What are Diabetes Patients versus Healthcare Personnel Discussing on Social Media?

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Abstract

Background

Use of social media is increasing rapidly, also in healthcare and diabetes. However, patients, healthcare personnel, and patient organizations discuss diabetes on social media very differently. This lead to lack of common ground when these stakeholders communicate about diabetes and a gap in understanding one another's point of view. Social media has a potential for improved communication if each stakeholder group knows about, acknowledges and accepts one another's perspective.

Method

We extracted and analyzed posts from three Norwegian Facebook groups representing patients, patients' organization and health care personnel. Qualitative content analysis was done to find the distribution of main categories, followed by a thematic analysis of subcategories that were posted and discussed.

Results

The Patient organization's posts are the most equally distributed over the four main identified categories: Scientific content, Healthcare services, Self-management, and Diabetes awareness. The closed Patient group's posts were dominated by Self-management, the Diabetes Nurses' open group were dominated by Diabetes awareness. The three social media groups differed substantially in what and how they posted and discussed within the main topics. The Nurses' open group had percentage-wise both the most liked and commented post, and the posts on self-management had the highest average number of comments.

Conclusions

There is a big discrepancy in posted information and discussions on social media, between patient closed group, patient organization open group and healthcare open group. To reach the aim of using social media for better health, there is a need for more information of what is posted and discussed in the other groups, to harmonize and ensure safe and accurate dissemination of information.

Introduction

Use of social media is increasing rapidly, including for health issues and especially for those with diabetes. Among health care personnel there is also a steady increase of social media use [1, 2]. This increase in use is generally good for those who are able to actively participate in, or follow the online discussions, but one pattern we see is that patients, healthcare personnel, and patient organizations discuss diabetes very differently. This can lead to lack of common ground when these stakeholders communicate about the disease and a gap in understanding of one another's point of view. Patients, patient organizations, and health care personnel organize in various forms of social media groups – e.g. Facebook, where some organize in closed groups whereas others prefer open groups [3, 4]. Of these three groups, patients seems to be the most common users of social media for health issues, with the most members and followers. One of the main reasons is that individuals living with the disease need frequent and detailed follow-up. Because healthcare personnel have limited ability to provide this due to their busy work schedules, patients are turning to one another with questions and answers about diabetes self-management on social media. More recently, individuals have also started sharing detailed and technical information about the many technologies popping up the last few years (e.g. CGMs, apps, smartwatches and fitness trackers).

This new situation has implications that change part of diabetes care. Not only social media, but technology in general have changed both how patients can choose to self-manage and which help and services the patients receive from different health care actors [5-8]. Traditionally, health care has taken the form of health personnel instructing their patients - often referred to as "doctor's orders". However, now that patients can be more informed and engaged in their disease management, they are more interested in explanation and shared decision-making than one-sided

instruction. Social media also provides a great potential for improved

communication *if* each stakeholder group knows about, acknowledges and accepts

one another's perspective [9], including what each believes is relevant for them in

diabetes care, so that care can be an informed compromise.

We have followed three different types of social media groups: patients, patient

organization, and health care personnel, over several years. We noted that

stakeholder groups on social media can be compared and contrasted to one another

because while they all may discuss common topics areas, their emphasis and

content for each topic area are different. The benefits of using social media to

communicate amongst peers as well as between patients and care providers has

been established by other studies [10-12]. However, few explore the content within

the various groups, likely due to the "closed", i.e. private, nature of some of these

groups.

Thus we want to enlighten this situation, based on the social media study we did 2

years ago, which focused on closed patient groups and open patient organization

groups [13]. By analyzing and disseminating what patients, patient organizations and

health care personnel are discussing in their respective groups, we hope to

contribute to this process of acknowledgment, acceptance, and compromise.

Objectives:

To exemplify the similarities and differences of how different stakeholder groups
discuss diabetes on social media by comparing and contrasting the content of
Facebook posts generated by patient, patient organizations, and healthcare
personnel groups, by:

a. Comparing how common themes in diabetes are discussed amongst different
   stakeholder groups on social media, and

b. Contrasting or differentiating emergent themes within the categorized posts, to demonstrate how these common themes are also uniquely discussed within each of these groups on social media.

