A Park or A Highway: Overcoming Tensions in Designing for Socio-emotional and Informational Needs in Online Health Communities

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ABSTRACT

Over the years online health communities (OHCs) have become an important source of information regarding health management and a place for social interaction and emotional support. Previous research suggested that these two types of social support have intricate and complex relationships. In this paper, we report on the results from a secondary analysis of qualitative interviews conducted during several studies examining how individuals make sense of the information collected within an online forum dedicated to diabetes self-management, TuDiabetes. The analysis suggested that informational and socio-emotional needs can at times complement each other, but can also lead to contradictory priorities and expectations for OHC members. Specifically, the study suggested that there are important tensions between these two positions in regards to *appropriate topics and focus of conversations*, the *desire for homogeneity and diversity in opinions,* the *perceived importance of identifying authoritative voices*, and the *importance of personal and health-related information in contextualizing members' posts*. We discuss these tensions and draw implications for the design of future OHCs.

Author Keywords

Online health community; collective sensemaking; informational needs; socio-emotional needs; community wellbeing; design tensions; design implications.

ACM Classification Keywords

H.4.3 Communications Applications: Bulletin boards; H.5.3 Group and Organization Interfaces: Computer-supported cooperative work.

INTRODUCTION

In recent years, online health communities (OHC) have emerged as an important complement to the traditional health care [31,43]. According to the 2009 Pew Report, close to a third of all American adults had accessed social media for questions related to health [84]. More than a half of e-patients (patients relying on online medical services) living with chronic disease consume user-generated health information and almost a fifth of these participate in generating that type of information [85]. In response, there emerged a large number of OHCs such as breastcancer.org, TuDiabetes.org, and PatientsLikeMe.com. Over the years, OHCs collected vast amounts of information and opinions on a variety of health issues and diseases. This inspired ongoing research in information seeking practices of members of these communities [15], ways they access and appraise information [35,38] and construct new knowledge together [54].

However, research on online communities in general and OHCs in particular also suggests that information seeking is only one of the many reasons why individuals join such communities [59,74]. Many members seek not only informational, but also emotional support [73,77]; for others it becomes a place to socialize and build relationships with others who may experience similar challenges [48,73]. Moreover, the same individuals may change their preference for informational and emotional support depending on their circumstances. Previous studies suggested that there exist intricate relationships between these different forms of support within online forums [39,66,76,81]. However, many questions remain as to how these different yet complementary needs and priorities impact individuals' preferences and behaviors and what impact the interaction between them has on the design of computing platforms.

In this research we examine the interplay between informational needs of members of OHCs and their need for socializing and building a warm, welcoming, and nurturing community. To this end, we conducted a secondary analysis of qualitative data collected during three different studies with individuals recruited among members of TuDiabetes, an online community for individuals with diabetes. The results of this analysis suggest that there exist a number of tensions between individuals' informational needs and their desire for promoting social interactions within the forum. Most participants valued both of these

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forms of support, yet there were important differences in how they described their preferences and priorities. For example, some individuals preferred discussions with a narrow focus on diabetes and its self-management, and considered off-topic conversations as contributing to information overload and noise in the forum. Others saw the community as a third place [42,69] where they could socialize with other individuals with diabetes but without focusing on the disease itself. Similarly, while some participants were interested in identifying "compatible" members with similar experiences and opinions, and in forming smaller compact cliques, others wished for more breadth and diversity in their interactions with the forum. A related tension existed between the need to identify credible and trustworthy members and posts, and the desire to allow each member to have an equal voice and influence within the community, which could further contribute to its warm and welcoming character. Finally, some participants wished for more information about members whose posts they were reading, in order to better understand their life and disease-related context and to contextualize their contributions. In contrast, others felt more guarded about personal information and did not wish members' privacy concerns to have a negative impact on their visibility within the community.

These findings are consistent with previous research that examined informational and socio-emotional needs of individuals within online health communities. However, more often than not the previous studies focused on either of these forms of support, rather than on the explicit juxtaposition of both in their coexistence. Correspondingly, the main contribution of this work is in providing a more detailed account of how these tendencies co-exist within the same community, and the specific dimensions in tensions that arise from their interaction.

These tensions have direct implications for the design of social computing platforms for online communities in general and OHCs in particular. Recent trends in the research on OHCs increasingly favor new computational solutions for optimizing access to information [3,12], expertise and interest matching [16,17], mining members' contributions overtime to infer their credibility [56], and using automated ways to extract personal information from members' contributions [23,51]. Undoubtedly all these solutions have the potential of addressing significant challenges related to information overload common in online forums. *However, drawing on the analogy with urban planning and characterization of urban life* [41]*, we argue that they have the potential of inadvertently disrupting the delicate social dynamics in these communities, thus deflecting user experiences and negatively affecting community's wellbeing.* In the rest of this paper we discuss our findings and their implications for future research and design in OHCs.

