Gauging the Reliability of Online Health Information in the Turkish Context

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Abstract. It is hard to gauge the reliability of health information that is provided on the internet as there are plethora of medical firms and other organizations promoting their massive marketing campaigns to sell their products and services. However, an initiative; Health On the Net (HON) foundation claims that it is possible to observe the credibility and trustworthiness of health information on the websites internationally by following HON-code principles. Keeping with the principles set by the HON foundation, we analyzed the credibility of Turkish health websites and portals related to health information seeking behavior from the point of view information seeker's benefit. We selected and analyzed 56 websites within three categories which are "psychology", "aesthetics and beauty" and "motherhood, baby and children". We then evaluated their credibility of health information as according HON principles. We found out that most of the selected websites do conform to the basic principles set by the HON foundation, in Turkey. However, this information of conformance to the standards has not been listed explicitly, as opposed to the health portals in the US. Furthermore, we observed that accessibility of health information for patients and other information seekers is another topic that is needed to be dealt with separately.

Keywords: Participatory health decision making · Patient-web portal interaction · Health information seeking behavior · Reliability of online health information · Seeking health advice on the web

1 Introduction

There hardly be any internet user who has never searched for information online. It is seen that there has been a constant growth in the community of people who seek health related information also known as health information seekers through the internet [1]. This community has been on the constant rise with the enormous population growth in the online world by 832.5 % between 2000–2015, as according to [1].

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Nonetheless, there has been a burning issue pertaining to this behavior of health information seeking that is: How health information quality can be defined that is presented at online platforms? To answer this issue, there was an initiative called Health On the Net foundation (HON) [2]. Founded in year 1995, it is also currently working on this problem. This foundation has been doing research and establishing guidelines within international standards for health information seekers and web publishers, inspired by many professional websites and studies that provide measurement tool for information quality with a trustworthy score [2].

This paper analyzes the credibility and trust standards of health information websites from the point of view of health information seekers keeping with HON principles in the Turkish context. In this paper the authors try to answer the research question: *Do the platforms that host health information in Turkish language on the internet conform to international standards of credibility as defined by HON?* This paper is organized as: Background and literature review is given in Sect. 2, research methodology is elaborated in Sect. 3, results are discussed in Sect. 4 and finally, conclusion and future work are provided in Sect. 5.

2 Background and Literature Review

Internet is seen as a great opportunity for patients especially, patients with chronic diseases are one of the major health information seekers due to possibility it offers by hosting a number of health portals. These portals allow more personal paths towards a better outcome through the chance of doing own diagnoses, treatments, symptoms and doing comparisons with many other similar cases [3]. There has been a plenty of research starting from accepting the notion that health information websites play an important role on disseminating health related messages, and focus on the quality of information. However, credibility of websites, considering the usability and reliability issues, are expostulated due to having lack of sufficient health information sources such as core concepts and guidelines related to diseases [4, 5].

Turkey, at this point, is not disparate from the world trends and there is hardly any study conducted to find out the trustworthiness of online health information. The aspect of health information in Turkey is of pivotal nature due to number of facts. 55.9 % of Turkish population claims that they use internet connection [6]. In Turkey, the internet is mostly used for social media 89 % as well as reading news, online journals or magazines, 70.2 %, respectively [6]. In 2013, 49 % of mobile applications were downloaded for health and sport activities [7]. Turkish ministry of health as according to Health Development Report of Turkey [8, p. 46] indicated that 70.5 % of the population aged 18 years and above gathers health information from mass media channels. Television has the highest rate in mass media to collect health information which is 76.4 % [8, p. 46]. It is followed by the internet (26.8 %), newspapers (10 %), smart phones (8.3 %), radio (3.2 %) and a category that includes banners, leaflets, journals, books, billboards (11.5 %), respectively. It is noteworthy to mention here that information seeking on internet is a purposeful and a goal oriented activity that is critical for a shared decision-making [9] and it is quite distinct from passively being exposed to traditional media such as TV etc.

The idea of providing a guide for online health information was first floated at the conference: "The use of internet and World-Wide Web (WWW) for Telematics in healthcare" in 1995 and 60 participants from 11 countries gathered under the same roof of non-profit organization which is called Health On The Net foundation (HON), and then they developed guidelines and tools for health related websites [2]. 250 % augmentation of HON code supply in almost 3 years after its foundation shows the need for guidelines of online health related information both for the web site developers and users [10].

