SPECIAL ARTICLE

Facing internet fake-medicine and web para-pharmacy in the total absence of official recommendations from medical societies

Davide Mauri^{1,2,3}, Lampriani Tsali², Nikolaos P. Polyzos⁴, Antonis Valachis⁵, Georgia Zafeiria³, Konstantina Kalopita⁶, Anna Tsiara⁷, Melina Yerolatsite^{1,3}, Georgios Zarkavelis^{1,3}, Eleftherios Kampletsas^{1,3}, Ioanna Mouzaki^{1,3}, Panagiotis Ntellas^{1,3}, Panagiotis Filis^{1,3}, Georgios Pentheroudakis^{1,3}

¹Department of Medical Oncology, University Hospital of Ioannina, Greece; ²Evidence Based Department, PACMeR Athens, Greece; ³Society for Study of Clonal Heterogeneity of Neoplasia (EMEKEN), Ioannina, Greece; ⁴Hospital Universitari Dexeus, Barcelona, Spain; ⁵Centre for Clinical Research Sormland, Uppsala University, Uppsala, Sweden; ⁶Department of Anaesthesiology and Pain Medicine, "Alexandra" General Hospital, Athens, Greece; 7Department of Medical Oncology, University of Athens, Greece

Summary

Purpose: Internet fake information, parapharmacy and counterfeit drugs are a market of hundreds of billion dollars. Misleading internet data decrease patients' compliance to medical care, promote use of questionable and detrimental practices, and jeopardize patient outcome. This is particularly harmful among cancer patients, especially when pain and nutritional aspects are considered. Provision of Web recommendations for the general audience (patients, relatives, general population) from official medical-providers might *be useful to outweigh the detrimental internet information* produced by non-medical providers.

Methods: 370 oncology and anesthesiology related societies were analyzed. Our objective was to evaluate the magnitude of web-recommendation for cancer cachexia and cancer pain for the general audience provided by official medical organizations' web sites at global level.

Results: Magnitude of web-recommendations at global level was surprisingly scant both for coverage and consistency. Seven official medical societies provided updated web-recommendation for cancer cachexia to their patients/family members, and 15 for cancer pain. Scantiness was unrelated by continent, developmental index, oncology tradition, economic-geographic area and society type scrutinized.

Conclusions: Patients need expert advice when exposed to fake internet information largely dominated by paramedical market profits. In this era of "new media" the patients' net-education represents a new major educational challenge for medical societies.

Key words: cancer, cachexia, counterfeit drugs, internet, para-pharmacy, pain

Introduction

growth during last decades [1], and this has had for health issues, is generated by non-official median astonishing positive impact in the development of science and medicine. In the real world, internet is a complex open-access phenomenon, where crease patients' compliance to the right treatment, anyone can surf and pick-up information. However, may promote the use of questionable and detri-

World use of internet had an exponential the vast majority of data provided in the net, even cal providers. Thus, internet substantially exposes visitors to fake and misleading data that may de-

Corresponding author: Davide Mauri, MD, PhD. Department of Medical Oncology, University Hospital of Ioannina S. Niarchos Ave, TK 45500, Ioannina, Greece

Tel/Fax: +30 2651 099394, Email: dvd.mauri@gmail.com Received: 06/07/2019; Accepted: 15/07/2019

mental practices, and jeopardize patient outcome [2-8].

Actually, this phenomenon has reached the dimension of a serious public health threat at global level. Indeed, the potential of large economical profits in para-pharmacy economics and counterfeit drugs, and the need of sustaining relative markets continually boost an enormous production of fake data in the internet (fake data outbreaks) with detrimental consequences on patients' health.

Super-foods, nutritional para-pharmacy and pain management are areas particularly exposed to harmful internet fake data outbreaks. The potential of economic gain for para-pharmacy in this setting is particularly high, since it pertains to a notable burden of exposed patients and clinical conditions (neurological, neoplastic, orthopedic diseases, etc) and vulnerable psychological environment. Malnutrition, cachexia and painful conditions severely jeopardize quality of life, occupational perspectives, moods and performance in normal daily activities. Thus, the "emotional" drive makes these patients and relatives being particularly fragile and motivated at internet surfing to find their solutions. This threat is particularly severe among cancer patients. Both cachexia and pain management are suboptimal in everyday oncology practice with half the patients believing that their quality of life is not considered as a priority in their overall care by their health care professionals [9-12]. Searching the internet, misleading data and counterfeit drugs para-economics may be felt as a "unique" solution from these patients. Thus, exposure to web misleading data is maximal.

The numbers are astonishing, since of the 18,000,000 new cancer cases diagnosed yearly worldwide, at least 30% will suffer of cancer cachexia and more than 50% of cancer pain [13-15]. The question that arises is how to protect these patients and the general internet audience from the fake internet data.

Provision of Web recommendation for the general audience (patients, relatives, general public population) from official medical-providers may be useful to outweigh the detrimental effects of fake information on internet produced by non medical providers. But little is known about the magnitude, coverage and consistency of the recommendation provision for the general audience from major official medical societies.

Thus, we set to evaluate the magnitude of webrecommendations for the general audience produced in official medical organizations' web sites at global level. Both recommendations for cancer cachexia and cancer pain were scrutinized among 271 and 364 related official providers respective-

ly. Variations in recommendations delivery were further analyzed by continental, national highest developmental index and national economic-geographic area.

Methods

Identification of pertinent societies and caregivers

In 2011, two research programs were launched to evaluate magnitude, coverage and consistency of evidence-based and updated guideline recommendation for physicians at global level on the web for cancer cachexia and cancer pain.

In the cancer pain program 181,200 WebPages were scrutinized and 370 anesthesiology and oncology societies/organizations were identified [16]. Similarly, in the cancer cachexia program 144,000 WebPages were scrutinized and 275 oncology societies were identified [17].

We considered societies and organizations that were intercontinental (with a global outlook), continental (including two or more countries in the same continent: African, Asian, European, Oceanian, North American, South American), or national belonging to one of the top 10 countries with the highest development index (Table 1) [18]. Countries with a long lasting tradition in medical oncology but not included in the top 10 high developed countries were further included in the internet searches (Table 1) [16,17]. Due to notable economy and development differences between South and North American countries, these continental entities were separately searched and analyzed [16,17].