RELATED WORK

Over the years, the growing popularity of OHCs have rendered them an important source of influence in the lives and wellbeing of millions of individuals around the world [43,72]. Previous research suggested that the value of these communities falls within three different dimensions: a) *enabling informational support* (in helping them find advice, referrals, education, and personal experience with the disease or health problem, among others), b) *enabling their members to seek and provide emotional support* (in providing understanding, encouragement, empathy, affection, affirming, validation, sympathy, caring, and concern), and c) *enabling companionship* (for example in engaging in chat, humor, teasing, as well as offline activities and daily life, not necessarily related to one's health problems) [74]. Below we briefly review scholarship along these three different dimensions.

Informational needs and seeking within online health forums

Previous research recognized information seeking and making sense of information among common goals and activities of OHCs' members. Previous studies described OHCs members' information seeking practices [15], and ways they access and appraise information [35,38], and construct new knowledge together [54]. Other studies that focused on how OHC members find information suggested that individuals prefer answers by others matched on profile similarity [82]; highlighted the importance of context when posing queries; and suggested that search results should be personalized based on a user's medical history [15]. Related to this, Huh and Ackerman explored how diabetes patients in OHCs help one another find individualized strategies for managing diabetes, touching on the importance of members' profiles and disease trajectories [38]. To reflect these findings, Nambisan suggested the need to focus on developing tools that make information seeking more effective and efficient [59].

In alignment with these studies, previous research investigated a variety of approaches to optimizing access to information. Much of this research, however, focused on online forums in general, rather than OHCs. From the information retrieval perspective, previous research focused on optimizing search engines in online forums. These efforts take advantage of the hierarchical structure of discussions, rather than relying on the more classical approach based on flat document collections [26,67]. From visual analytics perspective, representative examples include ForumReader – a visualization that includes thumbnail presentations of posts in a discussion [20] and ConVis – a dynamic topic-post-sentiment-author chain connection presentation of the discussion of interest [37]. Within this domain and in OHC setting, previous research focused on exploring relationships between topics and emotions [11], as well as health behavior and symptoms polarity [10]. While previous tools were generally intended for community members, another direction explored by recent research focused specifically on supporting community moderators. For example, VisOHC [49] is a tool for OHC moderators that integrally visualizes the forum, aggregating diverse dimensions of conversational threads.

Socio-emotional needs and support within online health forums

In addition to these explorations in information seeking, there is a growing body of work examining socio-emotional needs and support within online communities. Emotional support in online communities is often defined as a response of the community to a member's desire to change their mental state, usually to more optimistic, motivated and determined [59]. This support can take many forms but usually requires that a member who seeks it is integrated with the community and can capitalize on the existing social structures [18]. In our own work we rely on these definitions and conceptualize socio-emotional needs as a member's desire to change their mental state through social interaction with other members and as a result of their social integration with the group.

Social dynamics and interpersonal relationships

One of the common themes in the research examining socio-emotional needs focuses on the dynamics of online group interactions and the relationship between the participation in an online community and an individual's off-line life [52]. Other studies examined associations between community evolution and behavioral patterns and trends of its members [2,22]. Further extending this line of work, studies investigated different roles of community members [8,40], the communication dynamics between them [39] and how that dynamic changes and members adopt to the emergent new patterns of interaction [66]. Researchers also argued that it is possible to detect social structures from OHCs forum interactions to predict and influence them [14].

Another prevalent topic of investigations is related to issues of trust and credibility. Previous research identified correlations between profile similarity, similar interests and trust [29]. Several studies addressed the issues of trust in Wikipedia articles and challenges in establishing trustworthiness of these articles [46,70]. To automatically asses trust, Golbeck proposed two algorithms for calculating it in social networks, but also extensively discussed the definition, properties and values of trust, as well as ways to infer trust in binary and continuous networks [28].

Community wellbeing

One of the overarching concerns and challenges of each online community is ensuring its continuous well-being and longevity. This includes retaining its membership, attracting and recruiting new members, and encouraging frequent, high quality contributions. Many previous investigations focused on understanding the development of interpersonal bonds and group belonging in online communities and learning how those can build members' attachment to the community [48,64]. Kraut and Resnick laid out a categorization of design challenges to achieving these effects [47]. These authors identified 5 broad design challenges: starting a community, attracting and socializing new members, encouraging commitment, encouraging contribution, and regulating behavior. Further, they suggested a variety of features of online communities that can be deliberately and strategically chosen to promote its vibrancy and longevity. Some of those features include automatic solutions for matching assistance in building initiating posts with appealing language [48], securing fast and high quality first responses [76], and community wide messages and cues that raise the sense and awareness of belonging [64].