HON code is based on 8 principles that are authoritative, complementary, privacy, attribution, justifiability, transparency, financial disclosure, advertising policy. There are guidelines for three separate categories for patients or individuals seeking medical information, medical professionals and web publishers. Whereby, it is possible to analyze the website quality according to a related checklist. According to HONcode checklist for patients, a website is credible, hence trustable, if on the website:

1. The qualifications of the authors are indicated,
2. The doctor-patient relationship is supported,
3. Personal data and privacy regulations are respected,
4. Sources of the information and dates are indicated,
5. Claims of the information is justified,
6. Contact information of the information providers are transparent,
7. Financial disclosure is identified,
8. Editorial content and advertisement is clearly distinguished.

There is a checklist that specifies those qualifications with a checklist form which occurs from 15 questions. It then provides a trustworthy score depending on the patient's observation with the help of this check list that ensures the health information quality in international standard (See Fig. 1).

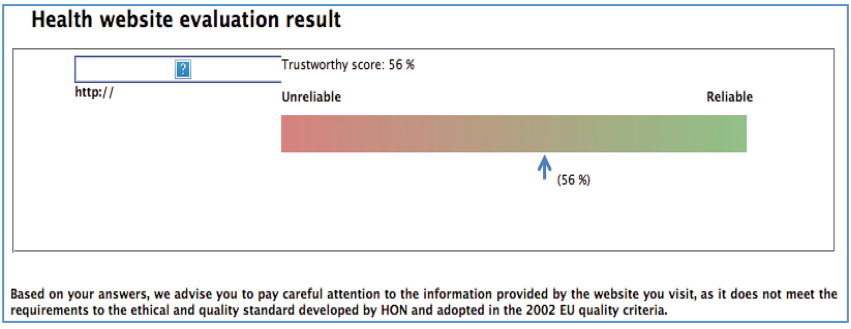

Fig. 1. A health website evaluation result taken from HON [11]

There are so many institutions and researchers that actually take advantage of HONcode criteria [10]. For instance, National Institute of Health (NIH), sets a highlighted path for elders on finding reliable health information on the web as if someone is asking the questions and an authority is answering. NIH [12] also gives its quick checklist questions as below:

1. Is the sponsor/owner of the website a federal agency, medical school, or large professional or non-profit organization, or is it related to any one of these?
2. If not sponsored by a federal agency, medical school, or large professional or non-profit organization; does the website refer to one of these trustworthy sources for its health information?
3. Is the mission or goal of the sponsor clear?
4. Can you see who works for the agency or organization and who authored the information? Is there a way to contact the sponsor of the website?
5. When the information written or the webpage was last updated?
6. Is your privacy protected?
7. Does the website offer unbelievable solutions to your health problem(s)? Are quick, miracle cures promised?

3 Research Methodology

It is vital to consider the fact that the internet presents a huge varied platform for health information seekers. However, it is very challenging and hard to know the whole picture of health information websites and know the total number of such portals in Turkey. This is because, there is no specific standardized health websites if we search in a health web browsers such as Kreshmoi (http://everyone.khresmoi.eu/hon-search/), mednar.com, health sciences online (hso.info) in Turkey by putting in keywords related to diseases or health information.

In Turkey, specifically, there are as much as 30,176 medical institutions both private and state [13] and most of them have websites. The private and state institutions include pharmaceutical companies, newspapers and journals as most of them have health related websites in addition to social media accounts, health professional personal websites and general health information websites. A keyword search was made with Google search engine because Google is the top search engine with 96.84 % rate in Turkey [14]. The search was made by providing keywords such as "psychology", "health beauty", "diet", "mother and baby health", "family health", "health", "disease and treatments", "alternative treatments", "general health", "doctors" and "medicine." The keyword search resulted in diversified amount of list including newspaper's health pages, journals in different languages. The first three pages given by Google search engine were only taken into account in this study.

After the search, the authors created a list of 497 health websites that also included the sites that are registered and supported by Turkish authorities such as: Chambers of Medicine, Chambers of Pharmacists, Chamber of Dentistry, and Turkish Republic local health authorities of 81 provinces of Turkey. The list of 497 health websites were further filtered based on the websites that focused on the patient's view or the health information seeker's context. The state or hospital websites that are already thought to be credible by the Turkish authorities were excluded from the list. The websites that presented the technical information were also excluded.