Since guideline release may be influenced by each nation economics and traditions, the national guidelines retrieved were further shared in groups by economicgeographic area: Australia-New Zealand vs. Benelux (Belgium and Netherland) vs German speaking countries (Austria, Germany, Liechtenstein, Switzerland) vs North American (US and Canada) vs Scandinavian (Denmark, Norway and Sweden) vs South European (France, Italy and Spain) vs United Kingdom of Great Britain and Ireland vs East Asian (Japan and China).

Details on study methodology had been elsewhere described [16,17,19,20,21].

Primary outcome: To scrutinize the global magnitude of web-recommendations for the general audience among official medical providers both for cancer cachexia and cancer pain in 2018.

Secondary outcome: To analyze the retrieved webrecommendations for eventual relationship with continental, national developmental index, and economicgeographic area, oncology tradition, and society type variations.

We considered as "updated" all the web guidelines that have been produced or revised or lastly adjourned within the last five years. Evidence-based were considered all guidelines including randomized controlled trials and/or meta-analyses in references to support sentences.

Since all medical societies may not have the possibility to produce recommendations (their own guidelines), we considered of value both guidelines produced by themselves and/or as a "link" to a specific web site of another official medical organization with web -recommendations for the general audience (since the general population may not be familiar with foreign languages, the "link" should have been in the same language spoken in the area analyzed).

Results

Overall 275 oncology societies were registered in the cancer cachexia database [16], and 370 societies were registered in the cancer pain database [17]. Fusion of the two databases led to 371 societies potentially eligible for data analyses. Since two societies were double reported and five societies ceased, 364 were eligible for analyses in 2018 (271 for cancer cachexia and 364 for cancer pain recommendation) (Figure 1) (Appendix 1). Analyzed organizations were covering a large spectrum of oncology settings (educational/clinical/research/ policymaker): most societies were devoted to comprehensive cancer management, cancer research, radiation oncology and medical oncology) while only a minority pertained to surgical oncology and supportive oncology. Demographic of eligible societies is represented in Table 1.

Cancer cachexia

Overall 271 eligible oncology societies were scrutinized for cancer cachexia web-recommendations for the general audience (Figure 1). Only 3.3% of scrutinized societies (9/271) was giving some form of structured cancer cachexia recommendation for the general audience in 2018 [22-30] (Figure 1) (Table 1). Seven societies (2.7%) were giving recommendation updated within 5 years [22-28]; of these, two societies [22,23] were providing recommendations for cancer assessment, six for management [22,23,25-28], and two societies [22,25] were providing references to support their sentences.

International societies: No recommendations were found among the scrutinized Intercontinental, Asian, African, Oceanian, and South American societies. Only one of the twenty-four European societies provided updated and structured web-recommendations for the general audience [22]. Thus, the comprehensive international guideline release was inconsistent independently by the continent analyzed (Table 1).

National societies: The level of cancer cachexia web-recommendations for the general audience was almost null across the different national soci-



• demographic patterns of the societies analyzed

Figure 1. Flow chart of the study

	Cachexia			Pain			
	All N = 271	Any Recomm. N=9	Updated Reco m. N=7	All N = 364	Any Recomm. N=17	Updated Recomm. N=15	
Continent							
Intercontinental	23	0	0	54	0	0	
North America	-	-	-	-	-	-	
South America	4	0	0	6	0	0	
Europe	24	1	1	35	1	1	
Africa	10	0	0	11	0	0	
Asia	4	0	0	5	0	0	
Oceania	2	0	0	2	0	0	
Countries by top developed*							
Norway	3	0	0	4	0	0	
Australia	12	0	0	16	0	0	
New Zealand	6	0	0	7	0	0	
USA	45	3	2	52	5	4	
Ireland	9	0	0	10	0	0	
Liechtenstein	0	0	0	0	0	0	
Netherlands	8	0	0	9	1	1	
Canada	16	0	0	17	1	1	
Sweden	3	0	0	4	0	0	
Germany	7	0	0	10	2	2	
Oncology tradition**							
Japan	11	0	0	13	1	1	
United Kingdom	13	1	1	18	3	2	
Italy	9	1	1	11	2	2	
Switzerland	12	0	0	14	0	0	
Spain	10	1	1	13	1	1	
Belgium	6	1	1	9	0	0	
Denmark	4	0	0	7	0	0	
France	9	0	0	12	0	0	
China	13	1	0	15	0	0	
Austria	8	0	0	10	0	0	
Geographic economic area							
Australia – New Zeal.	18	0	0	23	0	0	
BENELUX	14	1	1	18	1	1	
Germanophone	27	0	0	34	2	2	
North American	61	3	2	69	6	5	
Scandinavian	10	0	0	15	0	0	
South European	28	2	2	36	3	3	
Uk-Ireland	22	1	1	28	3	2	
East Asian	24	1	0	28	1	1	

Table 1. Demographics of the scrutinized societies and caregivers organizations analysed

Continued on the next page

	Cachexia			Pain		
	All N = 271	Any Recomm. N=9	Updated Reco m. N=7	All N = 364	Any Recomm. N=17	Updated Recomm. N=15
Continent Society type			·			
Cancer research	52	1	1	52	2	2
Radiation oncology	34	0	0	34	1	1
Medical oncology	25	1	1	25	1	1
Surgical oncology	15	0	0	15	1	1
Supportive care	10	0	0	10	1	1
Compr.Ca. MGM***	71	5	3	71	6	6
Other	64	2	2	64	2	2
Pain	-	-	-	14	2	1
Anesthesiol. comprehensive	-	-	-	45	1	0
Anesthesiology other	-	-	-	34	0	0

Distribution of the scrutinized societies and caregivers organizations by location, type, eligibility, and relative guideline recommendations. EB.U. Evidence based and updated; * Countries were selected from the top 10 country from the human development index available in 2011; **Oncology Tradition: countries with high oncology tradition but not included in the top 10 high developmental index. *** COMPR. CA MGM = Comprehensive Cancer Management; Economo-geographic area: Australia-New Zealand vs. Benelux (Belgium and Netherland) vs German speaking countries (Austria, Germany, Liechtenstein, Switzerland) vs North American (US and Canada) vs Scandinavian (Denmark, Norway and Sweden) vs South European (France, Italy and Spain) vs United Kingdom of Great Britain and Ireland vs East Asian (Japan and China).

eties scrutinized (Table 1). Paucity of recommendations was independent by the high developmental index of the Nation and the oncology tradition (Table 1). Societies from most nations analyzed do not provide any updated recommendation (Table 1). Only two American, one Belgian, one Italian, one Spanish and one U.K. societies produced cachexia updated web-recommendation for the general audience [23-28]. The level of cancer cachexia web-recommendations for the general audience continued to be inconsistent when national guidelines were analyzed by economic-geographic area (Table 1).

