





Patient and family support in the era of fake e-medicine: food for thought from an international consensus panel

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Fake internet medical information, parapharmacies and counterfeit drugs constitute a market worth hundreds of billions of dollars per year^{1–3} and pose a serious public health risk at the global level.⁴ Exposure of web visitors to fake and misleading information may decrease patients' compliance to medically recommended treatments, promote the use of questionable and detrimental practices and jeopardise patient outcomes and survival.^{4–6}

The threat posed by fake internet medical information may be of particular harm to patients where the burden of symptoms from the disease or treatment significantly influence quality of life, mood, daily activities and occupational and financial prospects or activity and family integrity.⁷ Across a range of cancers, where treatment toxicities, malnutrition, cachexia and pain can be significant factors the substantial functional and emotional needs and the motivation to find a solution leave patients with cancer and their relatives particularly vulnerable to fake information and treatments on the internet.

What are the factors that may result in patients being exposed to, and potentially influenced by, such on-line harm? Clinical areas where there is a lack of a high-quality research base make it easier for misinformation to be seen as fact. In cancer medicine, for example, research into pain, malnutrition and cachexia does not attract significant funding and is not a popular field for oncologists, researchers or pharmaceutical companies. This may be as a result of competition with research seen as more cutting edge, for example, that using genome sequencing or translational molecular medicine or advanced radiotherapy techniques. It may

also be a consequence of more difficult to define end points for clinical trials in these areas. Despite a slow observed improvement in symptom management in these areas over time, there remains an unmet need to adequately address patients' nutritional and analgesic needs.^{8–11}

Supportive service availability beyond that provided by oncologists varies among different health systems. However, only a few countries have structured supportive pain, dietetic, psychooncology and palliative care teams. A US survey documented that one-third of oncology patients do not receive pain medications proportional to their pain intensity levels, and concordantly, a European survey indicated that half of the European oncology patients believe that their quality of life is not considered a priority in their overall care by healthcare professionals.^{8–10} Consequently, the dissatisfaction of patients and their relatives is very high and, inevitably, they are prone to visit the internet and social media (Instagram, Twitter, Facebook, etc) which may be felt as unique sources to find solutions to their problems and disabilities. Exposure on the web to potentially misleading data, fake information and the counterfeit drug market is therefore maximised.

Globally use of the internet has grown exponentially over the last 20 years.¹² In the real world, the internet is a complex open-access phenomenon with few controls or regulations regarding factual accuracy or sanctions against fraudulent activity. One of the instruments that may be best suited to counteract the detrimental effects of misleading web information and unrestricted access to potentially harmful medicines is through official

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web recommendations by medical authorities (official medical societies/health policy-maker providers) both for healthcare providers and for patients and their family members.

Acknowledging that most oncologists are not trained, have restricted or no time or they do not have established tools to support or protect cancer patients from internet hazards, who should really support and 'e-protect' patients with cancer?

It could be argued that recognised 'approved' medical organisations should provide patients protection by imparting recommendations directly via the internet. Unfortunately, this is not the case. In 2018, only a minority of official medical societies provided updated and structured recommendations to patients and family members on their websites.⁷ In a web survey of 370 oncology/anaesthesiology societies, the scope and content of recommendations for physicians regarding cancer-related pain and cachexia were remarkably inconsistent. The proportion of societies providing up-to-date on-line evidence-based recommendations to physicians for cancer cachexia was only 2.96% (8 of 270)¹³ and for cancer pain only 4.7% (17 of 370).¹⁴ Surprisingly, the web guidelines provision for physicians was not found to be dependent on human development index, geographical region or oncology specialisation.

Surprisingly, the paucity of recommendations was evident even among the societies of specialties whose core purpose is the management of patients with cancer. The plethora of medical societies, organisations and health policy-makers that have developed over time offer a landscape of flourishing professional activity which does not seem to translate into adequate provision of practical on-line information for patients and family members.

Have we left our patients ... 'alone' in the WEB? Can, in the internet era, medical professionals oversee the overall management and the on-line support of cancer patients?

