

**Supporting Good Intentions with Good Evidence:
How to Increase the Benefits of Diabetes Social Media**

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Key words: peer support, social media, diabetes, online information-seeking

Word count: 2539

Figures: None

Tables: None

38 **Abbreviation List**

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40 PWD - People with diabetes

41 HCP - Healthcare professional

42 DOC - Diabetes online community

43 DUK - Diabetes UK

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Abstract

Social media provides a platform for easily accessible, relevant health information and emotional and practical support at the touch of a button for millions of people with diabetes. Therein however lies a challenge. The accuracy and reliability of such information is often unknown and unverified, not all interactions are deemed supportive; practically or emotionally, and not all members of society have equitable access. Cyber bullying, requests for personal information and uninvited sharing are among the risks associated with social media, yet the use of online social media is increasing exponentially. Such reliance on web-based health information has given rise to concerns about patients' ability to accurately assess the credibility of online sources as well as the potential detrimental effect on personal well-being and patient-provider relations. In addition, there are rising digital disparities for particular sub-populations. Further, these concerns apply to where and how healthcare professionals should engage or refer patients to in terms of platforms of online support. . There is little doubt regarding the popularity of social media, both within and outside of the health arena but there are also concerns. This article outlines five key areas associated with social media use in people living with diabetes and presents potential considerations moving forward. We focus on: 1) social media as a platform for information and support; 2) social media interactions that are not supportive; 3) lessons from the DOC; 4) concerns about accuracy, reliability and accessibility of information; and 5) differing priorities of healthcare professionals and patients.

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Introduction

The internet offers the opportunity to enable practical, discrete and cost efficient access to health information and support, especially where this access may otherwise be beyond reach (1, 2). These opportunities are enabled through a multitude of access points including; e-health interventions, apps, digital clinics, decision support software, health forums and websites providing gaming opportunities, peer-support groups or health information (3-5). We are now seeing increasing interest in these digital health opportunities to deliver treatments for diabetes and other chronic diseases from the financial, academic, and regulatory communities (6). Seeking health information in these ways is a relatively new phenomenon that can provide millions of people worldwide with relevant and easily accessible health data and support and appears to be a growing trend. In 2001 it was reported that 15.9% of American adults looked for health information online, and this number rose to 72% in 2012 (5). In 2014 it was reported that over 75% of Europeans considered the internet a useful resource to search for health information (7). Connecting to others online for health support has become a distinct method of help-seeking and social media has become a vehicle for widespread access to information and support, but this paradigm does not come without challenges. The ease of access to information and support via social media coexists with four significant concerns, including that: 1) the accuracy and reliability of such information is often unknown and unverified, 2) patients' might not be able to accurately assess the credibility of such information (8), 3) there is a potential for cyber bullying (9) and 4) there can be a potential detrimental effect on patient-provider relations (8). This commentary seeks to explore five key issues of contention concerning social media use in diabetes and suggest considerations for moving forward to increase the benefits of this burgeoning tool.

Social media as a platform for information and support

The use of web-based access to support and information has grown alongside rapid advances in mobile technologies which have led to a blending of face-to-face and online interactions, facilitating novel processes of interaction with health care systems. There is a growing use of email contact between patients and healthcare professionals (HCPs), Skype consultations and e-health interventions (10-12). However, while e-health (electronic technologies related to giving and managing health care) is becoming more mainstream in traditional health settings, patients are also looking elsewhere for health support (13). This is not entirely surprising considering that those living with diabetes spend such a small amount of their time with HCPs (1%) compared with the amount of time dedicated to self-management activities; and that 40-80% of medical information provided in health consultations is forgotten immediately (14).

