Understanding the social dynamics of Twitter, Facebook and Diabetes.co.uk and their value implications for patients and health researchers

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Abstract—**Health and wellness are dominant societal concerns, which is reflected in their presence on Social Media. People with diabetes use a range of Social Media to share information, build knowledge and seek peer support, but surprisingly little is known about how this behaviour varies across platforms. We drew data from a 10 day period in September 2014 from Twitter, Facebook and the Diabetes.co.uk discussion forum and classified these according to their informational and social properties, using Bales Interaction Process Analysis (IPA). Contrary to the generalisations made in previous research, Twitter is chiefly used for information dissemination, whilst Facebook and Diabetes.co.uk are also used for social interaction and peer support. These differences exist due to the structure of these platforms, including the potential for threaded discussions, the specificity of the user base and the presence of a moderator, each of which influence the nature of member interactions. Our novel findings contribute new insight about the social function of different Social Media in healthcare and the relative value of these Social Media as sources of data for health research, tools for health promotion and intervention, as well as forums for community and patient engagement.**

Keywords–health, diabetes, social media, social network, Facebook, Twitter

I. INTRODUCTION

Type 1 diabetes is a chronic autoimmune condition, which occurs when the pancreas stops producing insulin. This results in increased levels of glucose in the blood, putting patients at long-term risk of heart disease, stroke, nerve damage, kidney disease and blindness. There is currently no known cure for Type 1 diabetes and those diagnosed are treated either by insulin injections, insulin pump therapy, islet cell transplantation or a pancreas transplant.

Hamm et al. (2013) concluded that patients most commonly use Social Media as a means of supporting selfcare and that the literature is dominated by studies of online discussion forums and support groups, followed by dedicated social networking sites and micro-blogs [1]. Social Media has become an increasingly popular data source for public health researchers to understand how members of patient communities interact with each other regarding specific conditions [2], [3].

Previous research has focused on single platforms such as Twitter, Facebook or condition specific online communities [3], [4], [5]. We go beyond such studies with a view to gaining insights into the social interactions that occur across and within Social Media. We are not aware of any previously published study to have compared Twitter (twitter.com) Facebook (https://www.facebook.com/T1Diabetes) and Diabetes.co.uk (http://www.diabetes.co.uk/forum/category/type-1-diabetes.19/) in relation to Type 1 diabetes. Motivated by this, we considered the following research questions, the answers to which will help inform the design of future successful Social Media for the purposes of health and will help patients understand better how they can manage their conditions using them:

RQ1: Do diabetes Type 1 patients use different Social Media platforms for different purposes?

RQ2: Which Social Media are successful at encouraging social interaction and support for patients?

RQ3: What are the implications for Social Media design?

Our three Social Media embody different styles of social interaction. Twitter and Facebook are well known, general purpose sites. Diabetes.co.uk is a condition specific discussion forum where users can create content and others can comment.

The rest of this paper is organised as follows. Section II describes the methodology and datasets. Section III describes outcome of RQ1. Section IV describes the outcome of RQ2. Section V describes the outcome of RQ3. Section VI provides a conclusion to close the article.

II. METHODOLOGY AND DATASETS

For our comparison of Social Media use by diabetes patients, we took a two-stage approach: firstly we extracted and screened posts made by 533 users from each of the three sites and then categorised them using the Bales IPA categories.

Application of Bales Interaction Process Analysis Bales IPA system [6] was first introduced in 1951 and has been widely used in public health research as a means of identifying and recording the nature, not the content, of group interactions. Bales identified and defined twelve categories of group interaction each of which were considered when reviewing the Type 1 diabetes posts. Each post was considered a single unit of interaction and that the categories were not considered mutually exclusive when applied to the sample of posts.

Twitter A random 1% sample of all available Tweets was extracted on the 3 October 2014. The tweets were posted between 0:00:00 (UTC) on 1 September 2014 and 23:59:59 (UTC) on 10 September 2014 and were extracted by crawling the data through the standard publically available Twitter API using the pre-defined search terms *diabetes, type 1 diabetes, t1 diabetes, t1d* and *type 1.*

The data extracted included the date and time of posting in UTC, the Twitter account id and the text in the tweet. Re-tweets were identified and any duplicates and spam were removed. The sample of 1433 English language tweets was manually screened. Those that referred to Type 1 diabetes, produced a sample of 66 posts, which were subsequently included in the categorization stage. url links included in the tweets were not reviewed during the screening.

Facebook Using the Facebook search functionality, we searched for Type 1 diabetes and in doing so identified the largest Type 1 Diabetes Facebook community available. Known as the Type 1 Diabetes Community this community was established in 2011 and is intended to be an open forum for people who have Type 1 diabetes to talk about anything they want. As of 4 October 2014, it had 36,671 likes and on this same date all wall posts and replies that were posted between 1 and 10 September 2014 were identified by viewing the storyline of historical posts. These posts along with the author and the date of posting were manually extracted for further analysis. Given the particular focus of this online community, the sample of 479 posts were all considered relevant to Type 1 diabetes and therefore included in the categorisation stage.