If, for example, we again look at the areas of palliative and supportive cancer medicine and the drivers to seek out on-line information the numbers are impressive. Out of the 18 000 000 new cancer cases diagnosed annually worldwide,¹⁵ pain affects more than half of cancer patients, with a prevalence of 55% among patients on anticancer treatment, 66.4% among those with advanced metastatic or terminal phases of the disease, 39.3% following curative treatment and with 38% of all patients reporting moderate to severe pain.^{16 17} Conversely, one-third of patients with malignancy will suffer of cancer cachexia, with this proportion being notably higher among patients affected by solid cancers. Cachexia prevalence in advanced cancer might be as high as 60%–80%.¹⁸

Nutritional issues in patients with cancer are so important that the European Cancer Patient Coalition (ECPC) published a Cancer Patient's Nutritional Bill of Rights, which was presented in the European Parliament in Brussels in November 2017.¹⁹

But, ... has the scale of this issue been acknowledged or reflected in provision of adequate support?

Strongly motivated, anxious or worried patients and their family members may surf the internet or share their concerns through social media in an attempt to find complementary or alternative treatments, seek for clinical trials as well as to address symptoms and find ways to improve their quality of life.²⁰ This is especially when they feel that they have been let down by the Health System or their physicians' behaviour.²¹

Nonetheless, in the absence of web recommendation from official medical societies, the potential risk for patients and family members to be exposed to harmful fake internet information with potentially detrimental effects on patients' outcome and survival,⁴ is significant. The plethora of available web and social media information (Twitter, Instagram, Facebook etc), makes it difficult for individuals to be able to filter 'true' from 'false' information. Of note, the use of different social media impacts patients' communication and information variably. Traditionally, bloggers publish and exchange long texts with the major part of contents being shared not in real time. Nowadays, bloggers are switched from blogs to the more active microblogs (also known as nanoblogs) where instant messaging, direct conversations and the use of microposts in various content formats (including audio, video, images and text) are immediate and superfasts rendering the risk of uncontrolled e-information much higher, with low threshold of critical thinking. Microblogging is the new form of building connections as users continue to turn to mobile solutions as an immediate source of information. In fact, in 2018, the 52.2% of website traffic worldwide was generated by mobile devices.²² Real-time sharing, frequent posts, fast-paced environment and the possibility to maintain relationships make microblogs a microenvironment particularly sensitive to e-trade. Here, the potential customers may share time-sensitive information and have a personal interaction with sellers. Actually, we have different microblog platforms with contents designed for quick interactions of different audiences: Facebook (social network site where users share text, live videos and more to connect each other), Twitter (that allow quick and practical way to share short posts, GIFs (Graphics Interchange Format images), article links, videos and more), Pinterest (that links to products, articles and useful information for audiences) LinkedIn (social network site with professional profile); Instagram (visual form of blogging, allowing to share stories and snaps). For those reasons, patients' exposure to misleading medical information in microblogs' environment can be maximal.

In this setting, it is easy to identify and describe the economic drivers that result in the development formation of a vicious cycle of misinformation and fraud. The potential for enormous profits trigger the paramedical markets to self-perpetuating production of more extensive and persuasive misleading information and availability of counterfeit drugs or quack cures on the internet. The increase in web misinformation is so high that it may

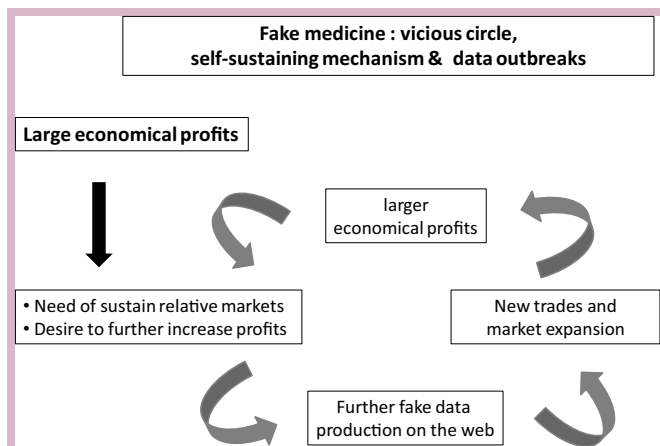


Figure 1 Fake medicine on the web and the new internet e-data outbreak disease: a vicious cycle of harmful self-sustaining and unregulated mechanisms driven by paramedicine markets profits. Fake medicine data outbreaks represent a new and uncontrolled internet disease with detrimental impact on patients' outcome and compliance to recommended treatment.

