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“That Should Be Left to Doctors, That’s What They are There For!”—Exploring the Reflexivity and Trust of Young Adults When Seeking Health Information

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ABSTRACT

This paper explores the health information-seeking practices of healthy young adults and how they assess and rank sources of information through a qualitative study. The findings show that participants (a) are strongly committed to searching for information about health and lifestyle, especially via the Internet; (b) healthcare professionals were perceived as the most reliable source of health information and advice; (c) online health information, although frequently accessed and experienced as empowering, is seen as a potentially unreliable source. Findings evidence how becoming better informed about health-related topics plays a pivotal role in individuals’ lives, most notably by using the Internet. Participants were able to reflect about what it means to know about health. The construction of trust regarding health information involved a heuristic process vis-à-vis source reliability and perceived credibility that places doctors as the most trustworthy medium of medical advice and health information. We conclude that participants’ trust toward professionals suggests the preference and need for more personalized care; and it is a response to the ambiguity and uncertainty that permeates the health information landscape, particularly that which is web-based.

Introduction

Information seeking is defined as “active efforts to obtain specific information outside of the normal patterns of exposure to mediated and interpersonal sources” (Niederdeppe et al., 2007, p. 155). People can also obtain health information through scanning behaviors, i.e. via incidental or routine exposure or browsing (Ruppel, 2016). Acquiring health information not only plays an important role in people’s lifestyles, well-being, and health management, but it is also a key component of widespread practices in today’s healthcare, such as shared decision-making and the involvement of increasingly “well informed patients” in medical interactions (Chiu, 2011; Han, 2012). People increasingly rely on health information mediated by sources other than health professionals, such as the Internet (Walsh, Hamilton, White, & Hyde, 2015).

There is a budding interest in the use of online searches for health purposes performed by young people. These so-called “Net generation” individuals, or “digital natives,” grew up within a context where the use of information and communication technologies (ICTs), especially the Internet, was highly encouraged (Selwyn, 2009), being more likely to be active online health information seekers (Fox, 2011). Young adults seek health information online driven by the fact that information from traditional sources does not meet their needs (Hu & Sundar, 2010), or when dealing with sensitive or stigmatizing issues, such as sexual health (Cohn & Richters, 2013); and also to monitor

doctors’ decision-making, prepare for future information demand, anticipate treatment outcomes, or self-diagnose minor symptoms (Beck et al., 2014; Genuis, 2012).

The surplus of health information made available by the Internet helped in the emergence of increasingly informed and empowered patients (Dobransky & Hargittai, 2012; Pitts, 2004). This has been perceived as a potential reconfiguration to the normative authority of biomedicine and in the way people access and evaluate health information (Wyatt, Harris, & Wathen, 2010). Increasingly, informed patients could transform the doctor–patient relationship and challenge professional expertise by enabling them to gain more control over their healthcare (Broom, 2005; Dedding, van Doorn, Winkler, & Reis, 2011). Such notion of informed patients as reflexive actors is prominent in many studies using the Internet, as a distinctive feature of contemporary social change in late modern societies (Kivits, 2009). Reflexivity in this context refers to how people engage with complex and sometimes competing and overabundant sources of information in terms of their allocation of credibility, reliability, and trust when trying to reach an informed choice (Giddens, 1991).

Although a number of studies have examined health information seeking practices among adolescents and young adults, there are only a few studies that explore healthy young adults’ experiences with health information seeking using qualitative methods. Therefore, this study

seeks to contribute to the literature as to the way young people who are not affected or identified as being at risk for any particular medical condition look for sources of health-related information and their level of trust in such information. The aim of this study¹ is to address the health information-seeking practices of healthy young adults, namely by exploring the hierarchies of credibility and pathways of reliability employed to assess and rank the information sources.

Methods

Participants for this study were recruited from a larger cohort of an ongoing longitudinal research program of the Epidemiology department of the Medical School of a public Portuguese university, in which participants were routinely checked for specific health dimensions (Bastos et al., 2013). Recruitment took place as follows: as participants in the mentioned research program would go for monthly routine follow-up appointments, the administrative staff would present them consecutively with basic information about our study; those who agreed to participate were provided with written information on the study; after their follow-up visit at the Epidemiology department, interviews for our specific study took place.

Fifteen interviews were conducted and these included the collection of basic sociodemographic data. Participants were healthy individuals born in 1990, without being diagnosed or identified as being at risk of a medical condition. The distribution of participants by gender was balanced—eight women and seven men. All of the participants were White European, single, lived in the metropolitan area of a northern Portuguese city, and were university students (with the exception of one who had already completed 6 years of higher education). Additionally, all of the participants described themselves as fairly frequent Internet users.

