranteed that patients would use these terms in their own research of penile cancer. However, given that the search terms used in this study are the most formal and objective, informal search terms would likely defer to pages with the formal terms by the Google search algorithm. One solution to this limitation is to encourage clinicians to use the formal medical terms for their patients, thereby empowering patients more accurately research their disease.

Conclusion

Health care workers must appreciate the lack of validation of most penile cancer websites, with discrepancies apparent in both quality and number of websites between languages. Clinicians must be proactive in identifying and directing patients to trustworthy and accurate information. HONcode is an uncomplicated search tool and can serve as the vanguard to detect appropriate and trustworthy websites.(7) The total percentage of HON-accredited websites was low across all languages and search terms. There were significant language differences in HON-accredited websites, with English and French websites having significantly more HON-accredited websites compared with Spanish and Portuguese despite these languages being native to countries with significantly higher rates of penile cancer.(19)

Internet use for symptom appraisal has the potential to influence the timing of health seeking for symptoms, and the communication between patients and health care professionals during consultations.(5) This is essential in penile cancer, a disease with typically delayed presentation, and has the potential to significantly impact on patient morbidity and mortality.

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	Percentage HON accredited				
Language	First 50 sites	Middle 50 sites	Last 50 sites	P value	Overall HON accreditation
English	34	8	6	<0.0001	16
French	42	18	10	<0.0001	23
Spanish	6	0	2	0.0484	2.7
German	10	0	0	0.0036	3.3
Portuguese	12	6	2	0.0123	6.7
All languages	21	6	4	<0.0001	

Table 1. Percentage of HON accredited websites

Other languages compared to Portuguese (first 50 sites)		
	% Accredited (PoHONA)	P value
English	34	0.009
French	42	0.0007
Spanish	6	0.1637
German	10	0.2377
All	**23**	**0.0865**

Table 2. Percentage of HON accredited English, French, Spanish and German websites compared to Portuguese