Finally, the list became limited to 138 health information websites whose raison d'etre is presenting health related information, treatments, advises and so on. Finally,

for this paper, we analyze 56 websites pertaining to three categories or keywords only which are "psychology", "aesthetics and beauty" and "motherhood, baby and children."

4 Results and Discussion

In this section, the chosen 56 health information websites in Turkey have been analyzed as well as discussed, as according to 8 principles of Hon code criteria [15]. Just to recapitulate, these 8 principles are mentioned in Sect. 2 and include concepts of: Authority, complementing and mission orientation, privacy, attribution, justifiability, transparency, financial disclosure and finally advertising policy.

Principle1 "Information must be Authoritative": This principle points out the qualifications of the authors that provide health related or medical information in a web portal i.e. whether the authors are trained and qualified professionals or not. Most of the chosen health information websites conform to the first principle of HON i.e. the information emanates from a competent and professional authority. This is evident because author's credentials are mentioned in 33 out of the 56 websites, if we see the first question of the principle 1 of HON Code website evolution form.

If we see the second question of the principle 1 of HON Code website evolution form, 23 health websites have medical advice given by professional who have their credentials listed. In 11 websites a clear statement (e.g. a disclaimer) is made whenever medical/health information or advice is offered by non-medical professionals or organizations. However, 22 of the websites contain some health/medical information that is not attributed to an author.

Principle 2 "Complementarity, Mission and Assistance": Principle 2 indicates that the information provided on the health website should support the doctor-patient relationship instead of replacing it. In our sample of 56 websites, 32 of the websites made a statement declaring that information provided on the site is meant to complement and not replace any advice or information from a health professional (see Fig. 2). Moreover, 33 of them are describing the intended mission of the site is provided on the site and 36 of the health websites clearly mentions the intended audience of the site.

Principle 3 "Privacy and Confidentiality": This principle refers to conformance to the visitor's privacy and confidentiality through meeting the legal requirements. Out of 56 websites, 20 of the websites have a complete privacy and confidentiality policy regarding e-mail addresses, personal, non-personal and medical information that is displayed on the website.

If we look at a check list of HON Code patient/individual "website evolution form" which has 15 items (questions). There are "yes, no, and I don't know" options for the item "Do my site and its mirrors respect the legal requirements, including those concerning medical and personal information privacy, that apply in the country and state of their location?" question. There were 11 websites that we could clearly answer as "yes". Generally people do not know legal requirements unless it is specifically mentioned. For the rest of 41 websites the answer was "I don't know" that means they

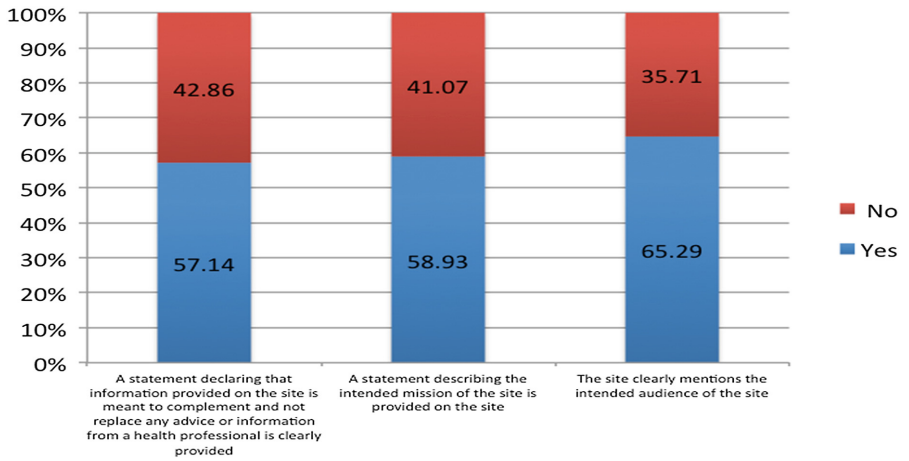

Fig. 2. Principle 2 "Complementarity, Mission and Assistance" results (Colored figure can be found in the online version of this paper)

haven't got any information telling about meeting any legal requirements and it is hard for us to say that whether they are meeting them or not.

Principle 4 "Information must be Documented, Referenced and Dated": This principle is the attribution part, focuses on modification date and external sources. Out of 56 websites, 14 of the websites do not have a modification date neither for a page or the content nor for website as a whole. Only for 5 of the websites, a bibliographic reference to the source data was given while 33 of the content of the sites were original, written by the editorial person/s. On the other hand we don't if any of the information was copy and pasted from another website.

