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An Investigation of Cyberchondria in ‘The Age of Risk’

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Abstract

The importance of this paper arises in light of the increasing frequency for consumers to approach online sources about symptoms of illness, a process that has previously been described as 'Cyberchondria'. Critics are increasingly questioning the quality of interactive health information in 'The Age of Risk'.

Research in this field is often concerned with a focus on the negatives of the Internet. This raises questions from sociological and feminist academics as to whether the Internet is a direct mediator of health and illness information, or whether there are other social and cultural factors involved which contribute to the risk of the ‘prosumer’. This paper approaches these problems discussing the importance of implementing software quality measures to control the potential negative effects of the information on those who are entering the information with a negative ‘lay epistemology’.

Drawing on techniques of discourse analysis, qualitative data was collected in interviews concerning laypeople’s use of health and illness channels. This paper identifies the system that laypeople use in gathering knowledge from a number of sources in order to form their own ‘lay epistemology’. Using the method of ‘intersectionality’, cultural and socially constructed categories have been used in analysis.

This paper suggests that although the Internet is a major source of information, there are decisions which the layperson makes prior to this approach which affect their discernment of their findings. This paper looks at how consumers differ in their interpretation of this information which aids academics in the development of systems to protect those groups that are vulnerable.
1.0 Introduction

The Internet offers widespread access to fountains of information relating to health and illness with the advantages of interactivity, information tailoring and anonymity [1]. Consumers no longer have to settle for the opinion of the medical professional, but instead can be more involved and proactive in establishing an understanding of their diagnosis. They are evolving into the ‘Prosumer’ [2].

Despite the Internet being a superb resource for teaching the consumer, the importance of this research arises in light of the growing concern for the quality of interactive health information. The field of literature indicates that much is inaccurate with technical defects and disorganisation which could put the consumer at risk [3]. This paper approaches these problems discussing the importance of implementing software quality measures to control the potential negative effects of the information.

This is particularly apparent for those who are entering the information with no epistemology or one that is of a negative nature; epistemology being the repository of knowledge that someone has or hasn’t built prior to their approach of the Internet. This may be via family, peers, medical professionals, the media and other interactive media such as television and radio shows.

This paper seeks to evaluate a potentially derogatory term that is being used to label those people who seek to diagnose themselves online; ‘the Cyberchondriac’: a group of hypochondriacs who have a strong, obsessive, and compulsive focus to their symptoms. White and Hovitz (2008) suggest that following their web search and the observation of the symptoms of an illness, the ‘hypochondriac’ becomes a ‘Cyberchondriac’. The consumer believes they are sick, often leading to them assuming the worst possible outcome [4]. This paper is going to look at these definitions and draw conclusions as to whether this term should be used on such a widespread basis through the literature. Additionally this research aims to identify who laypeople turn to which will reveal how the Internet, as a channel, fits into a layperson epistemology and its relationship to other channels.

This paper has determined the differences that occur between laypeople and has identified those groups that are vulnerable, with conclusions drawn which help to minimise adverse effects for these groups. For the purpose of this research the general population will be referred to as ‘laypeople’. The following objectives are addressed:

1. To determine which online source of information laymen use and trust.
2. Seek to discover whether the background of an individual affects their information-seeking behaviour.
3. To determine the sources that contribute to the layperson’s epistemology.
4. To evaluate the term 'Cyberchondriac' and establish what specific individuals this term covers.
5. To assess how software could account for the negative epistemology.
2.0 Background and Related Work

The proposed research that will be the focus in this chapter is that relating to the existence of cultural and social dimensions in the realm of health and illness. Through the summary and thorough analysis of the arguments of others, and knowledge that exists, it will aim to reveal similarities and differences, consistencies, inconsistencies and controversies in previous research. This will seek to reveal gaps in this research field.

2.1 The Age of Risk

One of the main debates in the literature is the way in which laypeople consider real risks, hazards and causes of illness compared with cultural and historical variations. Furthermore, these debates study the differences in people’s awareness, definitions and experiences via social ideas [5]. One can suggest that modernist thinking has caused this debate to arise amongst Post-Structuralists and Foucauldians.

