"Please Do Not Confuse Your Google Search With My Medical Degree"?

How Accessing Electronic Health Records (EHRs) and Online Searches can Support Information Needs and Increase Understanding for Patients and Relatives

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ABSTRACT

Patients' use of eHealth services and other online sources to identify medical information has become increasingly popular. For many patients the Web is an important source where they can find information and advice about symptoms and treatments. The majority of patients sees the information on the Web as reliable and uses it to influence their healthcare. Healthcare professionals on the other hand remain skeptical about the advantages of the Web as a source of medical information for the layperson. Physicians have raised concerns about patients using online sources to find information about their health as they can misinterpret or misuse information. This can occur because patients may have inadequate health literacy and eHealth literacy or are not able to distinguish accurate from inaccurate sources. The aim of this position paper is to outline a critical incident that illustrates the patient perspective of searching medical information online in relation to the eHealth service *Journalen* where patients and relatives in Sweden can access their electronic health record online. The critical incident is based on a true story and describes how Steve received his cancer diagnosis, and how his wife Tina sought information on the Web to learn more about his condition. The case illustrates how reading the electronic health record and looking online for further information can improve patients' understanding of their medical condition and empower them to make health decisions.

ACM Classification Keywords

H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous; J.3 Health; J.3 Life and Medical Sciences: medical information systems

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Electronic health record; Online search; Information needs; Patient Empowerment; Health Literacy; Patient Education

INTRODUCTION

There is a rise in the use of information and communication technology (ICT) by consumers in relation to health and medicine. People are making use of medical devices for self-managing their disease, using health apps for self-tracking, online sources to inform themselves, and learn more about their, or their next of kin's, personal health conditions etc. The availability of online resources has led to concerns in that it can be difficult for people to identify the quality and validity of the information. Some healthcare professionals (HCPs) expressed their disapproval about patients "googling" their symptoms, exemplified in a picture of a mug which went viral in social media, urging that one should not confuse a google search with a medical degree [13]. The individual's risk of encountering misinformation online has been described as a function of the proportion of inadequate information on the Web and the inability of the individual (or his/her tools) to filter the inadequate sites [8]. This can be challenging for the HCPs, who may be faced with patients' search results which need to be analysed and possibly refuted towards the patient [13]. A similar concern of patients not being able to comprehend and classify medical information is discovered in studies related to patients accessing their electronic health records (EHR) [10, 22].

However, the opportunity to access information about personal health has been seen as an important precondition for patients to make informed decisions about treatment options [19], and can contribute to patient empowerment. Enabling the access to health information is one important aspect in this context. However, according to Norman & Skinner, engaging with consumer eHealth requires a skill set (eHealth literacy), which is the "ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" [17]. As this has been described as an ongoing process rather than a final state [17], it is possible that reading one's own electronic health record can contribute to the evolving nature of eHealth literacy as well as improving the encounter with HCPs.

This position paper aims to outline a critical incident, in which the Swedish eHealth service *Journalen*, in combination with an online search, has been used by a patient and his relative in order to satisfy urgent information needs. The incident is based on a personal experience by one of the authors, and the names have been changed for reasons of anonymity.

BACKGROUND

The eHealth Service *Journalen*
In 2012 Uppsala County Council implemented the eHealth service *Journalen* which gives all patients over 18 years of age the opportunity to access their electronic health record online, sometimes referred to as a Patient Accessible Electronic Health Record (PAEHR), through a national eHealth portal using e-ID [11]. Among other things, patients can see a timeline as an overview of the health record, including medical notes, diagnoses, test results etc. (Figure 1). Moreover, patients can authorize relatives to access their records. The implementation of the PAEHR sparked a critical debate about potential negative consequences for the healthcare system in general and for patients in particular [6], as many HCPs did not think that the PAEHR is a good reform [21], nor did they consider *Journalen* being an important service for the patients [20]. Physicians were concerned that patients would not understand the medical language and reading the record would lead to undue anxiety [10]. Furthermore they anticipated a need to change their way of writing in a way appropriate and comprehensible for laypeople [10]. Patients however did not necessarily perceive the medical language as a problem in that they still felt to have a comprehensive understanding of the content, even if some parts were difficult to understand [19]. Another concern of physicians was related to how patients were informed about "bad news", which has been defined previously as "any information which adversely and seriously affects an individual's view of his or her future" [Buckman 1992, as cited in [5]]. When patients are given access to health information through *Journalen* it also means that they can read the "bad news" about their illness on their own, probably before having discussed this with a HCP, which physicians perceived as inferior compared to the way they had been trained [10].