Interviews were conducted by the second author of this study, from May 2012 to March 2013, during the participants' visits to the epidemiology department as described above. On average, interviews lasted for 1 hour. Written consent was obtained before the interviews were conducted, and access to participants was granted by the relevant ethics committees.

A loosely structured qualitative interview guide was used to explore the knowledge of participants about the conditions relevant for the purposes of the main research project and their health information-seeking practices and sources of access to such information, with a particular focus on the Internet. Thus, this article presents data on the participants' information-seeking practices for health and illness issues and how they assess and rank sources of information. Participants were asked to talk about their health information-seeking practices on different media and sources, with a special emphasis on the Internet, and the motivations and circumstances associated with these practices, as well as describe how they assess and rank sources of health information in terms of

credibility and reliability. Interviews were audiotaped with the participants' consent. Sampling was used for maximum variation of views and experiences, but given the homogeneity of the sample, theoretical saturation was reached after 15 interviews—which was the point when no new, significant data emerged from data analysis (Strauss & Corbin, 1998).

The interviews were transcribed verbatim, and grounded theory methods of coding and constant comparison were used (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The transcripts were reviewed and read several times by two researchers (first and second authors), and to further enhance the validity of the coding approach, the development of the analysis was discussed by these two members of the research team. Open coding was used to illustrate the specific features of the data deriving from similar and recurring ideas and themes; coded data were then constantly compared within and between the transcripts to consistently identify linkages and patterns. A process of continuous refinement was undertaken by repeatedly reading the transcripts and grouping similar ideas into themes with the aim of developing content categories. These were then charted to cover the emergent themes and were systematically compared through discussion with a third research team member (third author).

Results

Three major thematic categories emerged from the analysis of the participants' accounts: 1) *making sense of seeking: the virtues of being informed*—contextualizes participants' information-seeking practices for health matters as active and informed patients/citizens; 2) *assessing health information-seeking online: empowering yet unreliable*—relates to online information seeking in which the merits and drawbacks of the Internet as a source of health information are approached; 3) *health information: hierarchies of credibility and reliability*—describes how participants assess health information in terms of credibility. What follows below is the individual discussion of each of these groups. Passages from the participants' interviews have been used to illustrate related key points (content in square brackets is used to add intelligibility to the participants' contribution and ellipsis dots indicate lapsed text).

Making Sense of Seeking: the Virtues of Being Informed

During the interviews it was clear that participants greatly valued having access to health information. Generally, their searches were triggered whenever they experienced symptoms, or when relatives or significant others became ill or shared specific health concerns, namely issues related to family history of disease. Health information seeking also occurred in disease-free circumstances, as a way to expand their repertoire of resources for a healthy lifestyle, namely fitness and dietary tips. The key motivation to seek health-related information was the improvement of participants' informational background, since “knowing more” was broadly coupled with better health and illness management:

¹This study was conducted within the scope of a broader research project aimed at evaluating the type of knowledge and access to health information by the Portuguese population, and which also included the methods and networks of how this health awareness was formed and acquired.

The more informed I am, the better, because I want to understand things, I need to know what's happening and where things come from (I., female).

The Internet was the most frequent source for health- and illness-related information used by participants. Finding general information about illnesses, treatments, and medication (including complementary and alternative medicines) was commonly described. Using the Internet to search for other people's testimonies in dealing with the same issue was equally mentioned:

I was depressed and even with regular consults I used to go online (...) to find out what people going through the same [condition] had to say. It helped me a lot to know other people's experience (R., female).

Despite its extensive use, online health information seeking manifested itself as a complementary tool to other sources of information (e.g. healthcare professionals, relatives and significant others, books, and other media), and was mostly sought based on personal initiative and without direct guidance from any healthcare professional:

I do my own search and it is not just for the sake of knowing, but also to, like...to feel that now I am better prepared because I already know in advance; and this makes me more confident (I., female).

Self-reliance regarding access to information, particularly e-health, also illustrates the relevance of self-care for the autonomous management of one's health. For example, A. presented herself not just as an active information-seeker who is eager to make appropriate choices to achieve a better health level, but also as being an effective Internet user:

A.: *I love looking into health stuff. I mean, it's my personality. I am kind of "hyperactive" in this sense [laughs]! I think this is me because I like searching, I know my way round the internet. For instance, I got this tattoo on my back and before I had it done I was worried about safety and cleanliness; I did an online search and when I went to have the tattoo done I knew exactly what sort of questions I should ask to make sure everything was done properly.*

Interviewer: *And do you use other sources of information?*

A.: *Yeah, the newspaper, magazines, TV... but then you need to buy them or be there to watch it.*

Assessing Health Information Seeking Online: Empowering Yet Unreliable

Participants set the stage for their assessment of the Internet by describing it as a "major achievement of society" and a useful resource as it grants the widespread access to health information. They further stressed its interactivity, but particularly valued the possibility of obtaining instant individualized information while preserving anonymity:

I remember when I first looked for information on menstruation. I don't talk much about these things with my mother; the Internet is a place where we can look for this type of information without feeling embarrassed (T., female).