There is considerable evidence that the use of the Internet can be associated with improved health outcomes, not only through the delivery of health information but also through facilitation of peer and social support on a grand scale (15). Access to online peer-support could potentially enable people to access or address issues together that have not been dealt with (at least not satisfactorily) in traditional interpersonal settings (5, 13, 16). This evidence is underpinned by four psychological theories, including 1) social identity theory (17), 2) social impact theory (18), 3) social comparison theory (19) and 4) positive reinforcement through operant conditioning (20). For example, peer support is known to be associated with improving feelings of self-efficacy and group belonging (21). Allen et al. (16) found web-based peer-support to be of particular pertinence when HCPs, friends and family members were not in a position to provide desired self-management support. Further, Litchman et al.'s (22) cross-sectional study on diabetes online community (DOC) engagement found that people with diabetes who were interactive with the DOC were more likely to have better blood glucose levels, better quality of life and more resources for self-management than those who were not as interactive. They suggest that the online community provided a source and encouragement of

knowledge-seeking and support, which in turn benefited participants' ability to self-manage. Social media is a platform for information and support. Online communities through social media platforms appear to offer the opportunity to access support and engage with community members in ways that require less work and maintenance than offline friends and family members. This in turn may enable a wider and more diverse support network than would be accessible without being a member of an online community.

Social media interactions that are not supportive

Social networks and good social support can have positive effects such as: 1) promotion of self-management, 2) development of fewer psychosocial problems and 3) creation of a buffering effect during stressful situations (21, 23-25). However, there is more to social media than may initially meet the eye. It is clear, however, that there is a potential impact of unsolicited "support" received online, which may lead to decreased self-esteem. The charity, Diabetes UK, lists a number of different online communities and social media platforms on their website as 'a great source of information and support' for the diabetes online community (26). This organization clearly establishes that they do not run the groups, but acknowledges the importance of support provided by online communities. There is understandably no guarantee of safety, but rather simply a statement that "we want our supporters to be able to talk to us and each other online in an environment that is informative, supportive, engaging and – most importantly – safe" but they do not provide guidelines on how to ensure that these goals will be met.

Greene et al. (27) examined posts in Facebook groups focused on diabetes management and reported that >13% of the feedback received was at the request of users, and >28% was considered "emotional support". However, the majority of posts included a mixture of uninvited sharing of self-management strategies, requests for personal information or non-FDA approved product advertising. They found neither accountability nor checks for authenticity. There can also be concerns around how an online

community identity and authority are established, as well as how resulting issues are resolved and boundaries set. Armstrong et al. (28) sought to explore online communications in a closed diabetes community. Data came from a purpose-built discussion board, only available to participants participating in a research project that was part of a broader study of an internet-based diabetes self-management tool. They found that the purpose and identity of the community were established early on, and examined how these factors then shaped interactions. They was found that community members actively negotiated and enforced boundaries, as well as quickly corrected or challenged information or advice which was seen to be inaccurate, and this phenomenon has been echoed in other studies (4). Social media interactions are not necessarily supportive and various activities are now needed to reduce interactions that lead to low self-esteem.

Lessons from the DOC

The 'DOC' is a term coined by some members of people living with diabetes who communicate through social media platforms. The beyondtype1.org website (29) describes the DOC as a "conglomerate of people with diabetes, caregivers, diabetes healthcare providers, foundations, organizations and associations within the diabetes environment who are engaging online, offering support, and sharing knowledge to improve the lives and health of people with diabetes". Further, the DOC is described as "an online home for everyone and anyone touched by diabetes; it has no borders and unites a global community whose goal is to learn to live healthier". As well as surveying a sample of general "DOC" members (22) with findings that DOC engagement resulted in positive health outcomes, Litchman et al. (30) conducted a series of more in-depth telephone interviews with older adult DOC users. They report that specific aims of accessing this resource include: 1) to gain information to improve self-care, 2) to receive reciprocal emotional support based on shared experiences, 3) to develop a sense of belonging to a community, and 4) to validate information. Not all results were positive however, and several concerns were raised by participants. Many were discouraged by individuals who used the DOC to disclose overly emotional or non-diabetes-related

issues, while some participants reported that they could not relate to the overly-negative comments expressed by some DOC users. With conflicting findings, there is a potential to conduct additional research with members of this community especially to determine what are collective goals of membership and what are the perceptions of members' general experiences. Research on the DOC can provide important lessons about why social media is used and how it can be improved.