The relationship between informational and socio-emotional needs and support in online health communities

While most of the research discussed above focused on either the informational needs of community members or their needs for socializing and ways to maintain the wellbeing of the community, there is also emerging work examining interactions between them. For example, Kraut et al. claim that online communities are not solely information oriented, but also highly social systems and should be observed and analyzed as such [48]. Previous research also pointed that informational and socio-emotional needs have intricate and complex relationships. For example, Vlahovic et al found that users expressed higher levels of satisfaction with their experience when their information needs were matched with information, but less satisfaction when they sought informational support and received emotional support [73]. Wang et al. [77] found that members exposed to more emotional support were less likely to leave the community; however, informational support did not have the same strong effects on their commitment. In their newer studies, these investigators found that exposing members to more information often led to these members' leaving the group sooner than if they were exposed to emotional support [76]. Similarly, Ridings and Wasko found that a community with strong socio-emotional relationships may be less welcoming to newcomers, particularly those with the focus on informational needs. However, an attempt to address these needs through introduction of a medical expert had a negative impact on the social dynamics with the community [66]. Other researchers suggested that there may be relationships between members' engagement and experience within the community and their orientation towards information and socio-emotional support. Specifically, they found that members that form the core of the community are more likely to engage in socio-emotional interactions among themselves than with more peripheral members to whom they provided mostly informational support [39].

In summary, previous research etablished a rich account of different forms of support provided within online communities and suggested that there may exist complex interrelationships between them. In this work, we further build on these previous investigations and specifically focus on the following research questions:

1. What relationships exist between individuals' social and emotional needs and their need for information?
2. How those relationships shape members' perception of the OHC and their attitudes towards it?
3. What are design implications for future platforms for OHC that are sensitive to the different needs and priorities of its members?

METHODS

In order to address our research questions, we conducted secondary qualitative analysis of the data collected during three previous studies with members of an online health community for individuals with diabetes, TuDiabetes. TuDiabetes is an active forum that includes over 30,000 of English-speaking members and another 20,000 of Spanish-speaking members within its sister site, EstuDiabetes. At the time of these studies the forum utilized a commercial social network platform Ning, which included such features as discussion forums, blogs, and live chat, among others. Members of TuDiabetes could form groups based on shared interests, create public profiles, and subscribe to posts by others whose opinions they find interesting.

The studies included in this analysis were conducted in 2014 and 2015 and had different focal points; however, all three studies included open-ended interviews in which participants were invited to reflect on their perceptions regarding the forum and their experience participating in the discussions within the forum. The first study (Spring/Summer 2014) with 9 participants was an exploratory study of members' general experiences with the forum, but it also included a qualitative analysis of 30 of the most popular discussions in the forum [54]. In these interviews the participants were asked to talk about their habits and practices participating in the forum and approaches to reading and comprehending discussions. The second study (Spring 2015) with 10 participants focused on evaluating a novel discussion visualization tool [58]. This study included assessment of the tool's impact on participants' performance in answering discussion related questions and open-ended interviews to obtain in-depth feedback for the tool. During these interviews, the participants were asked to openly talk about their experience with the tool and give unrestricted suggestions for improvement. Additional information regarding these studies and their findings is available elsewhere [54,58]. The third study (Summer 2015) was a small informal brainstorming session with 6 experienced members of the community (who eventually became its moderators) regarding new ways to facilitate information seeking and sharing within the community. This brainstorming was conducted over email in which participants and researchers exchanged messages and replied to each other's ideas. The data for Study 2 was collected by the first author; both authors collected the data for Studies 1 and 3.

As a result, the total of twenty five (N=25) participants were included in the three studies. Pulled together, the participants of these studies were mostly regular users, with only a few occasional ones. Most of them were also experienced members in the community, with membership of several years, some even from the early beginnings of the community. There were few relatively new members with membership of less than a year who were actively using the forum. The majority of the participants were diagnosed with Type 1 diabetes, but there were several with Type 2. All of the participants were familiar with the disease having lived with it from 5 years to more than thirty: only few had it for less than 5 years and more than half had it for more than 20 years. While neither of these studies specifically focused on interpersonal relationships, these issues emerged as a strong recurring theme, which served as a motivation for conducting this secondary analysis.