Society type: Analyses for society type did not translate in any recommendation difference. Unexpectedly, the recommendations provided for the general audience were null even among the societies considered to be "gatekeepers" for the cancer patient; indeed, only one[25] of the 25 medical oncology societies provides web recommendation for cancer cachexia for the public, and no web recommendation was retrieved from radiation oncology and surgical oncology societies (Table 1).

Cancer pain

Overall 364 medical societies were scrutinized for cancer pain recommendation for the general audience. Despite the extensive search and the notable number of societies/organizations analyzed, we found only 17 societies/organizations (4.7%) giving some form of structured pain recommendations for the general audience (accessible for man, two Italian, two UK, one Dutch, one Spanish,

JBUON 2019; 24(4): 1318

patient, relatives, public) in 2018 [31-47] (Figure 1) (Table 1). Fifteen societies (4.1%) provided recommendations updated within 5 years [31-36,38-41,43-47]; of these fourteen societies [31-36, 38-41, 43,44,46,47] were providing recommendations for cancer pain assessment and fourteen for management [32-36,38-41,43-47]. No society was providing any references to support their guidelines or instructions.

International societies: No recommendation was found among the scrutinized Intercontinental, Asian, African, Oceanian, and South American societies. Only one of the thirty-five European societies provided updated and structured web-recommendations for the general audience [31]. Nonetheless, these recommendations were tailored to nurse personnel but were easy enough to be applicable for the general audience [31]. Thus, the comprehensive international recommendations release for cancer pain management for the general audience was inconsistent independently by the continent analyzed (Table 1).

National societies: The level of cancer pain webrecommendations for the general audience was very low across the different national societies scrutinized (Table 1). Paucity of recommendations was independent by the high developmental index of the nation and the oncology tradition (Table 1). Societies from most nations analyzed do not provide any recommendation for the public within the last five years (Table 1). Only four USA, two Gerone Canadian, and one Japanese society produced cancer pain updated web-recommendation for the general audience [32-36,38-41,43-47]. However, the proportion of official medical societies giving recommendation for cancer pain in USA did not overcome the 8%, even in the USA. Of note, the American Society of Medical Oncology has produced a well-structured and updated cancer pain informational PDF material for patients [48], but unfortunately these recommendations are not provided on its web-site, and was thereafter excluded from our analyses.

When national guidelines were analyzed by economic-geographic area, the level of cancer pain web-recommendations for the general audience was higher in North America (N=5, 7.2%), Southern European (N=3, 8.3%), UK and Ireland (N=2, 7.1%), and German-speaking countries (N=2, 5.8%). Consequently the overall rate of recommendation for cancer pain for the general audience was inconsistent and did not overcome 8% in any analyzed economic-geographic area (Table 1).

Cancer pain web-guidelines provision by society type: No updated cancer pain web-recommendations for the general audience was delivered in anesthesiology web sites. The web -recommendations of the American Society of Anesthesiologists did not report the implementation date [42], and was therefore considered as outdated. Societies devoted to comprehensive cancer management presented the higher recommendation rate 8.5% (N=6) [38-41,46,47]. Surprisingly, when the societies "gatekeepers" for the oncology patient were analyzed, we found that only one medical oncology society [32], one radiation oncology society [44] and one surgical oncology society [45] were providing any form of recommendation for their patients and their relatives. Overall, analyses for society type did not translate in any recommendation difference (Table 1).

Discussion

Internet fake medical information, parapharmacy and counterfeit drugs are a market of hundreds billion dollars per year [3,49-51]. This market phenomenon is of particular threat since the use of misleading data from the internet may decrease patients' compliance to the appropriate treatment, may promote the use of questionable and detrimental practices, and jeopardize patient outcome [2-8,52,53]. For these reasons the internet use should not be neglected by official health institutions and health policymakers.

Anyone can surf internet and pick-up fake information. Thus, unsatisfied or fragile patients and ropean Cancer Patient Coalition published a Can-

family members who use the internet to find possible solutions for their problems may be easily captured in the net-market of medical para-economy.

This phenomenon is a particular threat among cancer patients, especially when cancer pain and cachexia are considered. Indeed, health care professionals tend to neglect patients' nutritional issues and pain management. One third of patients does not receive pain medication proportional to their pain intensity levels, and half of the patients believe that their quality of life is not considered a priority in their overall care by their health care professionals [9-12]. Consequently, cancer patients' dissatisfaction is very high and the paramedical market drive is very strong.

Official controlled information in websites of medical associations, web position statements and positive "influencer" from official health providers may be important tool to counter-balance for fake information from the strong para-medicine market [8,52-54].

Nonetheless, despite the significant over-exposure of cancer patients to the fake-internet paramedical market, our study demonstrated that only an inconsistent minority of official medical societies provide updated and structured recommendation to their patients and family members in their websites (2.6% of 271 oncology societies for cancer cachexia, and 4.1% of 364 societies for cancer pain). The reported paucity was unrelated by continent, national developmental index, oncology tradition, and economic-geographic area scrutinized. Surprisingly, scantiness of recommendations was particularly evident even among the major societies of the specialties considered as "gatekeepers" for the oncologic patients (medical oncology, radiation oncology and surgical oncology). Similar lack was evidenced even for anesthesiology societies (0% of 79 societies scrutinized for cancer pain recommendation).

Inevitably, patients and their family members are prone to surf blindly in the internet of fake para-medicine and counterfeit drugs. This is a particular health threat and might be considered a health problem at global proportion.

