

Journey in the oncological global village: the true, the almost true, the not true

Alessandro Di Cerbo¹, Valentina Rottigni¹, Federica Pezzuto², Beniamino Palmieri¹

¹ Dipartimento di Chirurgia, Università di Modena e Reggio Emilia, Modena, Italy; ² Poliambulatorio del Secondo Parere, Modena, Italy

Summary. *Aim:* Internet has become the new gold standard, for most web users, when performing a screening on medical updates and/or therapies. The aim of this review is that of critically analyzing web contents highlighting the limits of a self-managed scientific culture which may induce the acceptance “as true” of wrong information. *Materials and methods:* We searched Pubmed/Medline using the terms “web”, “wrong information” and “tumors”. *Results:* Although provided with some scientific background, most of the oncological websites, blogs and videos (usually almost spread through Youtube) lack an Authority granting high level contents and quality; thus the patient and their relatives are at high risk of fall into the so called oncological “Web-Babel-Syndrome”, which arises consulting a great number of self referral websites without adequate medical knowledge and specific experience. *Conclusions:* A greater sensibilization of web users by the scientific community, to refer to medical data banks with the help of an expert or a pool of accredited professionals, would reduce both frustration and confusion generated by a “wild” approach to the medical web contents.

Key words: Web Babel Syndrome, web, wrong information

«VIAGGIO NEL VILLAGGIO GLOBALE ONCOLOGICO: IL VERO, IL QUASI VERO, IL NON VERO»

Riassunto. *Finalità:* La maggior parte degli utenti del web utilizza le banche dati come riferimento standard nella ricerca (screening) degli aggiornamenti e delle cure in medicina. Scopo della presente review è analizzare in maniera critica i contenuti accessibili evidenziando i limiti di una cultura scientifica autogestita, senza adeguata cultura della materia suscettibile di accreditare informazioni talora prive di fondamento. *Materiali e metodi:* Abbiamo effettuato un’accurata ricerca su Pubmed/Medline utilizzando i termini “web”, “informazioni errate” e “tumori”. *Risultati:* Pur avendo un fondo di scientificità molti siti, blog e video (che hanno come fonte principale Youtube) mancano di un Ente di supervisione accreditato che ne garantisca la qualità e l’accuratezza dei contenuti; tale incontrollata disponibilità di informazioni tende a generare false aspettative e/o convinzioni negli utenti, su determinate patologie, che possono condurre ad un’ossessiva quanto approssimativa e confusa ricerca interattiva che abbiamo denominato “Sindrome di Babele del Web” (Web Babel Syndrome). *Conclusioni:* Una maggiore sensibilizzazione degli utenti, da parte della comunità scientifica, a riferirsi a banche dati mediche con la mediazione di un esperto o di un pool di professionisti scientificamente accreditati, contribuirebbe certamente a ridurre la frustrazione e la confusione generate da un approccio “selvaggio” ai contenuti medici del web.

Parole chiave: Sindrome di Babele del Web, multimediale, informazioni errate

Introduction

Recent Italian epidemiological studies have highlighted that, in 2012, 50,000 new cases of colorectal cancer have been diagnosed both in men and women, 46,000 cases of breast cancer, 38,000 of lung cancer (with one-fourth regarding women) and 36,000 of prostate cancer (1). Among risk factors mainly the familiarity and the age are shown. Due to the large amount of information and the utmost importance of the topic, sometimes controversial, the web is undoubtedly one of the most powerful tools to find information for the common users.

The world wide web, hence, becomes more frequently a gold standard when dealing with health (2), alternative care approaches (3), care possibilities and/or pathology stadiation. Every technological-multimedial mean (pc, tablet, smartphone) becomes a link with the virtual world and, in addition, those who cannot afford these tools are used to exploit public emplacements connection (for instance within libraries) for their researches (4). Therefore old information vehicles (television, newspapers, magazines) have been set aside (5).

Searching criteria

We searched Pubmed/Medline using the terms “web”, “wrong information” and “tumors”. Selected papers from 1950 to 2013 were chosen on the basis of their content (evidence-based quality and reliability).

Results

In 2005, more than 56% of Americans with prostate cancer referred to the web for their treatment (6); in 2007 more than one-third of web users has preferred general browsers rather than medical portals or scientific libraries (7) and in 2008 more than 50 millions of Americans has obtained health information from the web (8). Although some websites have an accurate and scientific language, it happens, not rarely, that they do not provide the right information about the source where they refer to (9), that they are

not supervised by highly qualified persons (10), that do not offer both a pathology and care overview (9) and that, moreover, have a low degree of readability in terms of language used (11).

For instance Youtube allows everyone to watch, evaluate and comment thousands of videos about prostate cancer; 48 hours of footage are uploaded every minute and the website is visited by 3 millions of users every day (12).