Method:

Recruitment: We chose to focus on Norwegian groups only, to have a homogeneous cohort and also to be able to follow-up the insights provided by our previous study [13], where we compared posts in groups of patients versus in patient organization groups. Recruitment started end of April 2018 when co-authors (having no relationship to the participants) reached out to the administrators (private message) of three Norwegian Facebook groups: one closed diabetes patient group with 7,497 members, one open diabetes patient organization group with 32,124 followers, and one open healthcare personnel (diabetes nurses) group with 489 followers. All requests included an explanation of the study, which the Facebook page administrators could choose to post on the group's page, and explanation that any member could choose to exclude their posted content in the data extraction and analysis (no members opted out). No compensation for the administrators or individual members of the Facebook groups was provided.

Data extraction: After obtaining permission from all three Facebook groups, the content and reach of 100 posts from each group were manually extracted retroactively from April 30th, 2018 and backwards. The sample size was justified due to the rapid turnover of relevant posts on Facebook. It also allowed us to compare a similar amount of content for groups that vary greatly in their member numbers and frequency of postings. Also, we assessed that the predetermined categories, were, while in varying quantities within each different stakeholder group, well represented across the total 300 posts. The gathered data included the content, and the number of likes, shares, external links and pictures. These data were then imported into

Excel, translated into English by one of our co-authors (EÅ), and coded. No personal data was extracted.

Data analysis: Previous studies have identified major topics discussed amongst patients with diabetes [14], as well as diabetes care providers [15], or care providers in general [16], and diabetes organizations on social media . Therefore, qualitative coding and analysis of the Facebook posts was a hybrid approach to further utilize such research, consisting of, firstly, a priori thematic analysis whereby posts were assigned into four predetermined categories based upon these previous studies in own experience, and, secondarily, an analysis of sub-themes that emerged within each predetermined category for each stakeholder's Facebook group. The pre-determined categories and emergent subthemes allowed us to compare and contrast how common themes of diabetes were discussed between groups

The a priori thematic analysis, allowing for comparison between groups' posts, began with the assignment of posts into the following four categories: A-Scientific content; B-Healthcare services; C-Self-management; and D-Diabetes awareness. These categories were identified as common between different stakeholders' Facebook groups based upon previous studies [17], our own experience [13], and the publicly available descriptions of multiple open and closed Facebook groups related to diabetes identified under the groups' "About" sections. The three co-authors acted as independent reviewers and classified each post. Disagreements were discussed and the following final definitions of the four categories were agreed upon, to make the distinctions between categorization as clear as possible:

A - Scientific content: Refers to trends, reports, new tools in the medical/diabetes realm (e.g. news or published articles, new discoveries, new mHealth technology or novel technology), this includes specific results

and specific new information on the topic of diabetes and care, include

surveys or research asking for member participation

B - Healthcare services: Suggested disease management options/clinical

recommendations (e.g. medications that are commonly used, frequency of

self-management, usage of technology, references to health authorities

webpages for more authorized/accepted information), could be posted by

both patients themselves, organizations or health care personnel

C - Self-management: Patients' suggested disease management options,

recommendations, and questions about self-management from the personal

point of view (based on own experiences/data, e.g. HbA1c, medications

taken, self-management habits), including statements of own achievements

related to their diabetes

D - Diabetes awareness and other: Includes recipes, celebrations, celebrities,

notices of conference or group gatherings (Note: results offering new

evidence or information are classified as A)

Discrepancies regarding categorization of the N = 300 posts were discussed between

the three reviewers until agreement was reached. Fleiss' kappa was used to

calculate the inter-rater agreement. Descriptive statistics were used to summarize

the absolute numbers, frequencies, means and 95% confidence interval (95% CI) of

posts per category. The 95% CI was found using the generic formula (estimate ± SE

1.96). Chi-square tests were used to compare categories. All data were analyzed

with SPSS version 25 for Mac.