Malnutrition, cachexia and painful conditions are issues of particular importance and should not be under-estimated, since they severely jeopardize quality of life, occupational perspectives, moods and patients performance in normal daily activities. In some cases, patients may fear pain more than potential death from their cancer and this fear has aided the drive for the agenda of physiciansassisted suicide [55]. In turn, nutritional issues in cancer patients are so important that the European Cancer Patient Coalition published a Cancer Patient's Nutritional Bill of Rights, which was presented in the European Parliament in Brussels in November 2017 [56]. Thus, patients and their relatives are particularly fragile when exposed to fake internet information. But, ... who cares?

Cancer pain, malnutrition and cachexia are not considered items for cutting edge research from oncology specialists and researchers who actually are strongly fascinated by molecular biology, genome sequencing, and translational molecular medicine in general. The provision of recommendations for patients in official medical websites is likely the only available data-source to counterbalance the fake internet information from the para-medical market. Nonetheless, despite an impressive number of medical societies, medical organizations and health policymakers that have been developed over time offering a landscape of flourishing professional and scientific activity, this did not translate in equal adequate information for patients and their family members. In the era of "new media", medical authorities have lost the control of the most powerful media (the net-information), and patients and their families are left alone to surf directly in the mouths of the sharks of internet para-economics.

The question that arises is how to protect patients and the general internet audience from the fake internet data. What to do?

Medical authorities may face a new educational challenge: the patient net-education. A new chapter for official societies generally devoted to the education of specialized medical personnel and specialized researchers. Recommendations for patients and family members from official medical societies should be strongly promoted. We propose the development of a "patient corner" in each website of official medical societies. These recommendations should be updated and should not be confounded with the recommendations/guidelines for specialists. Recommendation provision for medical specialist from official medical providers is undoubtedly of value, but the information contained may be too complex to be accessed by the public.

Our study presents some limitations. First of all, since there are no established validated searches for unearthing professional societies and organizations, some of them may have been missed by our searches. However, given the multiple layers

of our search, and the large number of oncology societies retrieved, it is unlikely that prominent entities were missed and that missed societies might change the global patterns of web-guideline provision for cancer pain and cachexia for the general audience. Furthermore, the European Society of Medical Oncology (ESMO) is currently updating its physicians' recommendations on pain management and cachexia, and is developing its patient guides, however these recommendations were not available on line at time of data extraction and study writing [57]. Finally, the human development index (HDI) changes over time. Thus, in June 2018 (at the time of data extraction) [58], countries' position varied compared to the top 10 positions available in the June 2011 review [18,58]. Among the 188 Nations analyzed by the HDI, seven countries included on the top 10 HDI at the time of our analyses in the 2011 (Norway, Australia, USA, Ireland, Netherland, Canada, Germany) [18] continued to be on the top 10 at the time of our data extraction in June 2018 [58]. The remaining three countries continue to rank at the top of the list, all included in the top 15 positions (New Zealand 13/188, Sweden 14/188, and Liechtenstein 15/188) [58]. Thereafter, no significant biases may be attributed to country highest developmental national index migration at the two time-point of analyses.

In conclusion, surprisingly, in the era of "new media", official oncology and anesthesiology societies at global level do not provide web information/ education for their patients and their family members. Patients are left alone to surf in the darkness of an internet ocean where the information is largely misleading since dominated by the market of fake medicine and paramedical profits. We believe that the provision of recommendations (in official medical societies websites) tailored to the general public audience might be a cornerstone to counterbalance the detrimental effects of the fake information in the internet. This is a new educational challenge for official medical societies, and represents one new important way to control the flow of internet information in the era of "new media".

Conflict of interests

The authors declare no conflict of interests.

References

- 1. Internet growth statistics. https://www.internetworldstats.com/emarketing.htm
- 2. Jung M. Challenges of Vaccinations in the Era of New 3.

Media Communication. Health Care Manag (Frederick) 2018;37:142-6.

Arif N, Al-Jefri M, Bizzi IH et al. Fake News or Weak

Science? Visibility and Characterization of Antivaccine Webpages Returned by Google in Different Languages and Countries. Front Immunol. 2018;9:1215.

- 4. Bryant AG, Narasimhan S, Bryant-Comstock K, Levi EE. Crisis pregnancy center websites: Information, misinformation and disinformation. Contraception 2014;90:6015.
- Wu JT, McCormick JB. Why Health Professionals Should Speak Out Against False Beliefs on the Internet. AMA J Ethics 2018;20:E1052-8.
- Gary CJ. Fake News in Dentistry: Misinformed Consent. False and misleading information, easily accessible online, is complicating dentists' ethical and legal responsibility to provide their patients with the best possible treatment. N Y State Dent J 2017;83:2-3.
- Casazza K, Fontaine KR, Astrup A et al. Myths, presumptions, and facts about obesity. N Engl J Med 2013;368:446-54.
- 8. Alnemer KA, Alhuzaim WM, Alnemer AA et al. Are Health-Related Tweets Evidence Based? Review and Analysis of Health-Related Tweets on Twitter. J Med Internet Res 2015;17:e246.
- Strasser F. Nutritional support in cancer more formal recommendations are required. Meeting held 25-29 Sept in Vienna, Austria. P377 - Sunday 27th Sept 2015 – 16:45-18:45 Poster Session Hall C.
- Greco MT, Roberto A, Corli O et al. Quality of cancer pain management: an update of a systematic review of undertreatment of patients with cancer. J Clin Oncol 2014;32:4149-54.
- 11. Deandrea S, Montanari M, Moja L et al. Prevalence of undertreatment in cancer pain. A review of published literature. Ann Oncol 2008;19:1985-91.
- 12. Breivik H, Cherny N, Collett B et al. Cancer-related pain: a pan-European survey of prevalence, treatment, and patient attitudes. Ann Oncol 2009;20:1420-33.
- 13. Global cancer statistics 2018_ GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2018;68:394-424.
- Van den Beuken, van Everdingen MH, Hochstenbach LM, Joosten EA, Tjan-Heijnen VC, Janssen DJ. Update on Prevalence of pain in patients with cancer: systematic review and Meta-Analysis. J Pain Symptom Manage 2016;51:1070-90.
- 15. Cancer Cachexia Hub. Epidemiology. http://www.cancercachexia.com/epidemiology-hcp (lastly accessed 10th December 2018)
- Mauri D, Tsiara A, Valachis A et al. Cancer cachexia: global awareness and guideline implementation on the web. BMJ Support Palliat Care 2013;3:155-60.
- 17. Mauri D, Kalopita K, Tsiara A et al. Cancer Pain: global awareness and guideline implementation. Forum Clin Oncol 2013;4:19-31.
- Human Development reports. Human Development index (HDI) – 2010 Rankings. http://hdr.undp.org/en/ statistics/(accessed June 2011)
- 19. Polyzos NP, Mauri D, Ioannidis JP. Guidelines on chemotherapy in advanced stage gynecological malignancies: an evaluation of 224 professional societies and organizations. PLoS One 2011;6:e20106.