The implementation of *Journalen* has been much debated in Swedish media and recently caught public attention again. After several rulings of different courts, the Data Inspection

Figure 1. Screenshot of *Journalen* showing the timeline of the health record.

Board appealed to the Supreme Court to remove the functionality called "Ombudsfunktionen" [18]. This functionality allows patients to grant their relatives access to the EHR, including notes, test results, referrals etc. and by this giving them the opportunity to take part in the patient's record using an own login (i.e. the relative's login). The Data Inspection Board reviewed the PAEHR and concluded this to be against the law. Uppsala county council disagreed, so that after some judicial back and forth the case was brought to the Supreme Court this summer [18]. Furthermore, the government has now been asked to clarify the law in question - the Patient Data Act - in order to allow relatives' access to the record as a representative for the patient [18].

Patient Empowerment and eHealth literacy
Studies have shown that giving patient and relatives online access to medical information (e.g. their EHR) can improve quality and safety of care, encourage them to participate in their own care, increase understanding of their medical issues, and improve doctor-patient communication [15, 16, 19]. This is often denoted as patient empowerment. Patient empowerment describes a situation where the patient's role is changing from a patronized patient to a patient that is informed,

autonomous and engaged in his or her own care [1]. Even though patient empowerment has gained considerable importance, uncertainty remains about the best way to define and measure it [3]. However, a common view among researchers is that patient empowerment is the enhanced ability of patients to actively understand and influence their health status, where information is seen as key to patient empowerment. Access to information can contribute to increased knowledge and knowledge can in turn help the patient and their families to engage in meaningful discussions or make thoughtful decisions regarding medical care [4, 9, 23].

The emergence of the personal computer and the World Wilde Web has dramatically increased patients' ease of access to health information [4]. ICT such as different eHealth solutions can empower patients by providing them with easy access to health information and by providing a mechanism for electronic communication with HCPs and the healthcare system. ICT has thus the potential to reframe traditional power relationships by promoting information sharing and shared decision making. Nevertheless, eHealth solutions provide little value if the intended users lack a skill set, or literacy, to effectively engage [17]. eHealth literacy regards ability to seek, find, understand, and appraise health information from electronic sources such as EHR and to apply the information and knowledge gained to addressing or solving a health problem [17]. Among other things, eHealth literacy is influenced by a person's current health status and motivation for seeking information, and requires basic reading and writing skills, working knowledge of computers, a basic understanding of science, and an appreciation of the social context that mediates how online health information is produced, transmitted, and received [17]. Furthermore, it has been emphasised that eHealth literacy is not static, but a competence that evolves over time as new technologies are introduced and the personal, social, and environmental contexts change [17]. The use of ICT can contribute to the evolving nature of eHealth literacy, however ICT tools should be viewed in the light of the skills required for people to use them [17]. Suitable ICT together with support by HCPs can therefore help the patient to become empowered.

CRITICAL INCIDENT

Steve is an active and fit man, but a few weeks prior to the incident, he discovered a lump at his throat. He has never been at the hospital before, never had surgery, and never been ill so the situation feels completely new to him. His wife Tina works in academia, but not in a medical area. She uses ICT in her work and is an early adopter of most ICT-related technology and apps such as e.g. Pokémon GO. She is aware of the lump, but like Steve, she does not expect the condition to be serious, therefore Steve goes to the hospital alone.

This day, Steve visits the ear, nose, and throat (ENT) specialist, who looks Steve in the eyes and says:

"Since you have cancer we need to do a surgery to know more."

Steve looks back at the doctor and his mind is completely blank. He had no idea that he has cancer. He thought that the doctor's appointment was to check up on that lump he had found. He also remembers that the primary care physician called him last week to say that all blood tests were normal, and that there was nothing to worry about. All Steve knew was that the primary care unit had sent a referral to the hospital regarding the lump after his last visit. Steve is therefore completely unprepared for this new situation, and a few minutes later he understands that the ENT specialist is convinced that he has lymphoma. Instead of a simple check-up, this visit will be about describing the surgery that will be performed the following week, including the procedures, the possible complications, and the stay at the hospital. The ENT specialist also takes a biopsy from the lump and says that the results will be back in a few days.

The physician tries to joke about the whole situation, but the joke falls a bit flat and feels inappropriate.

"There is no need to throw in the towel."

On his way from the doctor's appointment Steve calls his wife and tells her about the new situation. A few days later the specialist calls back again, this time with the test results which indicates another kind of cancer, but the surgery will be the same. Steve sends a short text message to his wife Tina:

"They say it's definitely a tumour."

Tina stares at her phone and her mind goes blank. "Tumour?", she thinks, and quickly replies:

"What does that mean?"