Diabetes.co.uk Diabetes.co.uk is a global Diabetes community with over 125,000 members spanning all forms of the condition. The Type 1 discussion forum on Diabetes.co.uk was identified through the forum homepage and the list of discussion threads was then filtered based on the start date 1 September 2014. All original posts and replies posted between 1 and 10 September 2014, were identified and manually extracted. The total sample of 713 posts was included in the categorisation stage.

Extraction and screening of relevant posts The output of the extraction and screening of Type 1 diabetes posts are summarised in Table 1, where we see the number of posts extracted from each of the three Social Media, the number of original posts and replies included in the sample and their respective number of authors.

III. RQ1: DO DIABETES TYPE 1 PATIENTS USE DIFFERENT SOCIAL MEDIA PLATFORMS FOR DIFFERENT PURPOSES?

Surprisingly, although Twitter had the highest absolute number of total posts at 1433, these results revealed that it is a noisy source of data compared to other Social Media as only 66 posts were relevant to the condition of Type 1 diabetes. Contrary to expectations, the results also revealed that despite being a popular Social Media, Facebook, with a total of 479 posts, was not the most actively used platform for members to discuss the condition. Instead the discussion forum on Diabetes.co.uk was identified as being the most actively used Social Medium included in the study, with a total of 713 posts during the 10-day period.

The sample of Twitter data contained notably fewer responses to posts (0%), than Facebook (96.6%) and Diabetes.co.uk (94.2%). suggesting that there is a greater degree of two-way communication between users of social networks and discussion forums compared to micro-blogging platforms. Twitter has less developed conversational structures, making it harder for patients to read all related comments. Facebook and Diabetes.co.uk posts include associated comments that are easily found. Facebook and Diabetes.co.uk also provided much richer posts, both in terms of length and structured content, i.e. long chains of comments.

When analysing the data further, it was identified that the community moderator who posted questions from anonymous members of community created all original posts within the Facebook community. Thus creating a degree of uncertainty, as the number of authors contributing to original posts is not available This is in contrast to the Diabetes.co.uk discussion forum and Twitter where any registered member of the site could generate an original post and that 37 and 62 members created an original post, respectively.

It was also revealed that a single post within the Facebook community generated a higher response rate relative to others. The post Over/Under time again. 153. Are you over or under? was a request from the community moderator for members to post their current blood glucose levels. This post generated 101 responses, accounting for 21% of the total sample therefore performing a role similar to that of an online survey.

In summary, our results for RQ1 indicate that patients do use different Social Media platforms for different purposes as is highlighted by the volume and conversation structures represented in the sample. Whilst Facebook appeared to be heavily moderated, this was weakly present in Diabetes.co.uk and absent in Twitter. Given these differences in utility it is natural to ask how members of the Type 1 diabetes community use these Social Media to interact with others. Surprisingly, we find that Diabetes.co.uk was the most actively used Social Medium in terms of volume, whilst Facebook achieved the highest percentage response rate. A finding widely known within the Computer Science community but not yet reflected in much of the published Public Health research that is available.

TABLE I. SUMMARY OF POSTS FROM 1 – 10 SEPTEMBER 2014

Social Media	Sample size	Screened sample size				Posts included in IPA
		N (%) original posts	*N authors*	*N (%) replies*	*N reply authors*	
Twitter	1433	66 (4.6%)	62	0 (0%)	0	66
Facebook	479	16 (3.3%)	1	463 (96.6%)	310	479
Diabetes.co.uk	713	41 (5.7%)	37	672 (94.2%)	123	713

IV. RQ2: WHICH SOCIAL MEDIA ARE SUCCESSFUL AT ENCOURAGING SOCIAL INTERACTION AND SUPPORT FOR PATIENTS?

The results of Bales IPA reveal differences in the nature of interactions between users of these three Social Media. These are described in Table II, where we see the percentage of posts relevant to the Bales IPA categories for each of the three Social Media. The Over/Under post accounted for one fifth of the Facebook sample. It was therefore highlighted as a separate line item so as to avoid potential skew of results within the Facebook dataset.

Whilst the three Social Media are predominantly used to disseminate suggestions, opinions and information with other members, the highest percentage of posts; Twitter (36%), Facebook (44%) and Diabetes.co.uk (55%) represent members sharing their opinion. Noticeably fewer posts ask to receive suggestions, opinions and information from other members and the majority of these are original posts.

We observe several interesting differences in the nature of the posts. As noted, Twitter is mainly used to disseminate information (29%) and opinion (36%) and not for interaction. These posts are characterised by dramatization (18%), few friendly posts (18%) and no indications of agreement or disagreement between members. Below shows some examples of these Tweets.

- 33k kids in canada went #backtoschool with diabetes. it's time to make school a better places for t1d kids.
- sanofi launches mobile game for kids with type 1 diabetes in the uk
- did you know that the character elsa from the movie "frozen" was in part inspired by a child with type 1 diabetes?
- amazing revolution - bionic pancreas which will automatically inject insulin to type 1 diabetes patients
- an open letter to teresa may advice on her type one diabetes

In contrast, the Type 1 Diabetes Facebook community and Type 1 Diabetes.co.uk discussion forum were considered very interactive with friendly posts accounting for 47% of Facebook posts and 46% of posts on Diabetes.co.uk. The Facebook community generated a greater percentage of agreement (12%) and disagreement (5%) compared to the other Social Media. Whilst the posts within the Diabetes.co.uk discussion forum, indicate a higher percentage of tension (12%) and unfriendly posts (3%), particularly in relation to topics such as diet and the new treatments that are available. Limited moderation of this forum has, therefore, enabled a greater diversity of opinion to be represented.

