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Who can you trust? Credibility assessment in online health forums



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Abstract

As the cost of health care rises governments everywhere are examining how on-line services can replace or augment face-to-face services. Consequently, many health bodies are establishing on-line health forums where patients can share ideas with, or solicit information from, both other patients and health professionals. In the wake of this trend, many on-line forums have arisen which do not have the imprimatur of official government services but are run and managed by private individuals sharing experiences outside of the patient-clinician channel. This phenomenon creates risks and challenges for users who need to evaluate the credibility of unknown and often anonymous contributors to these forums. This paper examines how users assess the credibility of the information in these forums. Five criteria were discovered in the first stage of the work. We then quantitatively tested the relationship between those criteria based on two types of information. Our analysis shows that different criteria are used by participants in online health forums for scientific information and experiential information. We used these novel findings to develop a model for how information credibility is assessed in online health forums. These findings provide important lessons for health promotion bodies considering how to encourage the sharing of valuable health information on-line as well as guidelines for improved tools for health self-management.

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Introduction

The Internet is changing the way that people receive medical information, from the traditional doctor-patient model to one where patients supplement or even replace that interaction with a search for information and advice on the Internet.

People appear to be attracted to the anonymous and convenient information seeking that is possible via the

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Internet. However, unlike in face-to-face consultations with a doctor, there is no guarantee that the information and advice is objective, truthful, or up-to-date, and there is no follow-up to ensure that any information provided is used appropriately.

Information obtained from government or institutional sources typically does describe best practice, and published studies indicate that they are generally perceived to provide information that is highly credible, accurate, current, and complete [1,2]. However, research into health promotion by government agencies suggest that there are no clear policies and often no clear evidence-base around what is promoted on such sites [3]. Thus, despite some positive attributes, the information from these sites is not always ideal: it is frequently jargon-laden, difficult to comprehend, difficult to incorporate into treatment plans, and its inclusion not fully justified. Political ideologies and the values of individuals running such sites can also effect the type of information published [3].

Thus, many people also seek advice from social media sites, including social networking sites, blogs, and wikis. This type of interaction has been often treated with suspicion by medical professionals because the interactions are typically between patients with no medical training, and there are no formal mechanisms to ensure that advice is accurate, up-to-date, or even truthful.

This suspicion, however, may not be warranted. Some research indicates that social media sites are not a substitute for high quality information, but rather complement those sites by providing emotional support and information about the lived experience of a condition (experiential information) from other patients. However, very few studies have been conducted into this type of behaviour, so it is currently unclear how patients evaluate social media sites. This is even though previous research has identified the potential danger of incorrect information being put into the public domain and the difficulties in assessing the credibility of such information [4].

Online health forums (OHFs) have been chosen for this research, from among all user-centric social media applications. Firstly, OHFs highlight text-based content and are also the most popular tool adopted [5]. In contrast to blogs, OHFs centralise users in one place and better maintain users' anonymity. As opposed to wikis, OHFs enable social interaction and influence between users. To maintain the communication dynamics between users and assess online health information produced by anonymous users, we exclude those OHFs that are explicitly involved with and moderated by medical professionals such as general medical practitioners, specialists, and registered nurses which tend to be more like Q and A and lack emotional exchange. By removing a central authority and medical professionals, we can better answer the research questions:

What types of information are generated by OHFs? How do people assess health information generated by other anonymous end-users in OHFs? Do people use different criteria to assess different types of information?

The remainder of this paper is structured as follows: we start with a review of the key concepts and theories that guide our exploration, and then describe the methodology

used to execute this research. We then present the emerging results from two studies, and finally discuss the insights and implications of our findings. We show that fears that online forums provide high risk and under-validated information are generally unfounded. Instead, online health forums appear to be a useful complement to institutional sites, and indeed provide a vital service that has to date been largely ignored by policy makers.

What information do health consumers want?

There has been significant work done on what type of information health consumers require [6]. This work suggests that people want information falling under the following categories: Disease entity information (what is the disease?) [7]; Time information (how does it progress?); Self-information (why me?); Self-disease (what will happen) [8]; Self-disease-time (how will my condition change?) [6]. However research suggests that many doctors are unable to satisfy these information needs, either because of a lack of information or a lack of empathy, or just reasons of time and efficiency [9]. "Mutual acceptance, more emotional care, empathy" [9, p. 4] are some of the areas where patients feel the face-to-face provision of health information could be improved, and are cited as reasons for the increased use of On-line Health Forums as a way of satisfy patient needs, not just for different or greater information but for a different style of information communication [10].

Online health forums

Online Health Forums (OHFs) have evolved as a strong Internet presence in the area of both physical and mental health. These may be unstructured discussion groups or may be led by an individual, usually a non-professional, who shares the problem that the group addresses [11]. The prerequisite of the shared medical condition sets OHFs apart from other online communities. The usefulness of the support provided by these groups has been attested to in studies of eating disorders [12] and depression [13]. They have been found to allow patients to form supportive bonds with other people [11] and have been reported as being helpful by many users [14] particularly in providing the sort of information that health consumers want, as discussed in the previous section. Factors working against use have often been technological, such as error prone designs, rather than related to the benefits derived from participation [15].

What drives people to OHFs is the possession of a sense of alienation, feelings of isolation, anxiety about treatment and misconceptions and misinformation [16]. Emotional distress from a medical condition can be alleviated by satisfying informational needs [17], gaining emotional support [18] and engaging social comparison [19]. Thus, informational and emotional supports are appreciated and positively received by OHF users [20,21].

OHFs, like other user-centric platforms, place end-users under the spotlight. While medical professionals derive their knowledge from the experience of the majority of patients, patients obtain medical knowledge from living with their medical conditions every day. Thus, patients can articulate not only the location, intensity and duration of

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