She gets no answer, and then remembers that she can read the electronically available medical notes and test results of her husband, so she sits down in front of the computer and enters the eHealth service using her e-ID. The pulse banging in her head. After entering the PAEHR *Journalen* she starts looking for the information from today's doctor's appointment and at the same time she gets an answer from her husband saying:

"They will need to do surgery to know more."

Suddenly the diagnosis is there on the computer screen:

*Little differentiated squamous cell carcinoma
[Lågdifferentierad skivepitelcancer]*

Tina feels a bit relieved. The wording *"little"* doesn't sound too bad, and she does a Google search on the quotation only to find out that her first guess was completely wrong. In this context *"little"* refers to the degree of the tumour's differentiation and describes how much it resembles to healthy tissue. A *"little differentiated"* type of cancer is more aggressive than a medium or high differentiated cancer.

A few hours later Tina looks up from the screen after having googled excessively. Now she has a better idea of what kind of cancer her husband has, and also what kind of treatments other people have gotten when diagnosed with this cancer. She has skimmed everything she can find from trusted healthcare providers' pages to blog posts and Facebook groups. She realises that some of the information that she has read is probably incorrect, and she has insufficient healthcare knowledge to understand everything. However, she now understands

much better why the doctors need to do a surgery in order to know more about her husband's condition. When her husband comes home, they start talking about what the doctor said, and compare it with the information Tina has found in her online search based on the words in Steve's EHR. Together they create a scattered understanding of the disease based on the different pieces of information. However, when talking about the information she found, Tina did not remember exactly what information came from which source, as she did not make detailed notes and her memory got a bit blurred.

ASSUMPTIONS AND CONSEQUENCES

In this section we will outline the assumptions that lay behind the described incident, the idea of patients accessing their EHR, and patients searching the Web for additional information.

Breaking Bad News

In the beginning of the incident it is revealed to Steve by accident that he has been diagnosed with cancer. The ENT specialist that Steve met, was unaware that his patient had not been informed previously. This exemplifies that how physicians perceive the act of "breaking bad news" (e.g. in [10]), is not always the way how a patient actually receives information. Physicians have criticized the introduction of *Journalen* because it would interfere with their workflow of breaking bad news; i.e. first, all test results are gathered, second, results are interpreted and discussed by HCPs, and third, the final diagnosis is revealed and explained to the patient in person [10]. Leaving aside that the news on having cancer was revealed to Steve by accident, he received his results and final diagnosis in several steps, none of which resembles the "ideal" process that physicians might have in mind regarding how a patient is informed about a cancer diagnosis.

It is unquestionable far from ideal that patients might learn about a cancer diagnosis off-guard by reading their online EHR. However, even without using eHealth services, how patients are actually informed about a serious disease might not resemble established protocols for breaking bad news either. For example, the six-step-protocol SPIKES includes among other things the assessment of the patient's perception in order to "create a reasonably accurate picture" and possibly correct misinformation [2]. Two example questions are given in the protocol [2], which can be related to the above incident: What have you been told about your medical situation so far? What is your understanding of the reasons we did the MRI? As the incident shows, Steve's perception was significantly different and he had no idea that his medical situation was serious. Also the perception of the medical procedure and its intention was inaccurate. The ENT explained for example the procedure of the upcoming surgery, which from the HCPs' view served as a diagnostic tool to learn more about the specific tumour in question. This differed from the general understanding by Steve and Tina, who viewed "operating on a tumour" as a therapeutic measure.

Thus, introducing an eHealth service like *Journalen* that gives people access to their EHR is not necessarily to be blamed for "breaking bad news" being a difficult endeavour. Breaking

bad news is very difficult as it is for both patients and also HCPs (see e.g. description in [5]). However, accessing their EHRs can help patients and relatives to cope with the news, re-read at home what has been discussed during the face-to-face meeting, and inform themselves further on their condition. *Journalen* may, on the contrary, even be used to improve a difficult situation in that it could be used to involve patient in their care and also for further communication between HCPs and the patient/relative. Thus we argue that PAEHRs could be designed and used to facilitate patient involvement, which could increase the quality of care. The latter is in accordance to Dias et al who conclude: "The way in which patients are involved in their care and the way in which oncologists elicit and impart information contribute to the quality of patient treatment." [5]

eHealth Literacy

Concerns have been expressed that patients do not understand the medical terms in the EHR and thus reading the record would lead to undue anxiety. In the described incident, Tina's anxiety arose rather through receiving an inconclusive text message from her husband, combined with her having to wait for a response. In order to feel some kind of "being in control" and also perhaps as some kind of coping mechanism, Tina looked for the missing information herself by reading the EHR online. She did not understand the medical terms and her first interpretation proved to be wrong. However, by combining the medical information from the EHR with an online search, she was able to receive information directly, learn more about the diagnosis, and also to make sense of the short text message (i.e. why a surgery is necessary for diagnostics). As it turned out, she also received more information than Steven did during the discussion in that she learned about different treatments. By reading this, she felt more prepared for what she and her husband might have to face in the near future. Thus, while eHealth literacy might be considered by some as a precondition to make use of the EHR, reading the EHR can contribute to eHealth literacy in providing a starting point for an online search.

