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Oral Presentation / Research stream

"Where does my health information come from?": Information sharing in peer-to-peer health communities.

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Abstract

Background: Peer-to-peer health networks such as online discussion forums have created new ways for people, especially those living with a long term condition, to access health information. There have however been concerns about the quality of information, and the ability of the public to understand and evaluate that information [1, 2]. The term "apomediation"[3] has been used to describe the shift from professionals as the information gatekeepers, to individual-led signposting or use of technology-based solutions such as bookmarking.

This abstract presents the findings of a study analyzing how people using online discussion boards adopt this apomediation role, the types of information they share, and how they share this information.

Methods: Four discussion boards for people living with diabetes were selected for inclusion in the study, based on the volume and frequency of new posts. Ethical approval for the study was given by Bournemouth University, England. A snapshot approach was taken, with all threads started within a one week period in 2014 retrieved for possible inclusion. All retrieved posts were read, and posts that shared diabetes-related information were selected for inclusion in the study.

A qualitative content analysis approach was taken to data analysis, with the researchers reading all posts rather than using electronic data extraction methods because of the frequent use of 'web speak'/ abbreviations.

Results: A total of 148 posts were included for analysis, with posts often containing several types of information sharing activity. Two key themes were identified: "Information sharing from experience"; and "Signposting other sources of information". Experiential experience included sub-themes of "self-management strategies", "living with diabetes", "nutrition", "medication" and "healthcare interactions". Signposting included links to other areas of the same site and to external sources. The majority of external links were to websites, but YouTube, blogs and apps also featured. Research was signposted several times, although the problem of accessing research was also commented on as much of it is not openly available to the public.

Nine posters made some reference to quality of information, which included supporting previous posts and highlighting that the discussion board contributors were not healthcare professionals. The use of the term "Your Mileage May Vary" also indicates that what works for one individual may not work for another.

Conclusions: The individuals posting in this study did not make use of technology-based services such as shared bookmarks, preferring to signpost external resources individually (usually with comments about the type of information or the reason they were suggesting it). In spite of some posters warning that the site did not offer medical advice, the information shared included information that could be considered to be medical in nature, e.g. information about medications, diagnostic tests, and ways of managing blood sugar levels.

Peer-to-peer information sharing between people living with a long term condition challenges the nature of knowledge and expertise. The public are able to gather information from a wide variety of sources, and combine it with their own experience, testing what works for them and sharing that information back into their communities.

Conference website <http://medicinex.stanford.edu/program-2015/>