How doctors on social media can provide valid health information on novel coronavirus

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Abstract

In the wake of COVID-19, the information stream has overflowed with a mixture of valid knowledge, misinformation and constantly changing guidelines. The need for help in navigating what is trustworthy health information is great and the official channels are struggling to keep up. As a consequence we created a Facebook group where volunteer doctors would answer questions from laymen about the novel coronavirus. There is not much precedence in healthcare professional driven Facebook groups and the framework was thus invented on the go. We ended up with an approach without room for debate to keep the group calm, trustworthy and safe to enter for the inquirers. Substantial moderator effort was needed to ensure high quality and consistency through collaboration between the more than hundred doctors participating. In the end we were able to provide a much needed service to more than 34.000 people in Denmark in time of crisis.

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Viewpoint

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Abstract

In the wake of COVID-19, the information stream has overflowed with a mixture of valid knowledge, misinformation and constantly changing guidelines. The need for help in navigating what is trustworthy health information is great and the official channels are struggling to keep up. As a consequence we created a Facebook group where volunteer doctors would answer questions from laymen about the novel coronavirus. There is not much precedence in healthcare professional driven Facebook groups and the framework was thus invented on the go. We ended up with an approach without room for debate to keep the group calm, trustworthy and safe to enter for the inquirers. Substantial moderator effort was needed to ensure high quality and consistency through collaboration between the more than hundred doctors participating. In the end we were able to provide a much needed service to more than 34.000 people in Denmark in time of crisis.

Keywords

Introduction

We are facing a COVID-19-infodemic, and the immense information load complicates navigating what is trustworthy health information [1]. The substantial growth of the news-stream has resulted in a dilution of relevant and reliable information. Because of the novelty and worldwide spread of COVID-19 we learn more about the virus every day and deal with almost daily changes to the clinical recommendations. This is confusing for the public and for the healthcare professionals. In April 2020 Limaye et al. called for healthcare professionals to accommodate this by building trust on social media[2]. In this viewpoint we report on a grassroot e-health literacy project in Denmark, where we have built a network comprising 187 volunteer doctors delivering up-to-date knowledge to a broad audience in a Facebook group with thousands of members.

Health information on Social Media

The Internet has become the primary source of health information for many people despite often being unable to verify the reliability of the clinical evidence available online [3,4].
The emergence of Web 2.0 has further moved the development from top-down information distribution to platforms for collaboration, dialogue and content-sharing.
One of the most significant components of Web 2.0 is social media such as Facebook with about 2.4 billion users[5]. Since Facebook launched its community pages function in 2010 it became possible for people to create health-related groups turning into larger interactive communities[6]. Online communities provide a space for social support, experiential knowledge sharing, and a collective voice[7]. Layman-friendly explanations of medical terms help patients have more positive experiences when visiting their healthcare providers, thus improving the doctor-patient relationship[8]. However negative reactions from healthcare professionals about patients' social media activity might negatively affect patient-doctor symmetries[9] which underline the need for healthcare professionals to engage on social media to facilitate the positive dynamics.

With COVID-19, many new communities have been established on Facebook and with them a risk of misinformation being widely shared. The bombardment of emotionally evoking information makes it difficult for individuals to distinguish between good information and misinformation[10]. Although Facebook mainly is a lay-driven platform, health institutions, patients' societies and healthcare professionals are increasingly creating their own groups to meet patients where they are. As this is a rather new phenomenon, little research remains on the effect of Facebook groups created and moderated by healthcare professionals. First experiences indicate difficulties in establishing, disseminating and scaling such networks on Facebook[11].

The Facebook group

In response to the infodemic we initiated the Facebook group "Spørg en læge om coronavirus" meaning "Ask a doctor about coronavirus" on March 15, 2020 (Figure 1). The group was sparked by the sudden rise in waiting time on the acute medical telephone services and grew quickly and grows continuously to now 35.000 members (about 6‰ of the entire danish population), and approximately 187 doctors answering questions.

The rules are conservative. Group members can post a question that one of the doctors in the role of administrator can either accept and answer or reject. About 30% of the incoming questions are rejected due to violations of group rules, typically accompanied with an explanation for the rejection. All unauthorized answers, politically motivated comments and personalized health information are rejected. In parallel to the main group, where laymen ask questions and doctors give answers, we have a closed administrative doctors-only group used for sharing of guidelines, news, warnings against popular myths and debate.