According to sociologist, Anthony Giddens, a ‘Risk Society’ is a society increasingly preoccupied with the future and safety, which generates the notion of risk [6]. On the other hand, German sociologist Ulrich Beck defines it as a systematic way of dealing with hazards and insecurities introduced by modernisation itself [7].

Zinn (2005) identifies two alternative and competing approaches to risk. In one approach, risk is treated as an objective phenomenon that, with suitable technology, can be assessed or measured, and then managed. In the other, risk is seen as a subjective phenomenon, which is socially constructed and embedded within specific social situations and relations [8]. This demonstrates complexity and ambiguity surrounding the term ‘risk’ in relation to health, which one can observe from the numerous proposals by researchers.

Furedi (1997) suggested that certain categories of the population, which they have labelled as ‘risk groups’, are more likely to engage in risk. Many have pointed the finger at the mass media for these new risks for increased anxiety among some groups [9]. This suggests there might be other cultural and social factors playing a role.

2.2 Cyberchondria

With such a large number of people visiting healthcare websites to diagnose or seek information, the literature is focusing on the phenomenon of Cyberchondria. In light of this, this paper is questioning where the line is between someone who has been labeled in the literature as a Cyberchondriac and someone who is not seeking obsessively. This paper will approach the positives of this information-seeking behaviour that are ignored due to the negative connotations of the term.
Peter Yellowlees conducted research in 2000 proposing Cyberchondria to be a syndrome which occurs in patients that suffer from anxiety or hypochondria [10]. In 2007 however Harris commented that ‘Cyberchondriacs’ now represent 84% of all online adults, an increase from 72% in 2005. An increase in Internet users could account for this rise [11, 12]. This label could be potentially damaging to laypeople.

Support of this questioning of the term comes from research by Wathen et al. (2008) who demonstrate the concept of info(r)mediation and the importance of people in the realm of locating health information. Wathen et al. look at the middle space and question the impact of ‘local’ yet ‘distant’ mediators ‘those ‘like’ me but whom one has never met’. They have identified this blurring between avatars in online worlds and humans in the physical world. There is a consensus within the literature that web content providers must be cognizant of their potential to heighten medical anxiety and consider the ramifications of publishing alarming medical information thus the consideration of systems to control this is important [13].

White and Horvitz (2009) conducted two studies showing that Web-based concerns occur frequently for around one in five people, two in five people report that interactions with the Web increase medical anxiety and approximately half of people report that it reduces anxiety [4]. Further findings by White and Horvitz in 2010 show that the structure of the web page is a contributing factor to anxiety and in particular the order of wording, noting that a significant proportion of subjects considered the ranking of a list of results as somehow linked to the likelihood of relevant disorders [14]. This has been taken into consideration within the chosen methodology.

Their findings underscore the potential costs and challenges of Cyberchondria; however research largely observes negative associations, ignoring any positives that may affect how one consumes and responds.

2.3 Summary

With such a heavy focus on the phenomena of Cyberchondria, little detail and negative critique is provided about other social and cultural factors that affect the decisions of laypeople and supports Alaszewski (2005) who has highlighted social context as essential in response to a non-passive recipient of information [15]. The literature fails to establish the specific reasons for the searching behaviour of laypeople and how they respond to this.

In light of this, future research needs to address the Internet as part of the larger health communication system, not only focusing on information quality, but also addressing the inherently communicative and transactional quality of Internet use. Both interpersonal and mass communication concepts open avenues for investigation and understanding the influence of the Internet on health beliefs and behaviours, health care, medical outcomes, and the health care system [16].
3.0 Methodology

In light of previous research, which has seen a focus on quantitative research methods, this research has collected qualitative data which allows rich data to be analysed which focuses specifically on the individual differences between laypeople. Using a population of citizens of the United Kingdom, twenty face-to-face semi-structured interviews were recorded. These were split into two sections.