The data for the secondary analysis included: the full set of interviews from Study 1; the interviews for collecting feedback on the discussion visualization tool from Study 2; and the text of e-mail messages exchanged during Study 3. During the data analysis, all the transcripts (and written messages) were analyzed using inductive thematic analysis, but with a particular focus on relationships between informational needs and socio-emotional needs, how these needs manifested themselves, whether and how they were met, and whether and how they influenced members' perceptions of the forum. The investigators first read through the transcripts, independently for all three studies, to form general impressions. These were discussed in a meeting to refine the research questions. This was followed by inductive coding, in which researchers identified meaningful units of discourse in the transcripts and assigned them labels. This was done independently by the two authors. In the following axial coding, the researchers grouped similar categories and identified several recurring themes in the data. This was done collaboratively and through a discussion for building consensus, relying on the previous independent open coding. We describe these themes below in the Results section.

RESULTS

In this study, we found several tensions in the participants' attitudes towards the community, and in their expectations as to what they can accomplish within the forum. We argue that to a large degree these tensions arise due to ***the need to balance informational and socio-emotional needs of community members***. While both of these needs were universal to all study participants, the participants differed in whether they placed a higher importance on one or the other. We also found that these different needs can translate into different and sometimes contradictory expectations from the forum. In this section, we present our findings along four different continuums that are related to 1) *the perceptions regarding the appropriate topic of discussion*; 2) *the need for diversity*; 3) *distinguishing authority*; and 4) *the role of identity of contributors*. To distinguish between participants and studies, we identify each quote by its study number (S1-S3) and the participant ID within the study (P1-P10). To illustrate our findings we include representative quotes from 8 different participants from the three studies: S1 with 4 participants and 11 quotes, S2 with 2 and 2, and S3 with 2 and 4. The relatively balanced distribution of quotes between the studies and the participants suggests that the findings were consistent across the studies. Below we present our findings along four continuums that illustrate these tensions.

Focused Discussions Versus Free Socializing

The first tension identified in this study was related to significant differences in participants' expectations for how focused the discussions within the community should be and whether these discussions should be focused exclusively on diabetes. Some participants valued the opportunity to discuss a variety of diabetes-related topics in great depth; something they were rarely able to do outside of the forum. This was particularly the case for individuals with Type 1 diabetes, who present the largest sub-group of TuDiabetes members. Despite the high overall prevalence of this disease, Type 1 diabetes is considerably less common than Type 2. As a result, the vast majority of individuals with Type 1 did not have any friends or relations with the disease in their immediate surroundings, which often led to a rather lonely existence and the feeling of isolation. In a way, these individuals often felt "alone in a crowd" – having a common disease, but not having anybody else with this disease to share their ideas and experiences. These individuals took every opportunity to engage in discussions on a variety of topics related to diabetes, comparing and contrasting different opinions.

S2.P10 (regular [3 years], type 1 [3 years]): *"You know, it's just a way of reading that other people are similar in their answers, have different experiences but it gives me a broader feeling of community because I am the only, well I should say, up until Christmas, I was the only type 1 I knew in my area."*

In contrast, many others, particularly with Type 2, grew up witnessing diabetes affecting their family members, due to its strong hereditary component. For these individuals, having a community of others with diabetes was not a novelty. Instead, they appreciated the opportunity to look beyond the disease and to have a community of friends to socialize with and to discuss topics related to art, entertainment, politics, and many others.

S1.P3 (regular [8 years], type 1 [40 years]): "*As I said that was just not my experience but I think the majority of people out there feel that they are very isolated. I will tell that was not my experience [ ] I never viewed diabetics as having a life outside of diabetes. When I met diabetics that's what we talked about was diabetes and I was over it. I mean I was just finished with it but TuDiabetes allowed me to start a subgroup about movies, something I am passionate about, so it's pretty cool*".

Possibly as a result of these different social experiences, we found a tension between the need for accessibility, clarity, relevance and cohesiveness of information and the desire to socialize through chatting, humor and talking about non-disease topics. Some participants were hungry for any information on diabetes self-management, as well as for sharing experiences regarding what it feels like to have the disease. Others valued an opportunity to socialize with others on topics unrelated to diabetes. Interestingly, however, both of these groups of participants often complained of information overload within the forum and of the difficulties related to finding what they came to seek.

Seeking Diversity Versus Looking for Homogeneity

We also found that participants had important differences in regards to how they approached similarity and divergence in opinions of others. Some study participants were more interested in exploring opinions and experiences of members that had different life situations and different ways of looking at things.