Principle 5 "Justification of Claims": This principle stipulates that a health website must back up claims relating to benefits and performance. Consequently, it interrogates whether the site makes claims relating to the benefit or performance of a specific medical treatment, commercial product or service or not. Out of 56 websites, 35 websites had claims that were based on the author's personal research or opinions. Moreover, 16 of the claims were supported by clear references to scientific research results and/or published articles. And only in 5 websites didn't have any claims.

Principle 6 "Website Contact Details": This criterion is about transparency which is needed for accessible presentation, accurate email contact. It requires a valid email address for the webmaster or a link to a valid contact form is easily accessible throughout the site. 47 of 56 websites provided a contact link, form or information of the specialist (a doctor or a health professional who may be a writer of the website).

Principle 7 "Disclosure of Funding Sources": This criterion is for identifying funding sources of the website including commercial or non-commercial organizations, for personal or private sites, or those hosted without charge. Out of 56 websites, 48 of the websites do not have any explanations about funding.

Principle 8 "Advertising Policy": The most important thing for this criterion is to distinguish advertising from editorial content clearly. Out of 56 websites, 10 of the

websites have a page that provides a description of the advertising policy (see Fig. 3). In 3 websites there were no description but a separation between editorial content and advertising was clearly stated. For 27 of the websites there were no explanation regarding banner advertising was given. Therefore, it was not possible to understand if the content is a display of an advertisement or a claim from a personal experience. There were advertising, however, those were not identified as such in 16 websites and this is dangerous for patients (see Fig. 3).

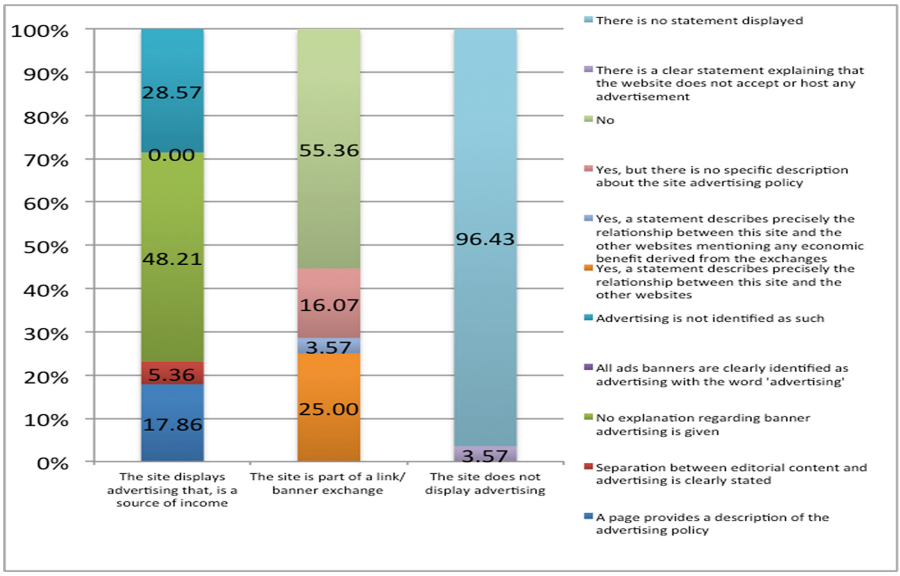

Fig. 3. Principle 8 "Advertising Policy" results (Colored figure can be found in the online version of this paper)

The other issue was whether the site was part of a link/banner exchange or not. 41 of the websites did not have an exchange banner or link (see Fig. 3). 14 of the sites have a statement that describes precisely the relationship between this site and the other websites. Only 2 of them have a statement that describes precisely the relationship between this site and the other websites mentioning any economic benefit derived from the exchanges, whilst in 9 of the websites had an exchange banner or link but there is no specific description about the site advertising policy. In total, only 2 of the 56 websites had a clear statement explaining that the website does not accept or host any advertisement while 54 websites had no statement displayed.

From the analyses of the results as according to HON code criteria, it can be stated that the Turkish websites conform well to the requirements and expectations of following principles: Authoritative (Principle 1), complementarity (Principle 2), attribution (Principle 4) and transparency (Principle 6). On the other hand, there needs to be more diligence for determining the policies of privacy (Principle 3), justifiability (Principle 5), financial disclosure (Principle 7) and advertising policy (Principle 8).