- 20. Polyzos NP, Valachis A, Mauri D, Ioannidis JPA. Industry involvement and baseline assumptions of costeffectiveness analyses: diagnostic accuracy of the Papanicolaou test. CMAJ 2011;183:e337-43.
- 21. Mauri D, Zafeiri G, Yerolatsite M et al. Global Coverage and Consistency of Guidelines Recommendation for Cancer Cachexia on the Web in 2011 and 2018. Contemp Oncol 2019;23:100-9.
- 22. ECPC (European Cancer Patient Coalization] http:// www.ecpc.org/images/updated%20Draft%20Consultation%20Document.pd (lastly accessed June 2018)
- 23. NCI (National Cancer Institute) https://www.cancer. gov/about-cancer/treatment/side-effects/appetite-loss/ nutrition-pdq (lastly accessed June 2018)
- 24. CC (Cancer Care) https://www.cancercare.org/ publications/140-coping_with_cancer-related_weight_ changes_and_muscle_loss (lastly accessed June 2018)
- 25. SEOM (Spanish Society of Medical Oncology) https:// seom.org/seomcms/images/stories/recursos/cancerde-pancreas-alimentacion-y-calidad-de-vida.pdf 2015 Pancreas & 2006 SoporteNutricionalen el PacienteOncológico (lastly accessed June 2018)
- 26. FCC (Belgian Federation Against Cancer) https://www. cancer.be/les-cancers/effets-secondaires/une-perte-depoids-extr-me-na-rien-dagr-able (lastly accessed June 2018)
- 27. CRUK (Cancer Research UK) http://www.cancerresearchuk.org (lastly accessed June 2018)
- AIMAC (Italian Association for Cancer Patient) https:// www.aimac.it/libretti-tumore/cancro-pancreas/gliaspetti-nutrizionali-per-il-cancro-del-pancreas, 2016 https://www.aimac.it/libretti-tumore/neoplasia-perditapeso 2017 (lastly accessed June 2018)
- 29. ACCC (Association of Community Cancer Centers) www.accc-cancer.org(lastly accessed June 2018)
- 30. CACA (Chinese anti-cancer association) Dietary nutrition care for cancer patients2009 -06-11 09:43 Source: Hunan Cancer Hospital. http://www.caca.org.cn(lastly accessed June 2018)
- 31. EONS (The European Oncology Nursing Society) Breakthrough Cancer Pain 2010 http://www.cancernurse.eu/ documents/newsletter/2010autumn/EONSNewsletter2010AutumnPage20.pdf and in 2014 for cancer pain assessment http://www.cancernurse.eu/documents/ magazine/2014Autumn/EONSMagazine2014AutumnPage12.pdf (lastly accessed June 2018)
- 32. SEOM (Spanish Society of Medical Oncology) https:// www.seom.org/seomcms/images/stories/recursos/ infopublico/publicaciones/F_Oncovida_17_BAJA.pdf (lastly accessed June 2018)
- AIMAC Ialian Association of Cancer Patients 2016 https://www.aimac.it/libretti-tumore/terapia-dolore(lastly accessed June 2018)
- 34. IACR Italian Association for Cancer Researchhttps:// www.airc.it/cancro/affronta-la-malattia/come-affrontare-la-malattia/dolore-oncologico-faq (lastly accessed June 2018)
- 35. MCS (Macmillan Cancer Support)https://be.macmillan. org.uk/be/p-290-managing-cancer-pain.aspx (lastly accessed June 2018)
- 36. CRUK (Cancer Research UK) https://www.cancerre-

searchuk.org/about-cancer/coping/physically/cancerand-pain-control (lastly accessed June 2018)

- The British Pain Society (BPS) https://www.britishpainsociety.org/static/uploads/resources/files/book_cancer_ pain_patients_1.pdf for patients 2010 (lastly accessed June 2018)
- 38. Canadian Cancer Society (CCS) http://www.cancer. ca/en/cancer-information/diagnosis-and-treatment/ pain/?region=on (lastly accessed June 2018)
- 39. NCI (National Cancer Institute) 2017 https://www.cancer.gov/about-cancer/treatment/side-effects/pain/painpdq#section/all, 2014 https://www.cancer.gov/publications/patient-education/pain-control (lastly accessed June 2018)
- 40. Cancer Carehttps://www.cancercare.org/publications/ 174-managing_cancer_pain (lastly accessed June 2018)
- 41. ACS American Cancer Society https://www.cancer.org/ treatment/treatments-and-side-effects/physical-sideeffects/pain/facts-about-cancer-pain.html (lastly accessed June 2018)
- 42. ASA American Society of Anesthesiologists www. asahq.org (lastly accessed June 2018)
- 43. ACPA The American Chronic Pain Association http:// www.theacpa.org/wp-content/uploads/2017/12/ACPA_ Resource_Guide_2016.pdf and https://www.theacpa. org/conditions-treatments/conditions-a-z/cancer-pain/ (lastly accessed June 2018)
- 44. Japan Society of Therapeutic Radiology and Oncology link to https://www.cancercareontario.ca/en/symptommanagement/3121 (lastly accessed June 2018)
- 45. NVCO (Dutch Society of Surgical Oncology) https:// nvco.nl/ link to https://www.thuisarts.nl/pijn/ik-heblast-van-pijnhttps://heelkunde.nl/search/inhoud/kanker%20pijnand https://www.kanker.nl/gevolgen-vankanker/niet-meer-beter-worden/lichamelijk/pijn(lastly accessed June 2018)
- 46. DKG German Cancer Society https://www.leitlinienprogramm-onkologie.de/fileadmin/user_upload/Downloads/Patientenleitlinien/Patientenleitlinie_Palliativmedizin_1980018.pdf