Next, emergent themes of each post within each category for each Facebook group

were identified. These themes were then grouped into subcategories, in the form of

summative descriptions of the most commonly discussed themes under each main category (see Table 1 for an example). One author (MB) proposed the themes and subcategory descriptions, which were then discussed, adjusted and agreed upon by the other co-authors (EÅ, EG). The subcategories were then compared between Facebook groups to highlight the commonalities and differences between groups' interests and priorities related to the same category or topic.

Table 1. Process for how subcategories were generated from emergent themes within each a priori category: example(*) using Patient group's posts in category C.

A priori category	Emergent themes (count of posts)– subthemes found within Patient Organization's posts assigned to the a priori category	Subcategories – summative description of related emergent themes
C – self-management	• Acknowledgement (1) • Announcement; education (1) • Self-management opinion (4) • Self- management questions (44) • Own management experiences (27) • Miscellaneous (8)	C2. Questions to peers regarding diabetes technology C3. Diabetes self-management practices C4. Experience with care providers, details of diagnosis and clinical measurements C5. Own medications, and its relation to secondary illnesses

*All results shown and explained in Table 2.

Ethical declaration: The study was presented to the Norwegian Regional Committee for Medial and Health Research Ethics (REC) [18] and was declared exempted from purview. On advice from REC, we consulted the "Ethical Guidelines for Internet Research" [19] and concluded that our study design was sound and ethical. Before gathering data from the three Facebook groups we asked and got consent from all groups' administrators/moderators, including presenting a text describing the study so that groups' members could have their postings excluded from the study if they wanted.

Results:

The closed patient Facebook group answered positively to participation the same day as the request was sent. The open patient organization group answered positively two weeks after request, and the open health care group confirmed participation four weeks after request.

Main categories of information in the three different Facebook groups

When assigning the posts into the main categories, our interrater agreement, measured using Fleiss Kappa was 0,756. According to Landis & Koch [20] this is a "Substantial agreement".

For the 100 posts analyzed for the patient organization open group there were totally 76 links, 10 pictures, 13 videos, 19732 likes, 4930 shares, and 1348 comments. For the diabetes closed group there were totally 12 links, 30 pictures, 1 video, 1725 likes, 1 share, and 1044 comments. While the diabetes nurses' open group's 100 posts had 70 links, 25 pictures, 3 videos, 1757 likes, 259 shares, and 69 comments.

A visual representation of the distribution of the main topics posted among the three Facebook groups can be seen in Figure 1 below. As seen, the Patient organization's posts, generated between August 15th, 2017 and April 30th, 2018, are the most equally distributed over the four categories. They focused most on Scientific content and Diabetes awareness within the 100 posts analyzed. The closed Patient group's posts, generated between April 10th, 2018 and April 30th, 2018, were dominated by Self-management, and include little discussions about Healthcare services. For the Diabetes Nurses' open group, the posts, which were generated between April 25th, 2016 and April 30th, 2018, are dominated by Diabetes awareness,

