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How can Online Resources for Cancer Patients be Useful?

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In the European Union, the necessity to help patients providing them with an equal, even if differentiated, kind of information about healthcare options is increasing. Patients have the same rights in any country to access prevention, diagnosis, and treatment of any type of disease. To achieve this end, the quality of information provided to the patients is crucial. Digital approaches aim at helping doctors and in general caregivers to reach all the patients to improve their empowerment, participation, and quality of life. In this paper, many questions are raised, and some solutions are provided including the INSIEME platform, where information about patient associations, companies, public and private services related to different types of pathologies in three languages are included.

Povzetek: Digitalne rešitve pomagajo zdravnikom in skrbnikom pri dostopu do pacientov z namenom izboljšanja kakovosti življenja pacientov. V članku je predstavljenih več vprašanj, ki se nanašajo na uporabo digitalnih tehnologij pri interakciji s pacienti. Poleg tega so predstavljene tudi izbrane rešitve, vključno s platformo INSIEME. INSIEME nudi podatke o združenjih bolnikov, podjetjih ter javnih in zasebnih službah, ki so povezani z različnim vrstami patologij. Vsi podatki so na voljo v treh jezikih.

1 Introduction

On 23 September 2020, during a virtual event organized by the European Cancer Organization (ECO), the European Code of Cancer Practice was launched. The Code is a citizen and patient-centered accessible statement of the core requirements for good clinical cancer practice, with ten key overarching rights of what a patient should expect from their healthcare system, supported by a plain language explanation [1].

Actually, the first Declaration on the Rights of Cancer Patients (Oslo) [2] dates 2002. Nevertheless, many principles are just a statement on paper and there is a long way to make them a reality.

The ten patients' rights of the 2020 Code are available in several European Community languages. Many of the points relate to the topic of patient information, in particular points 2 and 5, even if the information topic is crosscutting to all ten principles.

In detail, Principle 2 is about the Information and states: “You have a right to: Information about your disease and treatment from your medical team and other reliable sources, including patient and professional organizations. Patients should be informed that they can ask questions about the diagnosis, treatment, and the consequences of the disease and/or its treatment, as well as receiving information on nutrition, physical activity, psychological aspects, etc. The hospital should also refer the patient-to-patient organizations which can provide invaluable information and support at many levels” [3].

Furthermore, Principle 5 is about Shared Decision-Making and states: “You have a right to: Participate in Shared Decision-Making with your healthcare team about all aspects of your treatment and care. Increasingly in the era of patient-centered care, a shared or collaborative approach is being employed, in which a doctor recommends treatment but takes account of the patient’s situation and views after careful discussion”.

Also, the Picker Institute, a leading healthcare European charity researching patient and staff experience of care, has worked to promote the idea of person-centered care and defined the eight Picker Principles of Person-Centered Care, setting out a framework for understanding what matters most to most people, and what constitutes high-quality person-centered care [4]. One of the principles is about clear information and communication and enounce the importance for people to receive reliable, high quality and accessible information at every stage of the care process. The information should support people to make an informed decision and manage the care.

The rest of this paper is structured as follows. Section 2 presents an overview of the approach for designing IT healthcare solutions. The key questions that should be addressed when designing such solutions are discussed in Section 3. Finally, conclusions are given in Section 4.

2 Methods

Before designing an IT solution, it is necessary to analyze different key elements. Some of them are usually given for granted, e.g., the quality information evaluation and its impact on the solution. Therefore, the 5Ws for digital platforms have been considered when designing a platform for patients: why, what, who for, who with, where and how.

In the next section we will focus on the topic of health literacy and the evaluation of the information for lay people both written and online. We will also present the INSIEME platform, which contains the information that was chosen according to the considered key elements.

3 Key topics on information in e-health

There are several questions that need to be addressed when designing an IT healthcare solution. In the following sections we present the key questions and discuss about possible solutions.

3.1 Why do we talk about information in e-health?

The information, and communication as well, are part of the healthcare and the healthcare is becoming more and more digital. WHO defines eHealth as the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge, and research. Clear evidence exists on the growing impact that eHealth has on the delivery of healthcare around the world today, and how it is making health systems more efficient and more responsive to people's needs and expectations [5]. It is a fact that the Web is now part of patients' daily life, and/or that of their loved ones.