Running a group of more than a hundred volunteer doctors takes active managing. Early on we realized that rules and structure were essential to make every doctor feel safe. We chose a narrow approach, without room for discussion of the answers. Soon after a doctor has answered a question in a post, the thread is closed for further commenting. This approach was chosen because of logistics – it would be too time consuming for the doctors to ensure the validity and relevance of information posted freely in a thread. Surprisingly, the response from the users have been overwhelmingly positive. The calm and safety of the short threads of only doctor-validated answers has proven a valued factor, indicating a recognition of the need for authoritative sources, as a supplement to existing peer-groups on Facebook.

In the ongoing stream of new questions, we have a fine-tuned barometer to what is going on in the media world, including circulating fake news that are consequently dominating the content of the questions. We see a great perceptiveness in the users to any inconsistency in the answers from different doctors and quite quickly identify any disturbance in the sought sense of safety and security in the users. It is very literal; fear and insecurity are directly articulated in the questions and comments, confirming that to feel safe and in control is key in being e-health literate[12].

Meeting this need with consistency and empathic patience when answering, demands a considerable degree of active community building among the volunteer doctors. We have key administrators easily approachable for debriefing and conflict solving between the doctors in addition to a messenger thread for discussion of news and challenging questions as well as a more free and informal conversation, thus creating a safe space for critical feedback. The messenger thread and personal messages between the volunteer doctors contribute to a supportive peer interaction and real

personal connections. Few of the doctors knew each other beforehand, and we have watched how close relationships have evolved.

Once the workflow was established and the legal implications were cleared up, we had a running proof of concept. This, in turn, made recruitment of volunteer doctors via Facebook medical communities easier, as many had hesitated before seeing a working setup. We have mobilized working doctors as well as doctors otherwise excluded from contributing to the COVID-19 workforce due to sick leave, maternity leave, pregnancy or quarantine, all working from home on their own conditions. This provides an indispensable workforce for the group as well as meaningfulness to the doctors marginalized in this time of crisis.

Recruitment of the users worked by sheer diffusion. We have not had any control over how broad the group would travel. Starting out sharing the group in our own networks, the group has naturally grown from there. Some answers are shared in private networks and closed groups, thus expanding the awareness of the group and the service we provide. This is a compliment to the degree of trustworthiness our group has met, but also a point of consideration for every doctor in every answer given. They must all hold up to publication out of context.

A large portion of the questioners hold a low degree of e-health literacy[12]. Many answers are readily accessible on the public information sites, but the ability to navigate the information environment of the COVID-19 situation and apply the guidelines to their own everyday lives have been inadequate. At the other end of the spectrum, we find that many questioners show a high degree of health and science literacy. They ask about complex preliminary scientific discoveries embellished with distortionary clickbait headlines, recognizing their own limitations in interpreting such complex data. This diversity in the questions underlines a need for doctors of different backgrounds answering different questions in different tones and temperaments. Consequently, the challenge of keeping answers consistent coexists with the strength of the diversity in the group of doctors.

Future perspectives

We created a Facebook group to counteract misinformation and help people feel safe in a stressful time. The group has no funding, yet 35.000 unique members have joined, indicating a need for this type of health service. In the group we demonstrate classical one-to-one counseling and at the same time one-to-many communication where answers are seen by all members thereby illustrating the current discourse of health communication; where a newspaper article can spark a personal discussion in the comment section while a recording of an individual consultation can be distributed on social media. One can thus argue that we here illustrate the future health communication premise awaiting every doctor.

Our experience with this group provides unique insights into the potential of Facebook in health communication, but we cannot ignore the distinctive information-seeking environment of the COVID-19 pandemic providing an advantageous foundation for dissemination and upscaling. The extent and the validity of research on a health professional driven social media platform should be further explored, preferably with a multidisciplinary approach, using an array of methodologies. Firstly, investigating development in behaviour, e-health literacy, professional identity and impact on doctor-patient-relations. But the platform could also provide insights into patient adherence, navigation of health services, experiences of effect of new treatments, management of common and rare diseases, and peer collaboration and communication. Consequently, further research on health professional driven social media platforms is relevant, and insights from this group should be further

explored.