In 2010 Steinberg and co-workers examined 228 videos on Youtube about both diagnosis and treatment of prostate cancer and observed that 73% of these lacked information and two-thirds supported the PSA assay (and none against) or the prostate treatment (13). Moreover, many videos about prostatectomy described technical aspects without emphasizing the surgery in such pathology. Further, many videos described the PSA screening as a useful tool in reducing mortality, a fact that is not supported by literature (14).

Clerici *et al.* evaluated the reliability of rhabdomyosarcoma related Youtube videos. 37% of these had a content useful to the understanding of the pathology and only 1,5% resulted complete while 1,5% misleading (12).

Another aspect of web consulting is the e-counseling, that is the possibility of retrieving assistance when making a critical decision (15), and that in most of cases consist with a risk/benefit comparison (16).

It has been demonstrated that such requests for assistance, considerably increased in the last 5 years (17), may improve the self awareness, reducing both decisionary conflicts and decision anxiety (18).

As to the breast cancer (19), many reports are present in literature; interestingly a 2006 study in Texas revealed that 10 out 4600 web posts (0.22%) about this pathology were misleading. 7 of these were rapidly corrected within few hours after been proved to be wrong (20).

In 2008, at the Sheffield University, BC, HON e IQ tools have been approved for breast cancer websites reliability evaluation (21). BC resulted to be the most effective and the most easy to use offering a new alternative for a critical web consulting.

Two of the most popular English websites about prostate cancer (<http://www.prostate-cancer.org.uk>)

and breast cancer (<http://www.breastcancercare.org.uk>) have been extensively investigated for the quality of their contents (22). As to prostate cancer, a strong message to exclude both parents and friends opinion from treatment decision was addressed; while an appeal to family duties, neglecting medical factor, was identified within the breast cancer website. The aim of this study was to induce more awareness among physicians about oncologic patient's problems inducing them to better conceive and plan both environmental and psychological aspects (family, friends, web).

Full information supply and accuracy are the two main aspects of web consulting for tumor treatment. Air and coworkers (2007) reviewed the 50 most popular thyroid cancer websites by means of a novel instrument developed by a Delphi panel of endocrine experts and based on practice guidelines (23, 24). Almost 72% of these resulted not specific for thyroid cancer, 66% did not present scientific references, 50% were privately sponsored, 55% presented complete anatomy and physiology notions but only 29% dealt with surgical information, moreover 38% resulted updated during the last two years.

Morris *et al.* (2008) determined if people could find patient decision aids on the Internet using the most popular general search engines (Google, Yahoo, and MSN) (25). Only 16% linked to patient decision aids and these were more readily found for the breast cancer surgery decision. The searches using Yahoo and Google search engines were more likely to find patient decision aids while those using MSN were successful only in the 11% of the cases. However the combination of search terms: "condition", "treatment," "decision" resulted more successful across all search engines in the 11% of the cases.

Accuracy and quality of content regarding 33 head and neck cancer websites have been also evaluated by means of a Google search engine screening (26). The DISCERN instrument, the JAMA benchmarks and the displaying of the Health on the Net seal (HON) were the tool for such evaluation; 45% of websites satisfied JAMA criteria, none the DISCERN ones and 4 reached a low score. Only 39% of the websites had the HON certification highlighting the lack of scientifically proved information.

By exploiting the three most popular search engines (Google™ Yahoo™, MSN™), Soobrah *et al.* used the LIDA and FRE tool to assess the accessibility, usability and reliability of the first 50 websites about familial adenomatous polyposis (27). They also verified that each website was certified by the Health on the Net Foundation Code of Conduct. Of the 150 possible sites (50 for each search engine) 52 were repetitions, 21 had an irrelevant content, 29 were inaccessible links and 19 resulted certified. The mean LIDA and FRE scores for all websites were 62.59% (SD = 10) and 32.9 (SD = 16) respectively, indicating a low reliability and a poor readability of these.

Despite the widespread use of web-based guidelines and protocols for oncology practitioners, the quality of these has not been evaluated (28). Based on the Appraisal of Guidelines for Research and Evaluation instrument the quality of breast and sarcoma guidelines and protocol was assessed according to six independent domains. Quality scores range was similar for both guidelines and protocols, 29-73% and 31-71% respectively. However guidelines scored highly in terms of articulating their scope and purpose (72.6±11.2%) but poorly with respect to applicability in the clinical practice (29.0±17.3%); conversely protocols highly scored on clarity of presentation (70.6±17.6%) but poorly in terms of the processes used to synthesize underlying evidence, develop, and update recommendations (30.8±20.0%). This report prompted the resource developers to direct their efforts to improve both guideline and protocol development processes as well as their communication to end-users.

In 2009 at St. Joseph's Health Care Center (Canada) a Medication Website Assessment Tool (MWAT) was developed and evaluated both for health professionals and to explore the overall quality of methotrexate information presented on common English-language websites (29). By means of the "Google" searching engine the first 250 hits were screened; only 28 of these fulfilled all completeness, accuracy, readability, reliability, and credibility criteria; 8 out 28 were recognized as appropriate and reliable sources for methotrexate (an antitumor and immunosuppressive drug) information retrieving.