3.2 Why is it so important to be careful regarding online health information?

In the internet era, people have to disentangle themselves from the huge amount of information that they find on the Web. Information overload sometimes means making information useless, but a good information is necessary to empower patients and citizens in making decision about their health. Two important factors are to be considered related to quality information: **Health literacy** and **Evaluation tools of health information for people.**

3.3 What is health literacy?

Health literacy is the ability to access, understand, appraise, and use information to make healthy choices [6]. There are skills that make a person able to get the right information both on the prevention and health promotion, as well as on the treatment aspect. When a person has a good level of health literacy, he/she can better understand what is communicated to him/her by health services. Health literacy is a critical aspect for all the countries, but above all for the countries where the general level of literacy and numeracy competencies are low. This is because there is a correlation between low health literacy and low level of adherence to the care, and low consciousness regarding the prevention actions.

For cancer patients, literacy is even more important. As stated in the document *Health Literacy and Communication Strategies in Oncology: Proceedings of a Workshop* [7], health literacy is a critical skill for engaging in healthy behaviors to reduce disease risk and improve health outcomes across the continuum of cancer care. Low health literacy among patients with cancer is associated with poor health and treatment outcomes, including lower adherence to treatment, higher rates of missed appointments, and an increased risk of hospitalization. Low health literacy can also impede informed decision making.

Improvement of health literacy depends on the level of education, long life learning, and public policy on health literacy defined by the healthcare system/organizations. Health literacy on cancer information is challenging for frequent Internet users. As some authors state, health professionals, information specialists and librarians should orient people to reliable sources [8]. There are different tools in many languages for evaluating health literacy level of people related to different fields [9, 10].

3.4 Why and how should we evaluate the health information resources?

Evaluation of health information resources is a key process for increasing the information understanding by people. This task should be performed by healthcare organizations to guarantee the best quality of information to their users/patients. The Centro di Riferimento Oncologico di Aviano (CRO) IRCCS, along with the IRCCS-AUSL from Reggio Emilia, Italy developed the ETHIC Evaluation Tool of Health Information for Consumers as an instrument to easily evaluate the formal aspects of the written and online information resources for patients [11]. This tool is now under a strict process of validation that includes different aspects of patient centered care, as part of a research project granted by the Italian Ministry of Health with the title “Changing the future: can we effectively improve patient education and its effectiveness in cancer care?”. This project is the continuation of a very successful previous one about the power of patient education activities in empowering patients [12, 13].

Paying attention to the formal aspects of information resources [14] is one of the requirements for improving information literacy. It means evaluating the title and the authorship of the patient handouts, guides, booklets, webpages, the accuracy of date, the suitability of the images to the text, the readability of tables and figures, the simplicity (but not banality) of the language, the transparency of possible sponsorship etc. Actually, plain language is writing designed to ensure the reader understands as quickly, easily, and completely as possible. Plain language strives to be easy to read, understand, and use [15].

ETHIC includes the utilization of an application to evaluate the Gulpease Index, a measure that calculates the readability of a text based on the length of words (measured in number of letters), the number of words, and the length and complexity of sentences.

To sum up, we can state that formal aspects of information is not only important when we are dealing with scientific publications [16], but also when we are dealing with information resources for lay people are not only formal but real indicators of quality information.

Furthermore, it is important to remember that, since 1998, the Health On the Net Foundation (HON), a no-profit organization of UNESCO, proposed the HONcode certification based on eight ethical principles and a verification process [17] to address the quality of the medical Internet. The HONCode certification is certainly one of the most successful initiatives in term of quality information warranty also because of its revisions [18].

Integrating the above tools in building a portal of online information for patients and citizens should be a must in the current Internet era.