Concerns about accuracy, reliability and accessibility of information

As well as navigating engagements with peers, people utilising online communities increasingly face a range of extensive and unregulated information regarding health conditions and procedures when they seek support or information over the internet. This information is likely to affect expectations and decision-making, as they share information and are influenced by the views of others, known or unknown to them, trustworthy or not, well-intentioned or not, knowledgeable or not. How to navigate the online minefield of (mis)information and balance these choices with peer support that is personally meaningful and beneficial is more of an art form than a scientific process.

Swee-Lin Tan and Goonawardene (8) undertook a systematic review on internet information seeking and noted that information found online could allow better access to health information, but the information could also be inaccurate, misleading or anxiety-provoking. Patients may also hide their information-seeking from HCPs, which can ultimately have a damaging effect on patient-physician relationships. These investigators suggest that there needs to be a shift in how HCPs engage with patients about information seeking online, by allowing patients to openly discuss questions and concerns arising from seeking information or support online.

Evidently, there are pertinent concerns about the content and delivery of online health related information and support. In addition, access to web-based information and support remains elusive

for many with fundamental digital disparities. It is worth considering in this melee of information and opinion that there are, of course, whole sections of society who are excluded from participating. Those without access to the internet for example; there are approximately 6 million people in Great Britain without internet access as of 2017, or approximately 10% of the population (31) as well as those with a lower socioeconomic status, level of literacy, or internet self-efficacy in addition to some older adults who also require reliable information and peer support (32). We therefore note that diabetes social media has room to improve to be more accurate, more reliable, and more widely accessible to diverse populations.

Differing perspectives and priorities of healthcare professionals and patients

In addition, there are evidently disparities between HCPs and people with diabetes when it comes to social media use. Kuske et al. (33) found that there has been a shift from a paternal medical model with passive patients, to those who are more active and influenced by health information and support from peers. This difference in perspectives could lead to a potential conflict of priorities. In a year-long project investigating how different stakeholders make decisions about recommending peer-support The Quality Improvement Lab (34) determined the five top most important factors (Table 1). In this instance HCPs were more concerned about safety, while patients were more concerned with shared experiences from others experiential understanding. The role of social media in medical information-seeking has been asserted as a challenge to HCP expertise (8). Kingod et al. (4) describe the creation and use of online communities as a movement of expert “patienthood” which can test traditional medical roles. However in a spirit of both sides working together, Kuske et al. (33) suggest a more collaborative way of identifying reliable information on the Internet. Swee-Lin and Goonawardene (8) suggest that patients could be supported by HCPs by allowing or encouraging patients to discuss their concerns openly, and by HCPs engaging actively with the concerns patients may have. It is therefore clear that priorities and barriers for social media as facilitators of self-management vary depending on

one's perspective. Differing perspectives and priorities of HCPs and patients can then affect the potential use and confidence in peer-support.

Table 1: Top five factors for decision making about peer-support (34)

People who had used peer-support	Health care workforce
Opportunity to meet people with similar experiences	Evidence that the service makes a positive impact
Belief that it would improve health and well being	Confidence that the service is safe, confidential and high quality
Confidence that the service is safe, confidential and high quality	Belief that it would improve health and well being
Evidence that the service makes a positive impact	Easy access to the service
Easy access to the service	Rapid access to the service

Discussion

There is little doubt that social media platforms can facilitate peer support between people with diabetes as well as access to decisive health-benefitting information. This support has been suggested to be instrumental to receipt of support that is not otherwise readily available in offline communities in qualitative studies (16). This support could be argued to be a lifeline to many people. However, there are evidently concerns over safety with social media use, accuracy and reliability of information and accessibility in terms of digital disparities. HCPs can assist in enabling open use of social media to improve health outcomes, first by taking on a collaborative approach to health management, and second by offering clarifications and assurance for specific health concerns. Priorities and barriers vary depending on the user's perspective, and can affect the potential use and confidence in social media as a facilitator of self-management. However, if these issues are not directly challenged, then they are likely to remain unresolved. Either HCPs can feel threatened by patients' social media use and respond defensively, or they can collaborate with patients in obtaining and assessing the information and by guiding patients to reliable sources of information.