followed by Scientific content, and few about Self-management and Healthcare services.
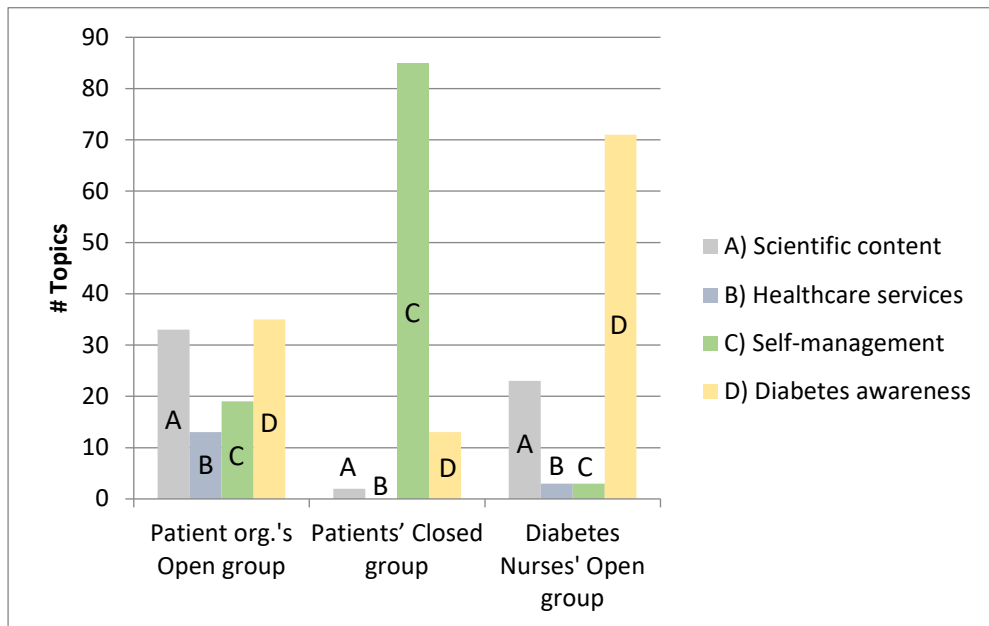

Figure 1. Visual representation of the distribution of the different main topics posted among the three various groups: Patient organization's group, Patients' group, and Diabetes nurses' group.

Content analysis

Within each of the four main categories A-D, the three social media groups differ substantially in what and how they post and discuss these topics. By examining the content within each of the main categories, we found 4 subcategories of Scientific content (A1-A4), 2 subcategories of Healthcare services (B1, B2), 5 subcategories of Self-management (C1-C5) and 6 subcategories of Diabetes awareness (D1-D6), see Table 2. For example we found that, in the C – Self-management category, the Patient organization group presented patients' stories about how patients self-manage their diabetes, while the Patients' closed group presented problems and solutions surrounding blood glucose sensors and other technical tools, and the

Diabetes Nurses' group provided a link to a Web-page about diabetes and depression.

Table 2. Unique subcategories emerging from the four main categories of information posted in the three different Facebook groups. Same subcategories are discussed in more groups, but listed only once – in the group where they were posted the most.

Group	Subcategories within the four main categories A-D
Patient Organization's group (open)	A1. Concerns and progress regarding access to technologies for patients A2. New research about the disease diabetes and self-management B1. Debunking myths about diabetes and providing specific self-management suggestions B2. Dissemination of information/guidelines from the health care services C1. Reposted links to stories written by those with diabetes D1. Announcements of various events D2. Acknowledgments and professional achievements in the field diabetes
Patients' group (closed)	C2. Questions to peers regarding diabetes technology C3. Diabetes self-management practices C4. Experience with care providers, details of diagnosis and clinical measurements C5. Own medications, and its relation to secondary illnesses D3. Recipes D4. Announcements of events for those with diabetes and their families
Diabetes Nurses' group (open)	A3. Invitations to participate in research, study findings and new diabetes guidelines A4. Minutes from professional meetings about diabetes nursing practice D5. Announcement of conferences and professional meetings D6. Job postings and continued education for nurses

Likes and comments for the groups

We considered likes, comments, and shares of the posts as a reflection of the members' engagement, whereby "likes" required the least amount of effort, "comments" required more effort and engagement, and "shares" suggested a person personally identified with the content within a given post and their willingness to reinforce it. The group with the most followers , i.e. the Patient organization's group with 32k followers, had the posts with the most "Likes" post, i.e. four posts with around 1000 likes (i.e. 3.1% of the followers liked these posts)

and 13 posts with more than 300 likes (1%). The Patients' closed group (7400

members) was the second largest group, and had one post with 103 likes (1,4% of its

members).The Nurses' open group (489 followers) had a post with 82 likes (16.7% of

its followers). Regarding the members' engagement as evident in their number of

"comments", the Patient organization's group also had the posts with most

comments, with the most being 115 comments per post, followed by the Patients'

group with 50 comments at the most, and the Nurses' group with the most being 7

comments per post. When corrected for member size, the Nurses' group scores 14.3

‰ (per 1000), the Patients' group scores 6.8 ‰ and the Patient organization's group

scores 3.6 ‰. Table 2 below gives a summarized presentation of the collected data

from the 300 posts.