- 47. DK German Cancer Aid https://www.krebshilfe.de/informieren/ueber-krebs/infothek/
- 48. ASCO (American Society of Clinical Oncology) Managing Cancer-Related Pain - A Guide for Patients, Families, and Caregivers 2017 https://www.cancer.net/sites/ cancer.net/files/managing_pain_booklet.pdf (lastly accessed June 2018) not form search in its web-site
- 49. Blackstone EA, Fuhr JP Jr, Pociask S. The health and economic effects of counterfeit drugs. Am Health Drug Benefits 2014;7:216-24.
- 50. Ozawa S, Evans DR, Bessian S et al. Prevalence and Estimated Economic Burden of Substandard and Falsified Medicines in Low- and Middle-Income Countries A Systematic Review and Meta-analysis JAMA Network Open 2018;1:e181662.
- 51. Wise J. Global operation tackles internet trade in fake drugs BMJ 2012;345:e6724.
- 52. Ebel MD, Stellamanns J, Keinki C, Rudolph I, Huebner J. Cancer Patients and the Internet: a Survey Among German Cancer Patients. J Cancer Educ 2017;32:503-8.
- 53. Liebl P, Seilacher E, Koester MJ, Stellamanns J, Zell J, Hübner J. What cancer patients find in the internet: the visibility of evidence-based patient information analysis of information on German websites. Oncol Res Treat 2015;38:212-8.
- 54. Lavorgna L, De Stefano M, Sparaco M et al. Fake news, influencers and health-related professional participation on the Web: A pilot study on a social-network of people with Multiple Sclerosis. Mult Scler Relat Disord 2018;25:175-8.
- 55. Nuland SB. Physicians-assisted suicide and euthanasia in practice N Eng J Med 2000;342:583-4.
- 56. Caccialanza R, De Lorenzo F, Gianotti L et al. The cancer patients' charter of rights for appropriate and prompt nutritional support. Nutrit Care Cancer 2017;25:3001-4.
- 57. https://www.esmo.org/Patients/Patient-Guides
- 58. Human Development reports. Human Development index (HDI) – 2017 Rankings. http://hdr.undp.org/en/ statistics/ (lastly accessed June 2018)

Appendix 1

List of the 364 societies / organizations scrutinized

- World Federation Societies of Anesthesiologists
- ACORN CRO
- Africa Oxford Cancer Consortium
- African Cancer Organization
- African Organisation for Research and Training in Cancer
- African Radiation Oncology Group
- African Women's Cancer Awareness Association
- Age Anaesthesia Association
- Alles Over Cemotherapie
- Alliance mondiale contre le cancer
- American Academy of Pain Management
- American Anti-Cancer Society
- American Association for Cancer Education

- American Association for Cancer Research
- American Brachytherapy Society
- American Cancer Society
- American College of Oncology Administrators
- American College of Radiation Oncology
- American Institute for Cancer Research
- American Pain Society
- American Society for Therapeutic Radiology and Oncology
- American Society of Anesthesiologists
- American Society of Clinical Oncology
- American Society of Preventive Oncology
- American Society of Regional Anesthesia and Pain Medicine
- American-Italian Cancer Foundation

- Anaesthesia Patient Safety Foundation
- Anaesthetic Research Society
- Arbeitsgemeinschaft Internistische Onkologie
- Asian American Network for Cancer Awareness
- Asian Clinical Oncology Society
- Asian Federation of Organizations for Cancer Research and Control
- Asian Fund for Cancer Research
- Asian- Oceanian Clinical Oncological Society
- Asian Pacific Organization of Cancer Prevention
- Association for Directors of Radiation Oncology Programs
- Association for International Cancer Research
- · Association for Research on Treatment against Cancer
- Association for the International Development of Anesthesia
- Association Latin American for Therapeutic Radiation Oncol-
- ogy (ALATRO) • Association of Physician Assistants in Oncology
- Association of American Cancer Institutes
- Association of American Cancer Institutes
 Association of Anesthesia Clinical Directors
- Association of Burns and Reconstructive Anaestheists
- Association of Cancer Executives
- Association of Community Cancer Centers
- Association of European Cancer Leagues
- Association of Freestanding Radiation Oncology Centers
- Association of Integrative Oncology and Chinese Medicine
- Association of Residents in Radiation Oncology
- Association of University Anesthesiologists
- Associazione Anestesisti Rianimatori Ospedalieri Italiani
- Australasian Society of Anaesthesia Paramedical Officers
- Australian Cancer Research Foundation
- Australian Society of Anaesthetists
- Austrian Cancer Aid Society
- Austrian cancer association
- Austrian Society of Anaesthesiology, Resuscitation and Intensive Care
- Austrian Society of Hematology and Oncology
- Austrian Society of Oncology
- · Austrian Society of Oncology Pharmacy
- Austrian Society of Radiation Oncology
- Austrian Society of Surgical Oncology
- Belgian Association for Cancer Research
- Belgian Association for Radiotherapy and Oncology
- Belgian Federation Against Cancer
- Belgian Pain Society
- Belgian Society of Medical Oncology
- Belgian Society of Surgical Oncology
- Berufsverband Deutscher Anaesthesisten
- British Accelerator Science and Radiation Oncology Consortium
- British Anaesthetic & Recovery Nurses Association
- British Association of Cancer Research
- British Association of Cancer United Patients
- British Association of Surgical Oncology
- British Oncological Association
- · British Oncology Pharmacy Association
- Canadian Association of General Practitioners in Oncology
- · Canadian Association of Medical Oncologists
- Canadian Association of Nurses in Oncology
- · Canadian Association of Pharmacy in Oncology
- · Canadian Association of Provincial Cancer Agencies
- Canadian Association of Radiation Oncologists
- Canadian Cancer Action Network
- Canadian Cancer Advocacy Network
- Canadian Cancer Research Alliance
- Canadian Cancer Society / National Cancer Institute of Canada
- Canadian Oncology Societies
- Canadian Partnership Against Cancer
- Canadian Society for Surgical Oncology
- Cancer Advocacy Coalition of Canada