Furthermore, the DOC is not restricted to tech-savvy youngsters. Older adults are increasingly partaking of social media to receive day-to-day diabetes management advice (30), although social media use is not desired or attainable by all and measures are needed to ensure information and support is available by other means. It was apparent that the benefits of social media interactions come with distinct episodes of online hostilities that can negatively impact on online community members. Armstrong et al. (28) demonstrated that if peer-led community negotiations occur and peer-led boundaries are constructed, then active community members will challenge inaccurate information and advice. What is not clear is how engaged are various segments of the patient community and how confident are various types of members to challenge or correct. Areas which require further understanding include; 1) how issues of identity and authority are established and 2) how aggressive behaviours are resolved with boundaries. Exploring the perspectives of those who lurk rather than participate might enlighten us to the experience of community members, who may lack the confidence to challenge. We also need to know more about the impact that more dominant members of the community have on the acceptability and value of the DOC.

Conclusion

Whilst online communities can test traditional medical roles in the creation of movements of expert “patienthood” it is suggested that where patients are utilising social media as a forum for information and advocacy, HCPs need to engage (35); accepting the priorities for patients and the importance of experiential evidence. This is especially important in areas of healthcare where HCPs and patients do not always agree. This article has focused on five areas where the benefits and drawbacks of social media are coming into clearer focus: 1) social media as a platform for information and support; 2) social media interactions that are not supportive; 3) lessons from the DOC; 4) concerns about accuracy, reliability and accessibility of information; and 5) differing perspectives and priorities of HCPs and patients. Since there are no agreed-upon theoretical and methodological approach for

272 online communities to extract maximal value from online social media, therefore, the scientific base
273 and policy guidance underpinning the use of such resources need strengthening (36). A better
274 understanding of how to extract value from online social media, especially through stratification of
275 user groups, will be crucial to address negative consequences and promote safe, effective use of this
276 emerging powerful tool.

References

1. Massey PM. Where Do U.S. Adults Who Do Not Use the Internet Get Health Information? Examining Digital Health Information Disparities From 2008 to 2013. *Journal of health communication*. 2016;21(1):118-24.
2. Amante DJ, Hogan TP, Pagoto SL, English TM, Lapane KL. Access to care and use of the Internet to search for health information: results from the US National Health Interview Survey. *Journal of medical Internet research*. 2015;17(4):e106-e.
3. Cahn A, Akirov A, Raz I. Digital health technology and diabetes management. *Journal of Diabetes*. 2018;10(1):10-7.
4. 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. *Qualitative health research*. 2017;27(1):89-99.
5. Zhao Y, Zhang J. Consumer health information seeking in social media: a literature review. *Health Information & Libraries Journal*. 2017;34(4):268-83.
6. Klonoff DC, King F, Kerr D. New Opportunities for Digital Health to Thrive. *Journal of Diabetes Science and Technology*. 2019;13(2):159-63.
7. European Commission. Flash Eurobarometer 404: European citizens' digital health literacy survey. November 2014.
8. Swee-Lin Tan S, Goonawardene N. Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review. *Journal of medical Internet research*. 2017;19(1):e9.
9. Bullying UK. 'What is cyber bullying?' [Available from: <https://www.bullying.co.uk/cyberbullying/what-is-cyberbullying/>].
10. NHS England. Diabetes transition and young adult service specification and guidance document. 2016.
11. Morris J, Campbell-Richards D, Wherton J, Sudra R, Vijayaraghavan S, Greenhalgh T, et al. Webcam consultations for diabetes: findings from four years of experience in Newham. *Practical Diabetes*. 2017;34(2):45-50.
12. Kaufman N, Khurana I. Using Digital Health Technology to Prevent and Treat Diabetes. *Diabetes technology & therapeutics*. 2016;18 Suppl 1(Suppl 1):S56-S68.
13. Moreland J, French TL, Cumming GP. The Prevalence of Online Health Information Seeking Among Patients in Scotland: A Cross-Sectional Exploratory Study. *JMIR research protocols*. 2015;4(3):e85.
14. Kessels RPC. Patients' memory for medical information. *Journal of the Royal Society of Medicine*. 2003;96(5):219-22.
15. Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. The future of mental health care: peer-to-peer support and social media. *Epidemiology and psychiatric sciences*. 2016;25(2):113-22.
16. Allen C, Vassilev I, Kennedy A, Rogers A. Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers. *Journal of medical Internet research*. 2016;18(3):e61.
17. Tajfel H, Turner J. An integrative theory of intergroup conflict. *Intergroup relations: Essential readings. Key readings in social psychology*. New York, NY, US: Psychology Press; 2001. p. 94-109.
18. Latané B. The psychology of social impact. *American Psychologist*. 1981;36(4):343-56.
19. Festinger L, Thibaut J. Interpersonal communication in small groups. *The Journal of Abnormal and Social Psychology*. 1951;46(1):92-9.
20. Skinner BF. *The behavior of organisms: an experimental analysis*. Oxford, England: Appleton-Century; 1938. 457- p.
21. Rosland AM, Kieffer E, Israel B, Cofield M, Palmisano G, Sinco B, et al. When is social support important? The association of family support and professional support with specific diabetes self-management behaviors. *Journal of general internal medicine*. 2008;23(12):1992-9.