Nekhlyudov (2009) evaluated, in the same way, Internet sites describing breast magnetic resonance

imaging (30). By means of the “Google” search engine, affiliation, content, media type, readability, and quality of 90 most popular unique sites about this topic were assessed.

More than 56% of these websites were commercially sponsored, with contents ranging from medical and procedural facts to information about clinical trials to grants and journal articles as well as human interest stories; 82% described the potential benefits of breast resonance imaging: 1) evaluation of newly diagnosed breast cancers (58%); 2) screening women at high risk for breast cancer (54%); 3) evaluation of abnormal breast findings (48%); 4) screening women with dense breasts (48%) or implants (27%); 5) surveillance for breast cancer recurrences (24%); 56% of all sites described the limitations of breast resonance imaging such as false positive findings (44%) and costs (24%). The overall reading level of websites contents was close to high school graduate.

Based on the “intervention mapping approach”, the E-info gene^{ca} website was developed, in 2009, to enhance counselees’ realistic expectations and participation during genetic counseling (31). Although the passive role of counselees when performing a genetic counseling the “intervention mapping approach” gave real expectations for the future genetic counseling. The website dealt with breast cancer development risk, being a carrier of a cancer gene mutation as well as emotional consequences and hereditary breast cancer.

Two years later the same group assessed the factors that could influence the use of E-info gene^{ca} (such as the duration of site and page views, the influence of topic sequence in the menu bar on the sequence of page views as well as the relationship between website use and the use of a blank question prompt sheet) and explored the comments of 101 counselees on this issue related to counselee psychological traits (32). Counselees, provided with a login access, spent an average time of 21 min. viewing the website, in particular those affected with breast cancer spent more time on the website than unaffected ones. Further, the explanation, within the web pages, of why it was so important to ask questions was positively accepted by counselees with higher information needs. As a result, the accessibility of this website was posi-

tively evaluated by both older counselees and those who had not searched the internet for information about hereditary cancer.

Notably, Ofran *et al.* assessed internet searching patterns of 232,681 anonymous users who initiated cancer-specific queries on the “Yahoo” Web search engine (33). Those focused on seeking information on aggressive malignancies exhibited shorter search periods, focusing on disease- and treatment-related information, conversely users seeking knowledge regarding more indolent tumors searched for longer periods, alternated between different subjects, and demonstrated a high interest in topics such as support groups. Based on these results the authors suggested the use these patterns to tailor information to the needs of patients and family members.

Recently, a 6 months web-assisted education and reminders about prostate cancer screening increased prostate examination rate and PSA measurement rate from 9.3% to 19.1% and from 6.7% to 31.4% respectively (34). Moreover interventions raised the susceptibility perception on prostate cancer and prostate cancer screening while decreasing the barrier perception ($p < 0.05$), suggesting the primary role of the web-assisted education for end-users.

Discussion and conclusions

An increasing number of patients use the “network” as a self medical education tool to face their health-related problems (35). However only few websites have both easily readable and updated reliable contents. Therefore it is mandatory to screen the quality and the information details that daily are intercepted by millions of web users who have an increased awareness of reliable medical sources (36).

In 2007 Health, Net Foundation and E-health Code of Ethics established both quality and ethical criteria, to which some websites adhered, but they could not control their contents for a long period due to the lack of funds (37). Based on the previous experience, NIH created a website for consumers (www.medlineplus.gov) which fulfilled those ethical criteria.

Hence, it is reasonable to assume the web information as a therapeutic strategy and to recommend the consultation of the best ones, focusing on real prognosis perspectives and treatment updates, avoiding to “stumble” into self-managing and/or self-validating identification processes lacking any scientific background.

The oncological “Web-Babel-Syndrome” (38) is the high impending risk of misunderstanding and following wrong promises and/or illusions generated by some deceiving advertising.

Non conventional, integrated, natural and holistic treatments, often autonomously mixed by the patient with the classic formal oncological protocols, require a greater synergy between oncologists, multimodal treatments experts, patients-users and their relatives. These latter often undertake extreme confusing web investigations to challenge further consultations or serendipitously trusting unqualified health care facilities.

The “Second Opinion Medical Office”, founded two years ago at the University of Modena (Italy), deals with patients unsuccessfully diagnosed or inadequately treated. This medical office, through a personalized network of consultations supported by objective information, clinical personal experiences and statistical data in a network of physicians with long lasting clinical practice and highly proved research experience, fulfills as much as possible the patient requirements following them also across their therapeutic path in a steady regular connections with institutions, hospitals, labs etc.

The Web Babel Syndrome may be prevented and correctly re-oriented if the mentoring doctors will be able to combine both the essential requirements of the patient identity and the satisfactory multiple answers fitting with the needs of an holistic modern medicine as much as possible.

Conflict of interest statement

The authors certify that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript.

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Address: Alessandro Di Cerbo PhD,
Dipartimento di Chirurgia, Università di Modena e
Reggio Emilia, Modena, Italy
E-Mail: alessandro811@hotmail.it