The vast majority of participants implicitly shared this positive view of the Internet, and it was against this background, which

recognizes the merits of the accessibility of information by wider audiences, that participants reflected on its use. However, "dangers" were also acknowledged, namely the promotion of an excessive centeredness and preoccupation around health issues. Furthermore, the overload of available information online may hinder the identification and selection of reliable sources of information, thus thwarting the credibility of some of its content.

I think that the Internet has many virtues, but it also has its dangers. Anyone can create a blog or something of the like and publish anything they think worthwhile and so it is freely available, you simply enter and look for it, but sometimes the quality of the information is very low (H., male).

While some participants were skeptical about online-seeking practices by the Portuguese population because of the low literacy levels, others acknowledged their own individual limitations on how to access online health information, such as insufficient web-based navigation skills or limited Internet access:

I think that [difficulties arose because] I started to use the Internet too late and then I read everything and I didn't know exactly how to filter the best sites and in which information I should believe (R., female).

Health Information: Hierarchies of Credibility and Reliability

The fact that virtually "anyone" can produce health-related contents online is perceived as a potential source of bias because reliable information might be difficult to identify. Participants ranked the Internet as generally less reliable than other sources of information. When asked about how the search for health and medical information would be processed in the event of having a health problem, participants described talking directly to a doctor as the most trustworthy way of obtaining information. Books are also seen as a reliable, although potentially outdated source of information, in contrast to the Internet, which is perceived as an appropriate channel to retrieve up-to-date information, despite its credibility issues:

The Internet has an enormous offer in terms of information, which makes it difficult to filter what is really trustworthy and what I want to know (...) I think that books are somehow more reliable because they are written by experts and the information is simple and always there, it cannot be changed with dubious contents, like what happens with Wikipedia, for instance (D., male).

Participants also described a set of rules aimed at evaluating the credibility of online information. The most frequent factor of reliability mentioned by participants was the identification of an "institutional seal," such as a link to a university or a hospital, or a public or governmental institution:

Interviewer: *How do you rank the credibility of online health information?*

H.: *First of all, if the information is from a university or a hospital, I believe it is [reliable] and I also look at webpages from the Ministry of Health; blogs are not [reliable] (H., male).*

Moreover, health information from public sources was perceived as more credible than the information found in sources produced individually. However, this was not the

case if the source was a well-established and/or recognized doctor:

Yes, I take it [a doctor's homepage] as more reliable because the doctor must know what he is saying, I mean, they are the professionals, the specialists, right? (C., female).

Scientific papers and information boards belonging to professional associations were also regarded as reliable, and the same was true for medical databases that were linked to scientific publishing sites (e.g., PubMed). In contrast, information gathered through the websites of pharmaceutical companies was perceived as influenced by commercial interests and, so, taken as misleading. Sites in English were also privileged over material written in Portuguese; the type of documents available online was also mentioned as a criteria (PDFs were preferred). Excessively intimate or personal information, like the one shared in chat rooms or relayed through personal testimonies, was ranked differently by participants (ranging from reluctance to usefulness) because it was the object of common complaints and questions; perusing the comment sections and/or frequently asked questions areas to look for similar questions and answers as their own was also mentioned. The layout of the site also seemed to be relevant when assessing the credibility of the source: sobriety is paralleled with scientific sensibility, while exuberant colors and animation is perceived as sensationalist. Finally, the use of scientific language is greatly valued, even if this demands a significantly higher effort to fully understand the message:

I prefer a scientific paper with more complex language rather than basic information, even if I need more time to understand it. If something is scientific and has been published, it must have been approved by experts (I., female).

Some participants often engage in repetitive searching schemes by using common search engines such as Google. In this process, different sites are compared until participants find consistency between sources or possess enough information. This process also takes into account and integrates their previously held knowledge conveyed to them by their relatives or by healthcare professionals. However, this self-obtained knowledge does not replace the one acquired through doctors, who are still seen as the most reliable source of advice and information on health:

*I think that certain things should be left to doctors. That's what they are there for! Even if the Internet helps us and gives us answers, the advice from my doctor gives me more confidence (...)
I trust my doctor 100% (S., female).*

Discussion

This study highlights how and why participants seek, identify, and select health-related information, and the rules they follow to decide if the information is or is not reliable within the considerable mass of information that exists online. Participants in this study utilized health information sources mostly to outline health management strategies, drawing on others' experiences or as a complementary tool to other (more formal) sources of information, such as health professionals. Health professionals were described as the most credible and

trustworthy source of health information, even for young adults, who are accustomed to turning to the Internet for every information need. Accessing information online was described as the primary means of obtaining health-related information, which reflects the ubiquitous role played by the Internet and social media in young people's lives. This aligns with recent research on health information-seeking practices among young adults (Fergie, Hilton, & Hunt, 2015).

