Evidence Summary

Individuals with Chronic Conditions Want More Guidance from Health Professionals in Finding Quality Online Health Sources

A Review of:
Lee, K., Hoti, K., Hughes, J. D., & Emmerton, L. (2014). Dr Google and the consumer: A qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *Journal of Medical Internet Research, 16*(12), e262. http://dx.doi.org/10.2196/jmir.3706

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Abstract

**Objective** – To explore how and when individuals with chronic health conditions seek out health information online, and the challenges they encounter when doing so.

**Design** – Qualitative study employing thematic analysis.

**Setting** – Urban Western Australia.

**Subjects** – 17 men and women between 19 and 85 years of age with at least 1 chronic health condition.

**Methods** – Participants were recruited in late 2013 at nine local pharmacies, through local radio, media channels, and a university's social media channels. Participants were adult English speakers who had looked for information on their chronic health condition(s) using the Internet. Semi-structured face-to-face interviews were conducted with each participant, audio recorded, and transcribed. The transcripts were coded in QSR Nvivo using two different processes – an initial data-driven inductive approach to coding, followed by a theory driven analysis of the data.

**Main Results** – Three major themes emerged: trust, patient activation, and relevance. Many of the participants expressed trust both in health professionals and in the efficacy of search engines like Google. However, there
was uncertainty about the quality of some of the health information sources found. Searching for information online was seen by some participants as a way to feel more empowered about their condition(s) and treatment, but they reported frustration in finding information that was relevant to their specific condition(s) given the volume of information available. Low health literacy emerged in participant interviews as an intrinsic barrier to effective online searches for health information, along with low patient motivation and lack of time. The many extrinsic barriers identified included difficulty determining the quality of information found, the accessibility of the information (e.g., journal paywalls), and poor relationships with health care providers.

**Conclusion** – Individuals look for online health information to help manage their chronic illnesses, but their ability to do so is influenced by their levels of health literacy and other external barriers to effective online navigation. Consumers may prefer to receive recommendations from health professionals for high quality health websites rather than training in how to navigate and identify these resources themselves.

**Commentary**

This study meets many of Tracy’s (2010) eight “big tent” criteria of good qualitative research. According to Tracy, “high quality qualitative methodological research is marked by (a) worthy topic, (b) rich rigor, (c) sincerity, (d) credibility, (e) resonance, (f) significant contribution, (g) ethics, and (h) meaningful coherence” (p. 839). Firstly, the study addresses a topic of clear importance. According to the World Health Organization (2014), chronic diseases caused 68% of all deaths in 2012, an estimated 38 million people. Few previous studies on health information seeking behaviour have focused on the particular needs of those grappling with chronic illnesses, and as such this study fills an important need (Greyson, 2015; Lee, Hoti, Hughers, & Emmerton, 2014). The researchers demonstrate the qualities of “rich rigor,” “meaningful coherence,” and “sincerity” by providing a very detailed description of the data collection, interview questions, and process of data analysis, and by clearly identifying the reasons behind the choices made in the study’s design (Tracy, 2010). The credibility of the findings is further enhanced by the decision to triangulate the findings by subjecting the data to two different forms of analysis involving multiple researchers.

The article would benefit from more detail, such as more information about the backgrounds of participants. Rather than providing the usual demographic table, only brief details about participants are provided. Participants’ highest levels of education and exactly how many fell into each age range are not made clear. Age and education have been linked with levels of health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006), and as such these details are relevant. It would have been helpful to have the researchers’ definition of chronic illness, particularly with regard to the recruitment process. Providing the wording used to help individuals self-identify would also have been helpful, and would not have compromised the privacy of participants. Particulars of the Australian health care system in which participants were operating would place their comments about the accessibility of health care professionals into context. Finally, like many other studies on health information seeking behaviour, no reference is made to existing theories around information seeking throughout the study (Devon, 2015).

It is notable that while participants expressed interest in more guidance from health professionals in finding quality health sources, information professionals and librarians were not mentioned in the study as potential partners in this work. The authors are trained as pharmacists, and this professional lens and background may have led to the limited appearance of references from information science journals investigating similar concerns. In their follow up quantitative study with a similar population (Lee, Hoti, Hughes, & Emmerton, 2015), the researchers highlighted the possibility of health professionals taking on a larger role as a trusted curator of online health resources or search advisor.
professionals may also be able to play this role to some extent, but this research suggests we should also work to address some of the extrinsic barriers consumers encountered in how health information resources were designed and made available, rather than focusing too narrowly on training users to navigate around roadblocks. The findings of this 2014 study may be of interest to information professionals providing consumer health information or training health professionals in information literacy skills, highlighting areas for future collaboration.

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