Table 2. Category of the posts and their reach for the three groups.

Category of the posts	Patient org.s' Open Group (32,124 followers) Mean [95% confidence interval]*	Patients' Closed Group (7,497 members) Mean [95% confidence interval]*	Diabetes Nurses' Open Group (489 followers) Mean [95% confidence interval]*
Scientific content Likes Shares** Comments	n=33 posts 199.2 [126.8, 268.0] 33.9 [21.0, 46.7] 19.2 [8.9, 29.4]	n=2 posts 5.0 [-58.5, 68.5] 0 6.5 [-76.1, 89.1]	n=23 posts 17.8 [10.7, 24.9] 3.4 [1.9, 4.9] 0.7 [-0.1, 1.5]
Healthcare services Likes Shares** Comments	n=13 posts 123.0 [73.1, 172.9] 44.4 [22.4, 66.4] 7.8 [0.6, 14.9]	n=0 posts 0 0 0	n=3 posts 12.0 [-33.3, 57.3] 0.3 [-1.1, 1.8] 0
Self-management Likes Shares** Comments	n=19 posts 198.6 [140.8, 256.4] 53.9 [18.4, 89.4] 15.8 [9.7, 22.0]	n=85 posts 13.7 [9.0, 18.5] 0 11.0 [9.0, 13.1]	n=3 posts 2.3 [-2.8, 7.5] 0.7 [-2.2, 3.5] 0.3 [-1.1, 1.8]
Diabetes awareness Likes Shares** Comments	n=35 posts 224.2 [125.9, 322.4] 63.2 [8.9, 117.4] 8.9 [4.3, 13.6]	n=13 posts 42.2 [13.2, 71.1] 0 7.2 [2.9, 11.4]	n=71 posts 18.4 [13.4, 23.4] 2.5 [1.8, 3.3] 0.7 [0.4, 1.1]

*Chi-Squared test, p<0.001

**Note – the "share" functionality is not an option in Facebook closed groups.

Discussion

Different agendas: Two universal truths are that we all experience situations in a different way and by understanding somebody else's perspective we can better communicate and collaborate. This study exemplifies how, in diabetes management, various stakeholder groups, i.e. healthcare personnel, patients, and a patient organization each have different agendas and messages to share and discuss. For example health care personnel and the patient organization discuss self-management much less, are much more general and less direct than the richer information found in patients' social media group. There are two sides to the rich discussions patients have in closed groups. On the positive side we see how extensively patients are able to help each other with even medical issues – e.g. [3, 4, 6-8], and on the negative side is the consequences this might have if they are misinformed by their peers [21] – due to lack of knowledge of all medical sides of the advices they receive. There might also be unfortunate situations where health care personnel not being up to date about what patients are discussing on social media, e.g. how to use "do-it-yourself solutions"[22-25] or how adjusting nutrition to improve their HbA1c. The findings from the content analysis exemplifies how each group can talk about the same main topic but with a total different focus. As expected was dissemination and spreading of information important subtopics for the Diabetes patient association group. The Diabetes nurses group's big focus on diabetes awareness was found to be oriented towards conferences, meetings and other opportunities relevant for their members. Finally, the huge focus on self-management in the patient closed groups was found to be very varied – with five different sub-categories, all from stories of peers, questions about technology, care providers, medication and clinical measurements.