The group, "Spørg en læge om coronavirus" was never intended to be a research project. The research potential was only recognized months after launch. It is part of a spontaneous health professional driven emergency response at a unique moment in time where all stepped up to contribute to their community in any way they could. This is a weakness to the research potential of the data. But it adds a distinctive value of authenticity.

Post scriptum: On September 17, 2020, the World Patient Safety Day, the group received the Danish Patient Safety Award 2020 in recognition of the work to promote health understanding and a sense of safety through knowledge.

Acknowledgement

Contributions

E.B.O., A.P. and D.F. are core administrators and initiators (E.B.O. and A.P.) of the Facebook group and developed the concept of this Commentary. The paper is written by E.B.O., A.P., N.K., and D.F.. J.S. provided insights in the direction of the content. All authors contributed to the editing of the paper.

Competing interests

The authors declare no competing interests.

References

1.   World Health Organization. Novel Coronavirus (2019-nCoV): situation report, 13. World Heal Organ. 2020.

2.   Limaye RJ, Sauer M, Ali J, Bernstein J, Wahl B, Barnhill A, Labrique A. Building trust while influencing online COVID-19 content in the social media world. Lancet Digit Heal [Internet] [doi: 10.1016/S2589-7500(20)30084-4]

3.   Jones E, Sinclair JMA, Holt RIG, Barnard KD. Social Networking and Understanding Alcohol-Associated Risk for People with Type 1 Diabetes: Friend or Foe? Diabetes Technol Ther [Internet]; 2013;15(4):308–314. [doi: 10.1089/dia.2012.0327]

4.   Wikgren M. Health discussions on the Internet: A study of knowledge communication

through citations. Libr Inf Sci Res JAI; 2001 Dec 1;23(4):305–317. [doi: 10.1016/S0740-8188(01)00091-3]

5.   Myers J. Nearly a third of the globe is now on Facebook - chart of the day. World Econ Forum [Internet] 2019 [cited 2020 Jun 18]; Available from: https://www.weforum.org/agenda/2019/08/facebook-users-social-media-internet/

6.   Kingod N. The tinkering m-patient: Co-constructing knowledge on how to live with type 1 diabetes through Facebook searching and sharing and offline tinkering with self-care. Heal (United Kingdom) [Internet]; 2020;24(2):152–168. [doi: 10.1177/1363459318800140]

7.   Kingod N, Cleal B, Wahlberg A, Husted GR. Online Peer-to-Peer Communities in the Daily Lives of People with Chronic Illness: A Qualitative Systematic Review [Internet]. Qual Health Res. SAGE Publications Inc.; 2017:89–99. PMID:27956659

8.   van Uden-Kraan CF, Drossaert CHC, Taal E, Shaw BR, Seydel ER, van de Laar MAFJ. Empowering Processes and Outcomes of Participation in Online Support Groups for Patients With Breast Cancer, Arthritis, or Fibromyalgia. Qual Health Res [Internet]; 2008;18(3):405–417. PMID:18235163

9.   Smailhodzic E, Hooijsma W, Boonstra A, Langley DJ. Social media use in healthcare: A systematic review of effects on patients and on their relationship with healthcare professionals. BMC Heal Serv Res [Internet] 2016 Aug;16:442. [doi: 10.1089/dia.2012.0327]

10.   Vestergaard M, Hendricks VF. Fake News : Når Virkeligheden Taber. 1. udgave. Kbh.: Gyldendal; 2017. ISBN:978-87-02-24726-8

11.   Cobb NK, Graham AL. Health behavior interventions in the age of facebook. Am J Prev Med [Internet] Elsevier Inc.; 2012;43(5):571–572. [doi: 10.1016/j.amepre.2012.08.001]

12.   Norgaard O, Furstrand D, Klokker L, Karnoe A, Batterham R, Kayser L, Osborne RH. The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e- health systems. Knowl Manag E-Learning 2015;7(4):522–540. [doi: 10.34105/j.kmel.2015.07.035]

Figure

Figure 1: Screenshot from the Facebook group "Spørg en læge om coronavirus", meaning "Ask a doctor about coronavirus"

Supplementary Files

Figures

Screenshot from the Facebook group "Spørg en læge om coronavirus", meaning "Ask a doctor about coronavirus".