- Cancer assistance network
- Cancer Association of South Africa
- Cancer Australia
- Cancer care,Inc.
- Cancer Control New Zealand
- Cancer Council Australia
- Cancer Cure FoundationCancer Federation Inc.
- Cancer Foundation of China / FORMER= Chinese Cancer Research Foundation

1323

- Cancer Hope Network
- Cancer Patients Foundation
- Cancer Project
- Cancer research foundation of America
- Cancer Research Initiative of South Africa
- Cancer Research Institute
- Cancer Research Society of Canada
- Cancer Research UK
- · Cancer Society of New Zealand
- Cancer Support Association of Western Australia
- Cancer Support France
- · Cancer Trials New Zealand
- Cancérologues Sans Frontières" / "Oncologists Without Borders
- Canteen Ireland
- Central European Cooperation Oncology Group
- China East Radiation Oncology Group
- · Chinese American Society of Anesthesiology
- Chinese Anti-Cancer Association
- Chinese cancer research foundation (China)
- Chinese Center for Disease Control and Prevention

Coc Member Organization Cancer Care Initiatives

Complementary and Alternative Medicine for Cancer

Danish Research School in Molecular Cancer Research

Danish Society of Anaesthesiology and Intensive Care

Deutsche Gesellschaft für Anästhesiologie und

Deutsche Interdisziplinäre Vereinigung für Intensiv- und

JBUON 2019; 24(4): 1323

Dutch Belgian Hemato-Oncology Cooperative Group

Confederación Latinoamericana de Sociedades de

Confederation of European National Societies of

- Chinese Medical Association
- · Chinese Medical Association Society of Oncology
- • Chinese Oncology Society (Taiwan)
 - Chinese Preventive Medicine Association

Chinese Society of Radiation Oncology

Clinical Oncology Society of Australia

- Chinese Society of Anesthesiologists
- Chinese Society of Clinical Oncology
 Chinese Society of Therapeutic Radiology and Oncology /

Clinical Cancer Research Center

Community oncology alliance

Conseils pour la chimiothérapie

Cris Foundation for Cancer Research

Danish Anaesthesiological Organisation

Danish Society of Intensive Care Therapy

Danish Society of Medical Oncology

Dutch Association of Medical Oncology

Dutch Association of Oncology Nurses

• Dutch Society for Radiotherapy and Oncology

Dansk Selskab for Cancerforskning

Cure Cancer Australia Foundation

Anestesiología

Anaesthesiologists

Danish Cancer Society

Medicine

Intensivmedizin

Notfallmedizin

Dutch Cancer Society

· Dutch Society of Oncology

Dutch Society of Surgical Oncology

1324

- Eastern Cooperative Oncology Group
- European (Spain) Website of Anaesthesia, Intensive Care and Pain Medicine
- European Academy of Anaesthesiology
- European Association for Cancer Education
- European Association for Cancer Research
- European Cancer Organisation
- European cancer prevention organization
- European Masters Program in Radiation Sciences for Oncology
- European Organization for Palliative Care
- European Organization for Research and Treatment of Cancer
- European Palliative Care Research Collaborative
- European School of Oncology
- European Society for Hyperthermic Oncology
- European Society for Intravenous Anaesthesia
- European Society for Medical Oncology
- European Society for Therapeutic Radiology and Oncology
- European Society of Anesthesiology
- European Society of Cancer Immunology and Immunotherapy
- European Society of Intensive Care Medicine
- · European Society of Oncology Pharmacy
- European Society of Surgical Oncology
- Federación Panamericana e Ibérica de Sociedades de Medicina Crítica y Terapia Intensiva
- Fédération Nationale des Centres de Lutte Contre le Cancer
- Federation of Spanish Cancer Societies
- Fight Cancer Foundation
- Foundation for Anaesthesia Education and Research
- Foundation for European Education in Anaesthesiology
- Foundation of Geriatric Oncology Netherlands
- Freesia Group for Cancer Charities Spain
- French National Institute of Cancer
- French Society of Radiation Oncology
- French Society of Surgical Oncology
- German Cancer Aid
- German Cancer Research Center
- German Cancer Society
- German Society for Hematology and Oncology
- German Society of Radiation Oncology
- Ialian Association of Cancer Patients
- Intercultural Cancer Council
- Intercultural Cancer Council Caucus
- International Agency for Research on Cancer
- International Anesthesia Research Society
- International Association for the Study of Pain
- International Cancer Biomarker Consortium
- International Cancer Microenvironment Society
- International Cancer Rehabilitation Association
- International Network for Cancer Treatment and Research
- International Organization for Cancer Prevention and Researc
- International Society for Biological Therapy of Cancer
- International Society for Cell and Gene Therapy of Cancer
- International Society for Oncology and Biomarkers
- International Society of Cellular Oncology
- International Society of Intraoperative Radiation Therapy
- International Society of Oncology Pharmacy Practitioners
- International Union Against Cancer
- Ireland Cooperative Oncology Research Group
- Irish Association for Cancer Research
- Irish Association for Nurses in Oncology
- Irish Cancer Data Association
- Irish Cancer Society
- Irish Institute of Radiography and Radiation Therapy
- Irish Society of Medical Oncology
- Irish Society of Surgical Oncology
- Israel Cancer Association