The former stage of the interview was to ascertain the sources that laypeople approach for information and which of these they trust the most. This method encouraged an active, open-ended dialogue with interviewees which gathered rich material suited to detailed analysis. The researcher took into consideration the sensitive nature of this research throughout.

The second interactive part perceived the behaviour of participants during their search for this, noting the sites that they were the most likely to trust. One of the limitations of interviews as a method of data collection is that they only provide access to what people say and not what they do. This therefore justifies the need for the latter part of this research study.

A sample of participants was selected which represented an even spread of the population, using an even split of males and females with a diverse age range. Analysis involved the rigorous transcription of recorded data where trends were identified. These were then transcribed and analysed in accordance with the research of Kvale (1995) who suggests that a systematic and rigorous method is appropriate for large amounts of textual data which can be lengthy to prepare and analyse [17]. In light of previous research which makes numerous generalisations, this will be avoided in concluding remarks.

4.0 Discussion

4.1 The Layperson’s Information-Seeking Behaviour

The Internet acts as a boundary between laypeople and the medical professionals. Laypeople follow up their findings using other sources and refer to professionals. They use the Internet as a tool, amongst others, to find information, which are increasingly aiding the diagnosis of the doctor.

We can see from the results of this study that the concept of ‘information therapy’ is one that quite accurately describes the reasoning for why laypeople search for information. It helps them feel more in control of their own bodies. Foucauldian theorists argue that medical discourse plays an important role in the management of individual bodies. Medicine is not just about medicine as it is conventionally understood, but also about wider structures of power and control. Parr has now put forward the 'Fourth spatialisation' of the medical gaze to be evaluated in the context of the Internet as a new geography of health promotion which enables human subjects to discipline and self-diagnose their bodies [18].
This change in the medical environment encourages physicians to prescribe information as well as listen to patients. We are observing a move to what occurred prior to ‘The medical gaze’, which brought considerable power and prestige to the medical profession [19]. Menegay and Stalder (1994) found that general practitioners prescribed more medications than expected, and almost never discussed prevention or prognosis [20]. The Lay Referral System suggests that in order to overcome the power professional medical practices have over them, laypeople use a network of consultants: those who they go to for advice who are part of the structure of the local lay community. This involves seeking out those who have, usually by virtue of their own medical histories, more extensive experience [21]. With a growing number of forums available online, laypeople are able to find hope through the recovery stories of others.

Gender, in this research was identified as a highly influential category as to the level of interest into the field of health and illness and the channels they use. Females, in particular, research into this realm as a direct consequence of their social role, which subsequently results in a higher level of Internet use. The Internet hasn’t caused this behaviour; it has always been apparent. Both genders spoke to friends and family, however women did this more often. Age and social role are important considerations within the feminine gender role. Marriage and parenting are identified as stages when anxieties can increase, not about themselves, but about other people.

Using this and previous research raises concerns as to how few men are visiting the doctors and shows how fewer men are concerned generally about their health. The Internet gives them the opportunity to quietly find out if there is a need to go to the doctors which they become anxious about so a tendency to delay. Using feminist theories we can observe how men enjoy having power over their own bodies and letting someone examine them takes this power away from them [22].

Individual differences exist between populations which can determine their information-seeking behaviour. The most popular online channels are those which are recognised in the offline world, for example NHS Direct was the most trusted website across the age range with those who are older being more cautious. The least popular are American websites which are recognised less due to cultural barriers and requests for payment. Despite stating they did not trust the website, participants would often still read the site which raises concerns as to the subconscious effects of the information [23].

It was common for laypeople to use the Internet to search for their symptoms before they escalated into ‘something worse’, or so to ‘not waste the general practitioner’s time’. This supports the health-beliefs model, developed in the 1950s, to help laypeople take preventative measures and act more rationally through the utilisation of medical services, complying with prescribed regimens [24, 25]. This model is based on the understanding that a person will take a health-related action if they feel that a negative health condition can be avoided.
4.2 The Lay Ontology and Discernment

'A classic problem common to sociology and other social sciences revolves around how people make decisions'. The findings in this paper surrounding rationality and how we make decisions identify best with the social organisation strategy framework [26].