In the observed websites there were no explanations of patient rights, advertisement policies, the sources of information, privacy of the individuals and state policies among webmasters.

HON principles do not include any rules or requirements about accessibility and usability issues even though it is lethal for patients. Nielsen [16], for example, gains attention to medical usability issue that matters not only for online health information but also for a wider perspective from hospital systems to medicine prescriptions that even cause deaths because of bad design. Actually HON Foundation also conducted a survey online to find out the most important user requirements and the problems of getting health related information on web within the frame of Khresmoi EU Project. There were 385 answers collected from 42 different countries [17]. The results revealed the need for helpful tools, medical dictionary, well designed Information Architecture (IA), easiness and directions for navigation to find content, and risk factor tools. If the ads are clear and controlled, they are acceptable on the web pages. There was a need to separate qualified information from the poor information as well.

These findings also indicate the importance of accessibility. No matter what information is available, how it is explained and shown online is also another pivotal issue to acquire comprehensible health knowledge corresponding to the accessibility for a user-friendly web environment. Eighmey and McCord [18] asserts that it is important to build a user-friendly web environment that considers cognition effects, motor skill diminishment, loss of hearing, vision decline and so forth, for disseminating preventive health information, forestalling mislead health information, balancing medical information gap and so on. In this way, it is also possible to examine reactions of web audience' needs about health related issues.

Web Content Accessibility Guidelines 2.0 -WCAG 2.0- [19], for example, provides all the directions for website builders for developing user-friendly websites for the relevant audience and public. The list of requirements include providing text alternatives for any non-text content; supporting time-based media; presenting an adaptable content; the content must be distinguishable for users to see and hear; all functions must be accessible from keyboard; there must be enough time for content to be seen and used; seizures must be avoided, the pages must be easily navigable, readable and appearing predictable; the input assistance must be provided, and the pages should be compatible for current and future user agents. Every single item of those criteria makes a website clearly comprehensible, measurable and testable. For a future study, there should be a study measuring the accessibility of those 56 websites to extrapolate a deeper analysis.

There are two important questions here: First, are web site developers aware of the standards of the HON code and do the developers consider those standards while developing the web platforms? Second, can we trust this information if it is credible? For the first question a future study, having a research with health website developers to understand their point of view is important.

The second question about credibility must be reflected up for participating health decisions because even doctors make mistakes [20]. According to Doctors Union of Germany, it was learnt about 2243 malpractices during the treatment of patients; 1864 incidents caused permanent damage whereas 77 patients passed away due to

malpractice of doctors were confirmed in Germany [21]. Many people became concerned about their treatments increasingly [22] i.e., health issue is not just about authority.

Trustworthiness about health information concept is quite ambiguous as health and health systems vary from person to person. Moreover this concept is full of uncertainty. It is complex and can also be manipulated by a rant [23]. This may be the reason why people try to find their own solutions or look for more information on the internet. Thus the most important thing that needs to be paid attention to is transparency, credibility and accessibility of the health information on the websites to help individuals to find and distinguish the most suitable information for themselves or for the ones whom are cared by them. There can be some studies to structure the information seeking behavior as it was done before [26–29] for the information seekers would be helpful for general public as well.

5 Conclusion and Future Work

Internet is seen as a high hope for empowerment of patients for participated health decisions through shared health information and experiences, showing parallelism with increased health information seeking world trends. An objective criterion for measuring or observing the standards of health information on the internet is yet needed to be decided. What treatment, doctor, service or environment is better for an individual is also a question mark for modern medicine, health professionals and medical services actually. In our paper, we keep with the claim of HON principles; they work internationally to define standards for credible and trustworthy health information. Based on HON principles and Hon code website evaluation form for patients/individuals or any information seekers, we conducted this research to see whether Turkish health websites were meeting the requirements of credibility or not.

We found out that most of the websites relatively conform to the HON principles. However, the matter of health information and health information on the internet is a much deeper subject that we cannot identify them with 8 principles as HON code asserts. We need to see it with a wider perspective because health is not just about the absence of disease; it is about a complete wellbeing of humans, physically, mentally and socially [24]. [25] What is also needed to be done about health information on the internet is to create accessible, user-friendly and transparent web environment to facilitate information seekers on decision making which is already an uphill battle in medical everyday life. Moreover, it is important for policy makers as much as for patients to support or built well-controlled websites for avoiding manipulation of health information. Because health information seeking on Internet is a very popular phenomenon in Turkey as it is for many other countries.

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