Title: Superusers engagement in asthma social media: motivation, challenges and potential interactions with healthcare professionals

Problem: Superusers, defined as those who write a large number of posts, play critical roles in online health communities (OHCs), structurally holding the network together, catalysing engagement and influencing self-care behaviours of other users. Little is known about their motivation for engagement, the challenges they face, and their interactions with healthcare professionals (HCPs). Our previous work showed the emergence of 10-20 superusers among 3,345 users of the Asthma UK OHC. Taking part in online communities for people with long-term conditions improves self-management, adherence to treatment, facilitates shared decision-making with HCPs. There is increasing attention on health social media, and a need to elucidate the mechanisms that make OHC engagement successful.

Approach: Online cross-sectional survey. The questionnaire was developed based on OHCs literature, our previous OHCs studies and face-to-face discussions with superusers. Superusers of the Asthma UK OHC and Facebook groups were initially recruited through Asthma UK moderator to pilot the questionnaire and subsequently to complete the survey. Open-ended questions were analysed using qualitative content analysis. We chose to do a qualitative survey to address our study aims and gain superusers’ perspectives. A thematic analysis was done to see common findings and then coded.

Findings: 17 superusers were recruited (15 patients with asthma, 2 carers), 15/17 were female; age range: 18-75y, were active in OHCs over 1-6 years, spending between 1-20 hours/week (median 2 hours) reading and 1-3 hours/week (median 0.75hours) writing posts. 10/17 users participated in two or more OHCs. Superusers participation in OHCs was prompted by curiosity about asthma and its medical treatment and being unwell. Their engagement increased over time as participants furthered their familiarity with the OHCs, interest in community members, awareness, knowledge and confidence of asthma and its treatment. Superusers were altruistic: financial or social recognition of superuser role was not important; their reward came from helping and interacting with others.

According to the replies provided, they showed careful judgement to distinguish what can be dealt with through peer support/advice and what needs input from HCPs. Difficulties were encountered when dealing with: misunderstandings about asthma and its treatment; patients not seeking advice from HCPs when needed; miracle cures or dangerous ideas. 3/17 stated their HCPs were aware of their engagement with OHCs. All superusers thought HCPs should direct patients to OHCs, provided they are well-trusted and moderated. 9/17 felt HCPs themselves should take part in OHCs.

Implications: Superusers from a national online community comprising thousands of patients with asthma and their carers are altruistic, mostly female individuals who exhibit judgement about the complexity of coping with asthma and the limits of their advice. Further work should explore how to address their difficulties and unmet needs, their interactions with HCPs and the integration of OHCs in traditional healthcare.


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