reach the dimension of harmful internet fake-data outbreaks (figure 1).

Apart parapharmacy, black-drug market and counterfeit drug market, another issue that is rapidly arising is how manage the web information on official but particularly expensive drugs, especially when promising treatments are addressed on a very early stage in the absence of a confirmatory study.²³ Redundant and extensive web information on a promising but unconfirmed and costly treatment may indeed both expose the patients to futile hopes and threaten the health systems economics. How to inform the media-industry on 'new, promising but unconfirmed and costly drugs and treatments' is an emerging issue that needs to be regulated in the next future.

In the era of 'new media, fake e-medicine and counterfeit drug e-market', medical societies, having been slow to capitalise the role of the internet as a tool to assist and inform patients and families, have left the door open for development of an unregulated and exclusively profit-driven sector.

There are convincing data that improved health e-literacy for patients with cancer and their families is an important instrument in understanding and evaluating information provided on the internet.²⁴ Therefore, the promotion, via the internet, of specific supportive care recommendations by official medical societies working in partnership with patient organisations directed both to physicians (specialists audience) as well as patients and their families (general audience), would likely be of significant value in protecting various internet threats. It will be important to ensure that development of 'official' on-line e-recommendations be of a consistently high standard and kept up to date with developments in the field. Of course, e-recommendation production should be notably improved at the global level. Recommendations for the general audience should not be confounded with

the recommendations/guidelines for specialists since the information needs may be different and the use of complex, technical language result in confusion.

The provision of patient-specific on-line information may be a novel endeavour for official medical societies generally devoted to the specialist education of clinicians and researchers. Thus, we propose the development of a 'patient corner' in each society website. This may not require all medical societies to have their own patient-centred recommendations. We believe in the value of both guidelines produced by societies themselves and/or of 'links' to recommendations on the web sites of other official medical organisations. To achieve the maximum global reach we believe that this form of patient specific guidance should be provided, in the local language of the target audience. In case of links to international recommendation, usually written in English, the role of national medical societies may be to provide a summary or full translation of such information. Use of web position statements and social media positive 'influencers' from official health providers²⁵ may also be important tools to counter-balance fake information from the strong paramedicine market.

A step in the right direction has been that the American Cancer Society (ACS), the National Cancer Institute (NCI), the European Society for Medical Oncology (ESMO) and the ECPC have recently provided some updated web recommendations for cancer-related pain and/or cachexia.²⁶⁻³⁰ Of note, ESMO also provides translation for patient guidelines in multiple languages.³¹ Form of guidance for patients with cancer and doctor-approved cancer information from the American Society of Clinical Oncology (ASCO) had been also supplied in cancer.net web site and in twitter by CancerDotNet.^{32 33}

We believe and suggest (in respect of each national society/institution legitimate rights, sovereignty of decision and freedom of expression) each National oncology society (radiation, surgical, medical, nursing oncology) to produce web recommendations for patients either of their own or as a cyber e-link to available official guidelines and translated to each country's national language(s). The ACS, ASCO, American Society for Radiation Oncology, ESMO, European Society for Radiotherapy and Oncology, European Society of Surgical Oncology, European School of Oncology, European Oncology Nursing Society, ECPC, National Comprehensive Cancer Network, NCI, International Society of Paediatric Oncology, European Society of Paediatric Oncology and all the other major international gatekeeper societies for oncology patients need to closely embrace and further develop this new field of internet education in order to protect patients against fake e-medicine and the counterfeit drug and supplement web market.

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