The three most popular discussion threads on Facebook community are listed in below, including the number of replies to the original post.

- Over/Under time again... 153 Are you over or under? (101)
- This may seem like an odd question but I'm more than a little curious if other T1s experience what I do. I get bit by mosquitos all the time. So much more than anyone else I know. Everyone jokes that mosquitos must love me cause my blood is so sweet. I laugh it all off cause it seems ridiculous. However, I also seem to attract bees. Kind of odd huh? I'm curious how many others experience this...if any? (63)
- Just want peoples advice really I'm 22yrs old been t1 diabetic since I was 6trs old I have one child but planning another but can't get my hba1c past 8.5 and the docs won't let me try till it's 7 any tips on how to get it down? I'm on injections novo rapid and levemir, thanks (54)

The three most popular discussion threads on Diabete.co.uk discussion forum are listed in below, including the number of replies to the original post.

- How highly would you recommend eating low carb? I know this is probably a silly question as it has quite an obvious answer! I love my carbs. I love pasta, rice and

potatoes. In the past, I've tried to take the right amount of insulin to cover this but it's so easy to get it wrong and misjudge it - it also means I can end up taking whopping amounts of insulin! Would you recommend I reduce my carbs? It should make my diabetes easier to manage, yes? (I'm also doing Slimming World so although I've read a little about LCHF, I'm not keen to start eating loads of 'fattier' foods!) (91)

- New Flash Glucose Monitoring from Abbott Bloodless Testing Its arrived and heres a video for all you guys who wanted more info (76)
- LCHF success stories from type 1's I created this thread as a place for fellow type 1 diabetics to share their success stories on the LCHF diet. I know there is a similar thread on the low carb forum but I found that most of the responses were from type 2's, so I thought it'd be nice to have a specific place for us to share experiences and hopefully inspire and learn from each other! (67)

In summary, our results indicate that although the three Social Media are all used to disseminate information about the condition, Facebook and Diabetes.co.uk are also used for social interaction and peer support. These findings provoke controversy as to the validity and application of Twitter as a popular Social Media for gaining insight into Type 1 diabetes and in its use as a means of delivering relevant health interventions.

V. RQ3: WHAT ARE THE IMPLICATIONS FOR SOCIAL MEDIA DESIGN?

Although the three Social Media can be considered a valid source of information about the clinical condition of Type 1 diabetes these platforms should not be considered equal or synonymous as has been the case in previous public health studies. Exciting implications are also revealed into the utility of condition specific Social Media as a potentially more effective means of health promotion and patient engagement.

Studies into the social shaping of technology reveal that technology does not develop according to an inner technical logic but is instead a social product influenced by the conditions of its creation and use [7]. With this in mind, we find that the way Social Media are configured and moderated as well as, through the opportunities that they offer for certain types of interaction [8] can shape the behaviours of Social Media users.

For patients living with chronic and life threatening conditions such as diabetes, different utilities are derived from dissemination directed Social Media such as Twitter than from interactive and community building Social Media such as Facebook and Diabetes.co.uk. These differences in use within healthcare are contrary to the generalisations made in existing public health studies, which extrapolate the findings from a single Social Media. This therefore provides interesting and novel applications for a diverse range of research directions that aim to understand how Social Media are used by patients with other clinical conditions and what effect this has on the use of Social Media for research, health interventions and patient engagement.

TABLE II. APPLICATION OF BALES IPA TO DIABETES POSTS

Social Media	Bales IPA Categories					
	Shows tension	*Dramatises*	*Agrees*	*Gives Suggestions*	*Gives Opinion*	*Seems Unfriendly*
Twitter	8	18	0	20	36	0
Facebook	4	5	9	29	33	1
Facebook (minus the over/under post)	4	6	12	37	40	1
Diabetes.co.uk	12	7	5	18	55	3
	Gives info	*Asks for info*	*Disagrees*	*Asks for Suggestions*	*Asks for Opinions*	*Seems friendly*
Twitter	29	8	0	5	6	18
Facebook	33	6	4	1	3	37
Facebook (minus the over/under post)	15	8	5	1	3	47
Diabetes.co.uk	32	10	1	1	6	46

VI. CONCLUSION

We presented the first results from this unique study on how different types of Social Media are used by patients living with a chronic condition. In doing so we defy popular assumption and conclude that Type 1 diabetes patients use different Social Media platforms for different purposes, with Twitter primarily used by members for information and opinion sharing, with little support or empathy. Whilst Diabetes.co.uk and Facebook, by virtue of their user base, design and self moderating communities are more successful in their utility for social interaction and peer support by those living with this live long condition. These findings have important implications for Social Media and their application in the context of healthcare.

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