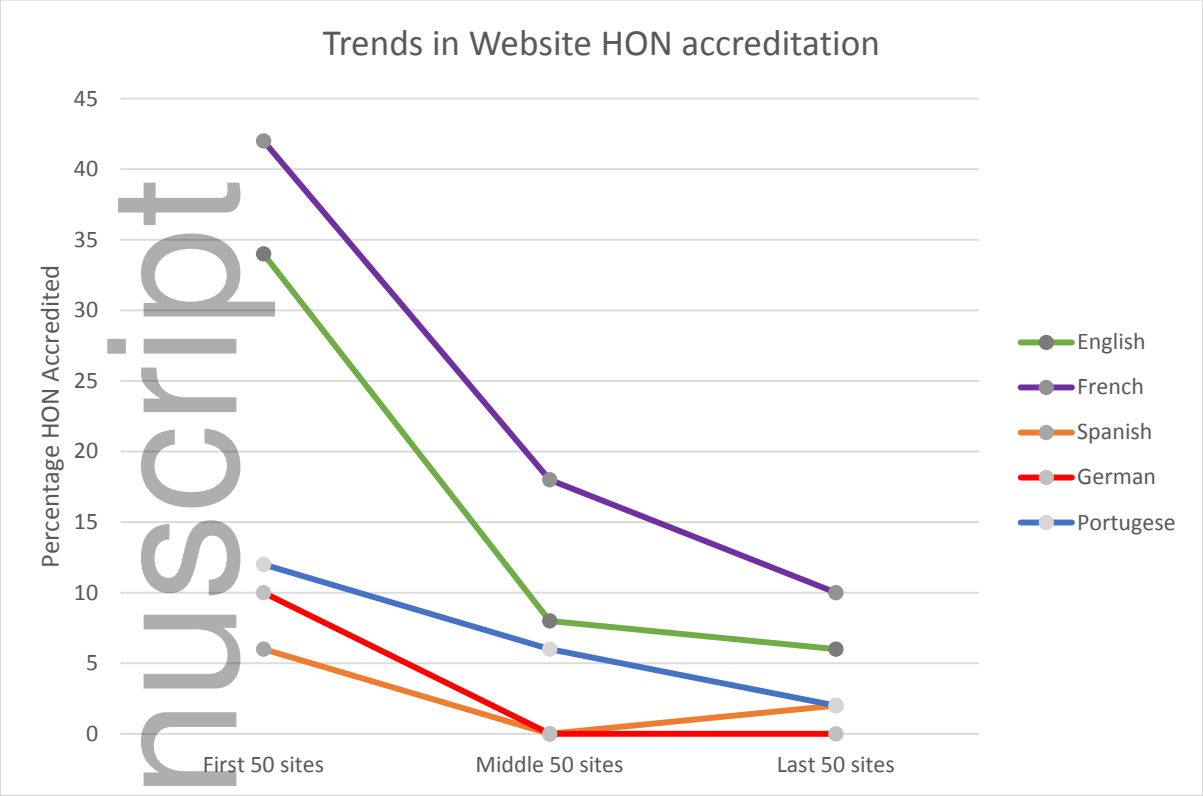

Figure 1. Trends in website HON accreditation versus tertile.

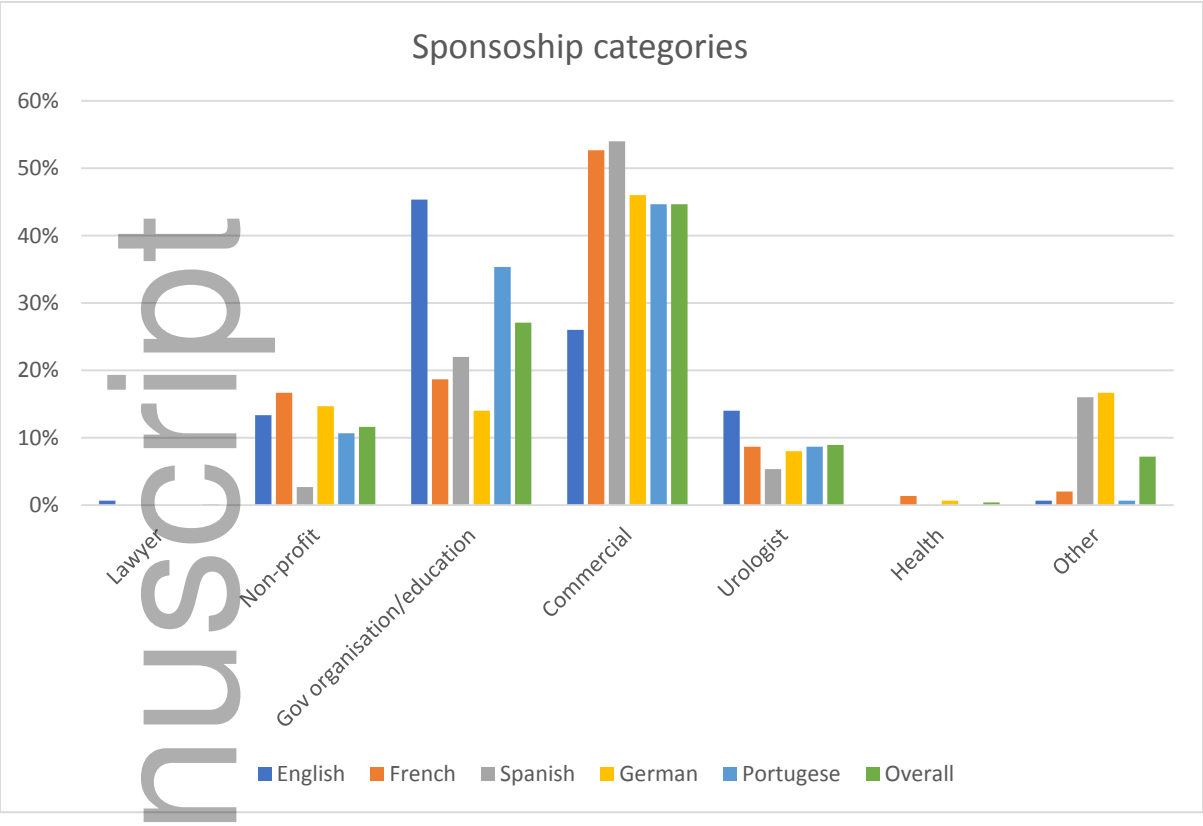

Figure 2. Sponsorship categories of website