Participants also reflected on the role of the Internet as a source for gathering information about health, while discussing actively how they assess and rank it between evidence-informed, professionally produced content and user-generated content. This reflects how the Internet epitomizes the porous boundaries between lay and professionally produced health information, in line with Nettleton's concept of e-escaped medicine (Nettleton & Burrows, 2004). Participants not only highlighted the merits of the Internet, but also stressed its potential unreliability. This ambiguous view is reminiscent of the general lay conceptions about the information age and the risk society (Dutton, Blank, & Groselj, 2013), which suggests the construction of trust regarding health information as involving a heuristic process vis-à-vis source reliability and perceived credibility. Participants' accounts on reliability and trustworthiness were similar to previous studies of everyday engagement with health information online (Kivits, 2009; Nettleton, Burrows, & O'Malley, 2005). In doing so, participants were also being reflexive and responsible citizens, striving for more information for the sake of healthy living through the employment of rational reasoning over their choices. Nonetheless, the opposite was also observed in that there is a reluctance to be immersed in an excessively informational environment, which establishes how to be healthy. However, our participants perceive health professionals as the most reliable source of health information and advice.

Participants' assessments on source credibility and reliability place doctors as the most trustworthy medium of medical advice and health information (Chiu, 2011; Sillence, Briggs, Harris, & Fishwick, 2007). The relationship with their doctors was perceived by participants as a crucial aspect in their understandings of "what it means to know about health." This may be due to the centrality of the figure of the doctor as the main source of information and knowledge on health for the Portuguese population, as well as the centrality of the universal and tendentiously free National Health Service in the life of Portuguese citizens (Cabral & Silva, 2009). This context may explain the indisputable trust placed on doctors' expert discourse, and the prevailing normative authority of medicine and the doctor-patient relationship in matters of health (Lupton, 1997).

Implications

The findings of the current study shed light on some important implications for "reaching out" to "digital natives" with health information. For example, the participants inferred greater credibility if the online information was originated from public sources and in a PDF format and a specific layout (as well as in English and scientific language). In order to enhance the health literacy in the general population, these aspects should be taken into account if our aim is to improve

the availability and accessibility of online information and support for health. This study also points the need to look at the interface between young people and healthcare professionals. Since professionals are seen as the most trustworthy sources of health information, they should be encouraged to explore opportunities for synergy between Internet searches and subsequent consultations, namely learning which sources were used and how patients intend to act upon the information they found.

Limitations

As many other exploratory studies, the limited size of the sample restricts the scope to generalize the findings of information-seeking practices more broadly, but it provided us with very interesting meta-themes to contribute to literature. Although our aim was not to make generalizable empirical claims, rather to understand the data qualitatively, data collected from larger samples might reveal additional insights on the topic; mostly, it allows comparisons taking into consideration socioeconomic and demographic variables (such as gender and socioeconomic status, health status, and Internet experiences). The sample characteristics can also be seen as a limitation of this data corpus: our participants are part of an age-specific group often called “digital natives,” who have been characterized as technology-savvy, i.e. possessing solid technology knowledge and skills, notably access and use of the Internet; also, nearly all of the participants were healthy university students. Other demographic groups may be less likely to use the pointed out health information-seeking channels. The extent to which our findings can contribute to debates about “digital divides” based on socioeconomic status and social position on information-seeking practices may be therefore limited. More qualitative work with a different population would offer additional input on what factors might have on health-related information-seeking practices.

Conclusion

The relationships established with healthcare professionals remain a crucial aspect in healthcare management and in this study they seem to trump information found online. Participants’ allocation of trust toward professionals may suggest their preference to be engaged in personalized care as a response to the ambiguity and uncertainty that permeates the health information landscape, particularly that is web-based. Despite the accessibility of online information, its credibility still needs to be endorsed by healthcare professionals. Even though engagement with information-seeking practices is touted as a key outcome in health (self-)care, our findings suggest the need to pursue health communication policies that can promote reliable health information and can be accessible to the general public. However, perhaps more importantly, communication applied to health should acknowledge individuals as “selves in relation,” rooted in the circumstances of one’s life, so that communicational channels could go beyond

formulaic information sites and simplistic assumptions of human rationality.

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