Action needed: Our findings, although limited to an analysis of only 300 posts within Norwegian Facebook groups, indicate a big variety between the groups. All three stakeholders have an important role in diabetes self-management. We believe that actions are needed to make each stakeholder better informed about what is being disseminated and discussed in the other groups to achieve the best possible cooperation and optimal health outcome [2, 26, 27]. For example, the different groups could include more content from each other's perspective, with the goal of harmonizing the information disseminated in all groups. Health care personnel groups could repost patients experience from the patients' discussion forums – after receiving permission from the involved parties - or from public reports, e.g. patient organizations' newsletters. In fact, intervening more directly with patients is along the new aim of an emphasized focus of patient involvement [28]. For research, we have demonstrated and reported several ways we as researchers have used social media and other digital channels to interact with patients, such as Google Play, Facebook, Twitter, YouTube, Instagram and e-mail [29, 30].

Ethics: According to the National Committee for Research Ethics in the Social Sciences and the Humanities' (NESH) Guidelines, researchers can use material in general from open forums freely without obtaining consent from the parties covered by the information [19]. Even though two of the analyzed group fall under this category, we chose to explicitly asking them for permission, including information about the purpose of the presented study. We found this to be both fair to the groups and advisable due to the fact that this is research within such a sensitive field of health.

For the closed groups, consent is absolutely necessary. By posting requests and information directly in this forum, we were able to also clarify their questions such

as what we are doing with the information we gather, assure anonymization of the data and to let those who wanted to opt out of including their data in the study.

High interest for self-management and scientific content: In a previous study, we found that two thirds of the posts in the patients' Facebook closed group were on self-management (64%), and almost a third on diabetes awareness [13]. Another study carried out in a closed online community also reported diabetes management as one of the main interests of individuals affected with type 2 diabetes [31]. In this new study, the proportion of posts on self-management in the same closed patient group reached 85%. Interestingly, in both studies, the posts on self-management also had the highest average number of comments. We hypothesize that the reason for this is related to the nature of the group – a closed group of patients allow more honest and personalized posts and discussions of the topics that often interest them the most – daily diabetes self-management. Also in our previous study we found that 65% of the Facebook patient organization open group's posts were on diabetes awareness, with the rest of the contents equally discussing healthcare services and scientific issues and only 1 post was classified as referring to self-management. In that study the type of posts that received the most comments were the ones focusing on scientific content [13]. In the presented study, we found that the distribution of posts in the organization's open group is more homogeneous among categories. Self-management, closely followed by Scientific content were the categories of posts receiving the highest number of comments.

Patients want to participate: Performing this study demonstrated how easy it can be to get in contact with patient groups – there are both many of them and much less hierarchical than the other two groups. We reached out to three patient groups (before we finally decided to only include one due to homogeneity – including one

group from each stakeholder) and within a few minutes we had a positive response from the groups' moderators. Social media opens up for rapid communication for interventions both clinically and in research. However, finding and including health care personnel was much harder than anticipated. The reason for a later response from the healthcare and patient organization groups was that the request needed to be shared, discussed and decided in a more formal part of their organization, while the answer from the patient group was only dependent on the group's administrator in combination with feedback from the members after posting study information in the group's Facebook page. Thus, future studies should further address the limitations and possibilities in using social media, within and between the various healthcare stakeholder groups. We believe there will be a substantial increase in social media use in research in the years to come.

Limitations: Our analysis were based on three groups of very different size, leading to different chronological time periods analyzed. Attempts were made to select more similar group sized, but unsuccessfully. Thus, future studies should aim to study more homogeneous group sizes and time periods.

Conclusion

There is a big discrepancy in posted information and discussions on social media, between patient closed group, patient organization open group and healthcare open group, based on Facebook as the social media case, and Norway as the case country, analyzing 100 posts for each group. Patients focus the most on self-management, healthcare personnel on diabetes awareness and the patient organization have the most evenly spread focus on the four main identified categories: Scientific content, Healthcare services, Self-management, and Diabetes awareness. Even though all

three groups' posts were within these four categories, the actual content discussed

varied a lot between the groups. To reach the aim of using social media for better

health in health interventions, there is a need to inform each group of what is

posted and discussed in the other groups, to harmonize and ensure safe and

accurate dissemination of information. Seeing the rich and engaged discussions the

patients' have in the closed social media group, makes us aware of the potential this

might have if used the right way in future interventions.

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