22. Litchman ML, Edelman LS, Donaldson GW. Effect of Diabetes Online Community Engagement on Health Indicators: Cross-Sectional Study. *JMIR diabetes*. 2018;3(2):e8.
23. Schiotz ML, Bogelund M, Almdal T, Jensen BB, Willaing I. Social support and self-management behaviour among patients with Type 2 diabetes. *Diabetic medicine : a journal of the British Diabetic Association*. 2012;29(5):654-61.
24. Joensen L, Fisher L, Skinner T, Doherty Y, Willaing I. Integrating psychosocial support into routine diabetes care: perspectives from participants at the Self-Management Alliance meeting 2016. *Diabetic medicine : a journal of the British Diabetic Association*. 2018.
25. Joensen LE, Almdal TP, Willaing I. Type 1 diabetes and living without a partner: psychological and social aspects, self-management behaviour, and glycaemic control. *Diabetes research and clinical practice*. 2013;101(3):278-85.
26. Diabetes UK. Online communities [Available from: https://www.diabetes.org.uk/how_we_help/community/online-communities.
27. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *Journal of general internal medicine*. 2011;26(3):287-92.
28. Armstrong N, Kotevko N, Powell J. 'Oh dear, should I really be saying that on here?': issues of identity and authority in an online diabetes community. *Health (London, England : 1997)*. 2012;16(4):347-65.
29. Beyond Type 1. The Diabetes Online Community 2019 [Available from: <https://beyondtype1.org/the-diabetes-online-community-doc/>.
30. Litchman ML, Rothwell E, Edelman LS. The diabetes online community: Older adults supporting self-care through peer health. *Patient Educ Couns*. 2018;101(3):518-23.
31. Office for National Statistics. Internet access – households and individuals, Great Britain: 2017. Office for National Statistics; 2017 03 August 2017.
32. Jacobs W, Amuta AO, Jeon KC. Health information seeking in the digital age: An analysis of health information seeking behavior among US adults. *Cogent Social Sciences*. 2017;3(1):1302785.
33. Kuske S, Schiereck T, Grobosch S, Paduch A, Droste S, Halbach S, et al. Diabetes-related information-seeking behaviour: a systematic review. *Systematic reviews*. 2017;6(1):212-.
34. Patel H, Pagel C. How do people make decisions in peer support? Understanding what's important when referring, recommending or using peer support. London: The Health Foundation; 2018 May 2018.
35. Mazanderani F, O'Neill B, Powell J. "People power" or "pester power"? YouTube as a forum for the generation of evidence and patient advocacy. *Patient Educ Couns*. 2013;93(3):420-5.
36. Ziebland S, Wyke S. Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *The Milbank quarterly*. 2012;90(2):219-49.