This framework proposes that instead of focusing on the individual making the decision, we should look to social networks as providers of the mechanism through which individuals learn about, come to understand and attempt to handle difficulties. This in turn shifts to socially constructed patterns of decision, including consultation with others. One can propose that in the context of health and illness, problems may arise if someone does not draw on their social networks to make decisions about visiting the general practitioner and it is then when risk may arise which could be potentially fatal.

The term ‘discernment’ was used on several occasions throughout the interviewing process, and was therefore identified as an essential element to look at in analysis. According to interviewees, the techniques used to discern the information they find on the Internet relating to health an illness affects whether it has a positive or a negative impact due to unreliability of some of the material. Nettleton comments that ‘much of the information available online is unregulated and unrated, meaning that the onus for determining accuracy and relevance often falls on the consumer, who, may have no experience in making such judgements’ [27]. In response, the
overall consensus of participants is that the dangers come when one is unable to discern the information that they come across.

The increasing availability of information online allows laypeople to become more educated, which plays a role as to how one discerns the information they find and how rational they are in response. If the user exaggerates his or her symptoms it can be easy for them to begin gazing incorrectly. Furthermore, there is the risk that the layperson when in the sick role may not act as rationally. If the user is only collecting theory one could question to what extent are they relying on their own interpretation of their symptoms compared to gazing at their own bodies as they lack the appropriate medical equipment.

Laypeople were able to show some of their symptoms to friends and family externally, which they liked. Their reasons for using the doctors also were that the doctor knew their previous medical history and context and could examine their bodies, which supports the practical elements of the medical gaze. The population in question commented that they were far less likely to trust the Internet over their general practitioner due to the amount of time the professional has spent acquiring knowledge and skills during the course of their study. In light of this, it is important that professionals understand their responsibility to educate prosumers.

Following the diagnosis, laypeople can conclude whether they responded rationally or irrationally to the acquired information which influences their future information-seeking behaviour. Laypeople become sceptical if they have a bad experience of the Internet or doctors.

4.3 Minimising the effects for vulnerable groups
Those interviewed in Hardey's (1998) study recognised the importance of the right terminology when searching for information: 'It can take a bit of lateral thinking to come up with the right terminology'. This however is a finding that has not been identified in this research. Interviewees were quick to type something into 'Google' and did not comment on their choice of terminology [28] Laypeople would access ‘Google’ and type into the search box what information is required and click ‘search’. Users would then select sources based on the blurb underneath each title, and if they recognised the source. What differed between interviewees was the number of websites they claimed to check and compare prior to making a decision. They would keep looking if the information was inconsistent or they thought it was inaccurate.

With the development of the Semantic Web we are now observing opportunities for the development of automated systems which could discard information from particular sources and opportunities for knowledge ranking systems, warning messages (spoken and on-screen) and top tips that appear when the consumer enters the website. Also, the automatic monitoring of user input on forums.

Reputable organisations are responsible for filtering the Internet, and an approval system of sorts would be appropriate to monitor this. White and Hovitz (2009)
provided insight into how this could be developed suggesting ‘As Web content and search are evolving, such surveys conducted periodically and with different cohorts can help the medical informatics community to understand and track perceptions, activities, and outcomes associated with retrieving online health information’ [4].

Developers could learn from systems that have been created to regulate websites and look to gain the certificate for their websites. The HonCode certificate is expanding and is a way in which consumers can quickly identify a reputable website. Compliance with the HONcode principles is indexed with MeSH terms and HON labels with more than 8,000 sites in 102 countries which correspond to more than 10 millions pages indexed by Google 5 millions of webpages [29].

eHealth standardization is also aiding the control of the web. The importance of standardised, accurate, timely data and health information is important for health systems and services, particularly with the merge of the online and offline worlds. It was also highlighted that the security of this information, and privacy of personal clinical data, must be protected. It also emphasises that health-related global top-level domain names, including “.health”, should be operated in a way that protects public health [29].