Quality of Information

An assumption behind the critique of patients looking online for health and medical information is that information on the Web might be wrong or misleading and that patients might not be able to identify unreliable content. In the critical incident, Tina was aware of differences in quality and validity while reading, e.g. she did not consider information on blogs as reliable. It can be assumed, that Tina's academic background equipped her with the skills to identify reliable sources. However, as described in the incident, a while after her excessive online search, her memory was blurry regarding which information came from which source. Thus, in hindsight all these newly processed information might blend together. This might especially be the case in exceptional situations like the one Tina experienced, in which the emotional aspect might have influenced the memory as well.

Relatives and Patient Data Act

The current debate about the functionality of *Journalen* where patients can give relatives the authorization to access their

EHR evolves around legal aspects such as whether this is in accordance with the Patient Data Act. It has happened before that the research project preceding *Journalen* was considered to be against Swedish law [6]. Back in 2004 patient digital access to healthcare information was illegal, which changed due to the introduction of the aforementioned Patient Data Act. After this act came into force in 2008, it became legal for patients to digitally access their own healthcare information [6]. It is not our intention to discuss the legal implications of the specific law. However, we want to point out, that similar to the previous situation, this law may also have to change in order to reflect current needs of society. The functionality seems to be much appreciated by relatives and patients, who otherwise might just find a workaround by e.g. sharing their own login-data instead of authorizing the relatives to access the patient's EHR with their own login.

DISCUSSION AND CONCLUSION
The communication between healthcare providers and patients and relatives is accompanied by many barriers and struggles (as discussed e.g. in [5, 12]). All participants are emotionally burdened when it comes to the disclosure of having a serious disease. Special attention should be paid to the whole healthcare process in order to avoid patients being caught off-guard, e.g. by informing them in advance about tests that are supposed to rule out a specific diagnosis, so that they are able to make a deliberate decision whether they want to log into their EHR or not. This way of preparing a patient about the possibility has also been discussed by a Swedish physician in that by taking the time to explain the intentions of the tests, the patient would then be involved from the start and could also start processing the possibility of having e.g. cancer [14].

While concerns have been raised that laypeople may not understand medical terms in the EHR, the incident could also show how one can make use of the medical terms in order to look for more information. By performing an online search using the medical terms, Tina could educate herself about her husband's medical condition and felt better prepared to talk about it with him and also with the HCPs afterwards. This helped her to cope with the exceptional situation. A translation of EHRs into a language specifically tailored for laypeople would not only increase the HCPs' workload, but might also prevent patients from learning the medical terminology, which otherwise could increase their eHealth literacy. To learn the language of healthcare is especially useful for patients with chronic diseases who are already engaged in self-management.

However, it cannot be assumed that reading the EHR is helpful for everybody, that all patients are interested in or motivated to look for further information (instead of being satisfied with the first interpretation, e.g. that "little" is something positive), and equally equipped to distinguish between reliable and unreliable sources. Research has shown that some cancer patients do not want to read or know anything about their disease, and that they prefer not to be informed at all [19]. In addition, along with Tina's description of her blurred memory, it has been reported in another study that "very few internet users later remember from which websites they retrieved information or who stood behind the sites" [7].

An improvement for the future could be to support patients in developing an understanding of the medical text. Similar to connecting and linking the medication entries in the EHR to FASS (Farmaceutiska Specialiteter i Sverige, the Swedish national formulary database), medical terms of the diagnoses and treatment options could be linked to a similar database with reliable information. A function like this implemented in the eHealth service might prevent patients in some cases from reading unreliable information. Exposing patients to reliable and highly valuable information through different ICT solutions, is however not enough. It is also necessary to have an interaction between HCPs and patients. According to the Swedish National Board of Health and Welfare HCPs should not assume that patients are not searching for information online about their diagnoses [24]. Instead, they should have an open dialogue about online information and, if necessary, guide patients to quality-assured information on the Web.

Looking online for information is not without drawbacks, but instead of discouraging patients and relatives to involve themselves by using the rather condescending phrase like the one we referred to in our title ("Please Do Not Confuse Your Google Search With My Medical Degree"), we wanted to highlight some of the opportunities and possible ways forward.

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