JBUON 2019; 24(4): 1324

Italian Association for Cancer Research

- Italian Association for Radiation Oncology
- Italian Cancer Society
- Italian Foundation for Cancer Research
- Italian Institute for Cancer Rasearch and treatment
- Italian Institute of Medical Oncology
- Italian League Against Cancer
- Italian Society for Surgical Oncology
- Japan Clinical Cancer Research Organization
- Japan Society of Clinical Oncology
- Japan Society of Therapeutic Radiology and Oncology
- Japanese Cancer Association
- Japanese Foundation for Cancer Research
- Japanese Organization of Radiotherapy Quality Management
- Japanese Society of Anesthesiologists
- Japanese Society of Hyperthemic Oncology
- Japanese Society of Medical Oncology
- La Ligue Nationale contre le Cancer
- La Sociedad Española del Dolor
- La"Sociedad Española de Anestesiología, Reanimación y Terapéutica del Dolor
- l'Association Ensemble contre la douleur
- L'Association pour la Recherche sur le Cancer (ARC)
- Latin American and Caribbean Society of Medical Oncology
- Latin American Association for Palliative Care
- Latin American Cancer Research Coalition
- Macmillan Cancer Support
- Medical Oncology Group of Australia
- Mediterranean School of Oncology
- Multinational Association of Supportive Care in Cancer
- National Association of Professional Cancer Coaches
- National Cancer Institute

Navy Anesthesia Society

Norwegian Cancer Society

meine Intensivmedizin

Prevent Cancer Foundation

•

Oncology

Coronarias

Terapia Intensiva

Peripheral Regional Anesthesia

Royal College of Anaesthetists

Suisse de Médecine Intensive

Physician Assistants in Anesthesia

Radiation Therapy Oncology Group

Nordic Cancer Union

• National Cancer Registrars Association

National Comprehensive Cancer Network National Foundation for Cancer Research

· National Institute of Health and Excellence

National Health and Medical Research Council

Nederlandse Vereniging voor Anesthesiologie

- National Cancer Research Institute
- National Cancer Research NetworkNational Coalition for Cancer Survivorship

New Zealand Society for Oncology New Zealand Society of Anaesthetists

Norwegian Group on Inherited Cancer

Norwegian Society of Anaesthesiology Oncology Nutrition Dietetic Group

Organisation of European Cancer Institutes

Organization for Oncology and Translational Research

Österreichische Gesellschaft für Internistische und Allge-

Royal Australian & New Zealand College of Radiologists

Scientific Association of Swiss Radiation Oncology

Scottish Intercollegiate Guidelines Network

Sociedad Española de Enfermería Oncológica

Schweizerische Gesellschaft für Intensivmedizin-Société

Sino-American Network for Therapeutic Radiology and

Sociedad Española de Medicina Intensiva, Crítica y Unidades

Società Italiana di Anestesia, Analgesia, Rianimazione e

- Societé de Réanimation de Langue Francaise
- Société Française d'Anesthésie et de Réanimation
- Societe Francaise du cancer
- Société suisse d'anesthésiologie et de réanimation / Schweizerische Gesellschaft für Anästhesiologie und Reanimation
- Society for Ambulatory Anesthesia
- Society for Anesthesia and Resuscitation of Belgium
- Society for Education in Anesthesia
- Society for Education in Anesthesia
- Society for Integrative Oncology
- Society for the Advancement of Geriatric Anesthesia
- Society of Academic Anesthesiology Associations
- Society of Neurosurgical Anesthesia and Critical Care
- Society of Radiation Oncology Administrations
- Society of Surgical Oncology
- South African Oncology Consortium
- South African Society of Clinical and Radiation Oncology
- South African Society of Medical Oncology
- South East Asian Radiation Oncology Group (SEAROG)
 South east Anosthesialogy Consultants
- Southeast Anesthesiology Consultants
 Spanish According Concerner
- Spanish Association Against Cancer
 Spanish Association for Cancer Passar
- Spanish Association for Cancer ResearchSpanish Association of Radiotherapy and Oncology
- Spanish Association of Radiometapy
 Spanish Society of Chemotherapy
- Spanish Society of Chemotherapy
 Spanish Society of Medical Oncology:
- Spanish Society of Medical Oncology.
 Spanish Society of Surgical Oncology
- Supportive and Rehabilitation Oncology
- Swedish Cancer Society
- Swedish Society for Anaesthesiology and Intensive Care
- Swedish Society of Oncology
- Swedish Surgical Society
- Swiss Bridge Foundation
- Swiss Cancer League, Swiss League Against Cancer
- Swiss Cancer Research Foundation
- Swiss Federation Against Cancer (Oncosuisse)
- Swiss Group of Clinical Cancer Research
- Swiss Institute for Experimental Cancer Research
- Swiss Radiation Oncology Centers
- Swiss Society for Oncology
- Swiss Society of Medical Oncology
- Swiss Society of Surgery
- Taiwan Clinical Oncology Society
- The American Academy of Pain Medicine
- The American Board of Anesthesiology

- The American Academy of Anesthesiologist Assistants
- The American Chronic Pain Association
- The American College of Surgeons Oncology Group (ACOSOG)
- The Anaesthesia Research Trust
- The Anesthesia Foundation
- The Association of Anaesthetists of Great Britain and Ireland
- The Association of Anesthesia Clinical Directors
- The Australian Organisation for Young People Living with Cancer
- The Australian Pain Society
- The Australian Patient Safety Foundation
- The Australian Society of Post Anaesthesia and Anaesthesia Nurses
- The Austrian Cancer league
- The Belgian Society of Intensive Care Medicine
- The British Medical Acupuncture Society
- The British Pain Society
- The Canadian Anesthesiologists' Society
- The Cancer Information and Support Society
- The European Cancer Patient Coalition
- The European Oncology Nursing Society
- The European Society of Digestive Oncology
- The European Society of Regional Anesthesia and Pain Therapy
- The Global Regional Anesthesia website
- The Intensive Care Society of Ireland
- The International Society for Anesthetic Pharmacology
- The International Spine Intervention Society
- The Japan Cancer Society
- The Japanese Association for Molecular Target Therapy of Cancer
- · The National Board of Anesthesiology
- The Neuroanaesthesia Society of Great Britain and Ireland
- The New Zealand Association of Cancer Specialists
- The Royal College of Radiologists
- · The Society of Anaesthetists of Hong Kong
- The South African Society of Anaesthesiologists
- The South Asian Association for Regional Cooperation
- The UK Society for Intravenous Society
- Trans Tasman Radiation Oncology Group
- World Anesthesia Society
- World Cancer Research Fund International
- World Federation Societies of Anesthesiologists
- World Federation of Surgical Oncology Societies
- World Institute of Pain