3.5 Which are the patients' and citizens' frequently asked questions?

The e-health solutions should also consider the questions that people are asking on the Web about their health conditions. Some of the frequently asked questions are:

- Where can I find an inexpensive accommodation near the hospital where I have to go for treatment?
- What can I do to help my loved one not to give up...?
- What can I eat to help me get better?
- Where can I find someone who can tell me exactly what my rights are in relation to my work?
- Who can tell me whether this supplement is safe or there is a risk of interaction with my cancer treatment?
- Can I easily book online an exam?
- What physical activity is suitable to my condition?

Asking for the previous questions, a person can find many reliable heath resources on the Web. In addition, by talking with people who have experienced some treatments such as forest bathing, one can find information about this opportunity near him/her. Forest bathing is a practice, known in Japan as shinrin-yoku, consisting of slow walk into the forest, being calm and quiet amongst the trees, observing nature around you whilst breathing deeply. This practice can help both adults and children de-stress and boost health and wellbeing in a natural way. There is literature also related to cancer patients [19] and experiences in our interregional area as well [20].

There is a need to integrate in one place all these different resources and also to let people find them exactly when they need them.

There is a huge amount of associations and authoritative bodies offering online heath information such as websites, guides, FAQs, interactive booklets, forums, services, commercial sites, chats etc. But very often, people rely on the Google's page ranking and read the Google's knowledge panels and featured snippets [21]. However, the question is whether what is found online is really helpful to patients when they need help [22].

According to the 2022 Italian Censis Annual Report on Welfare and Health, 66.9 % of the respondents to their survey search autonomously on the Web about their own health condition, 41.6 % have a dialogue with their clinicians, 94.3 % still hope for a real patient centered care, and 93 % is expecting tailored care based on the patients' needs, focused on the continuity of care. Nevertheless, more than 92 % of the respondents rely on their doctors and healthcare professionals [23].

Therefore, the fragmentation of the resources that people can find on the Web, even if optimal resources, is a poor answer to the patients' needs.

3.6 What is really missing?

Currently, patients really miss an accessible digital web app ecosystem ensuring that they can be always up to date with their medical information but also find information about important aspects such as nutrition, sexual life, physical activity, communication with loved ones, rights etc. Furthermore, it would be important for a patient to see all his/her upcoming and past appointments in one place.

It is very useful also to have the option, in the same electronic place, to record his/her own symptoms or side effects at any time and share them with his/her treating team during next visit. Virtual and physical aspects can walk together with patients can feel more empowered when using patient-centered mobile applications, and mobile applications have potential for improving collaboration with healthcare professionals and care coordination [24].

There is a long way to go but this is the right direction. The INSIEME platform (https://ise-emh.eu/) developed by an interdisciplinary team within the ISE-EMH (Italian-Slovene ecosystem for electronic and mobile health) Italian-Slovene Interreg project [25], is a prototype having the potential to give a correct answer to the patient's needs. The platform aims to share good practices between the two countries to increase the mutual benefits. Other than information related to the primary care, the contents are enriched with secondary aspects that are important during and after the therapy. Even specific applications were developed to help people (e.g. elderly patients) during daylife. INSIEME includes the following categories: Hospital services, Social services, Physiotherapy services, Physical activities opportunities and related opportunities, Psychological services, Accommodation services for patients and/or family members, Information and counselling services about health topics and patients' rights, Administrative services, Local social and health services – screening, Local social and health services - palliative care, Voluntary associations, Independent information on cancer, Independent Dr Information Desk and Information on fake news. Some aspects are peculiar such as the program Forest Bathing, and the module for appropriate communication with patients during the normal life based on cognitive science, which aims at preventing the development of pathologies.

The creators of the INSIEME platform were instructed about the above described issues and principles, and they acted to assure that the data provided on the platform are reliable. The information was collected by medical professionals and cancer information experts to guarantee that the information is good both about content and formal aspects.

4 Conclusion

Online health information is a resource only if it is of good quality and well-integrated in an ecosystem tailored on the patients' needs. Most of the time people use search engines or friends as a source of information to find a solution to their problems. In this context, there is an urgent need to provide free services for the patients where professionals take care both of content and formal aspects of information to bridge the gap between healthcare providers and citizens. The INSIEME platform could be a solution in which all the actors of the healthcare system (private and public) are included.

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