5.0 Conclusion
Reviewing the literature brought to the researchers attention that there was a heavy focus on the term ‘Cyberchondria’. By definition this has strong negative connotations and puts too much emphasis on the Internet as solely exasperating the layperson’s anxiety. Laypeople use channels to different extents. Offline sources can trigger anxiety or more often uncertainties which lead them to the Internet. The findings of this research are quite similar to Nettleton (2005) who found that the use of the Internet meshes with other approaches to seeking help and advice and it is prompted by specific health needs [27].

Each layperson uses and favours different channels, collating their own epistemology. These can be of different depths depending on the individual and their lay ontology, hence why this research is labelling them channels and not sources. Someone with a medical background is understandably more likely to rely on their own background knowledge and confidently discern their findings elsewhere. Someone without computer literacy isn’t as likely to use this as it is not part of their everyday routine which would explain why those who are older are less likely to use online channels; they take fewer risks.

This research concludes that firstly: laypeople use multiple channels to acquire information supporting the work of De Mul (1999) who says that an ‘informationistic worldview’ ignores the underlying relationships between people that allow information to be produced and shared in the first place [30, 31]. Even if they do trust the source those questioned still draw on their own lay epistemology to discern the information. Seeking to discover the different channels used by laypeople can help to find out how information seekers can best manage conflicting, or overwhelming, information when confronted with messages from
multiple channels [32]. The concept of ‘info(r)mediation’, has received relatively little attention in the health or social sciences.

5.1 Recommendations
To account for those vulnerable groups, this research should assist the NHS and other medical institutions in the management of their response to patients’ queries and requests. This research puts forward the argument that there is a necessity and responsibility for practitioners to initiate discussion with patients about their use of the Internet and for them to direct them to reputable health websites. Regardless of limited skills in information retrieval or ‘shared decision making’ it has become increasingly expected of healthcare providers to expect patients to bring in information [13]. It is particularly useful to consider the fact that female partners are more likely to speak with their male partner about cautionary procedures when absorbing information via the media and Internet. This is important in light of a long-standing concern that men are not encouraged to find out about their own health [33].

As laypeople connect their online and offline realms, this research proposes that medical practices consider a portal that can be accessed easily by patients which clearly displays links to reputable sources. By incorporating this in the design of browsers, laypeople could be encouraged with tips (provided by the browser) which provide on-screen assistance in the discernment of information.

Where possible, it is recommended that the websites of health institutions continue to, or begin to, state that the site is only a source of information and should be used alongside other channels. Of those asked, no one used the Internet as a standalone sources but used other channels alongside this. Certainly some put a great emphasis on what they found on the Internet which is when these risks begin to arise.

5.2 Future Research
It is important that the literature does not place all potential risks solely on this medium without questioning the trustworthiness of other offline sources and their use. This is supported by Wathen et al (2008) who suggest that there has been too much attention on technology as a health info(r)mediator, using Brown and Duguid (2000) ‘We are increasingly prone to [i]nformation fetishism...the superficially plausible idea...that information and its technologies can unproblematically replace the nuanced relations between people’ [13, 32]. Consequently this research would recommend that a decline in the use of the label ‘Cyberchondriac’. It is important to recognise the concern that could develop in the minds of laypeople if they begin to label themselves as this.

In light of this, future research should address the Internet as part of the larger health communication system, not only focusing on information quality, but also addressing the inherently communicative and transactional quality of Internet use. Both interpersonal and mass communication concepts open avenues for investigation and understanding the influence of the Internet on health beliefs and
behaviours, health care, medical outcomes, and the health care system [16].
Finally, using a sample of people who would describe themselves as
hypochondriacs would be useful in evaluating the behaviour of this vulnerable
group.

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