S1.P1 (community manager [3 years], type 1 [lifetime]): *"So the perspectives are good because they give me a point of reference for figuring out, for making my own decision, really choosing among their decisions"*

In some situations, new perspectives caused members to think about their own questions and challenges in a different way and have their attention drawn to issues they haven't considered important or interesting previously. In that regard, they often valued contributions from new members.

S1.P3 (regular [8 years], type 1 [40 years]): *"At the time when I started, I was not using the pump and I didn't really seek out pump information from TuDiabetes but the number of pump users on the site helped me gain courage, I guess, to explore the pump… So stuff like getting a pump was influenced by TuDiabetes but I didn't really go there for information about pumps in particular."*

Yet other participants actively sought out members whose opinions they shared and whose personal experiences they could relate to.

S1.P3 (regular [8 years], type 1 [40 years]):*"… if somebody tells me that red cars are better than blue and I like red cars a lot, then it's human tendency that I am probably going to favor their point of view more than the person who says blue cars are better, that's just a human tendency…"*

These individuals valued personal bonds over exposure to new information and diverse opinions. They tended to create small and informal sub-communities, or even cliques, members of which felt stronger engagement with each other, than with a greater TuDiabetes community.

S3.P2 (moderator): *"If there is a way to support that so that you can see posts from people with whom you have established a social connection (like looking at their posts, profiles or messages) that might be a way of encouraging the formation of small supportive social networks in the face of a vast sea of 100,000 members."*

As a result, we suggest that there exists a tension between the need for diversity in opinions that could increase objectivity and lack of bias in the information, and members tendency towards homophily that helps to establish relevance of the information, and also serves to reinforce social connections between members. According to the study participants, the optimal experience lies in the careful balance between having a small group of like-minded virtual friends, and a way to sample perspectives in a larger community; yet establishing this balance is non-trivial.

Favoring Authority Versus "Every Voice Counts"

Yet another tension was found in participants' perceptions of authority and importance of identifying authoritative voices. Many participants felt overwhelmed with the amount of information and differences in opinions among the members, and expressed concerns about lack of indications as to whose opinion can be trusted.

S3.P2 (moderator [6 years], type 2 [10 years]): *"I want answers from members who are considered competent and objective. I want answers from members that other members trust."*

This was a particular concern for newcomers, who may often feel overwhelmed and need guidance. While most of the participants in our studies were experienced members of the community, they all remembered how it felt like to be a newbie and not know who to trust.

S2.P1 (regular [8 months], type 1 [10 years]): *"...but if you are new and maybe also have no idea about diabetes, you are open to every advice and then you might follow advice that this is really nice or not really doing very good and if you can see Oh! this person doesn't really give often good advice, then I can't follow."*

Yet for others, the main reason for their sustained commitment to the community was its welcoming and friendly nature. For these individuals, creating a nurturing environment where each member felt welcomed, heard, and understood was among their top-most priorities.

S1.P4 (regular [5 years], type 1 [7years]): *"So, somebody who needs some kind of help that I feel that I have to offer; somebody who is emotionally struggling or in need of support or just an interesting discussion about a topic that's related to diabetes or even not that related."*

For these participants, any initiative within the community that promoted the sense of inequality between members was at odds with its spirit of comradery and companionship.

S1.P4 (regular [5 years], type 1 [7years]): *"I don't like, I might be getting off the topic so I will be just brief, I don't like the popularity contests like when they give awards every year, even though I have been the recipient of some I don't like the fact that they do that, I think everybody contributes something, I openly say 'thank you for selecting me but I think everybody has something great to contribute"*

Similarly, these individuals resisted the idea of using visual features (for example different font size) to indicate common contributors or otherwise distinguish between members based on their contributions:

S3.P2 (moderator [6 years], type 2 [10 years]): *"I like the leveling aspect of everyone having the same font. If we start sizeism, it seems likely that people will end up with virtual antlers and use it to take over the herd."*

Particularly in the context of a diabetes self-management community that values supportive and welcoming atmosphere, these kinds of differentiators were perceived as potential contributors to increased emotional distress, and decreased confidence.

S3.P4 (moderator [5 years], type 1 [31 years]): *"I think the problem would be non-antlered being intimidated by big names, like on the "tu [TuDiabetes] isn't as friendly as it used to be..." thread. I don't agree with that but diabetes grinds people down and some people are less confident than others. I think the community provides its own regulation through conviviality and kibbitzing."*

As a result, we suggest there exist a tension between members' need for assessing authority, credibility and trustworthiness of the information and their socio-emotional tendency for belonging to a group and need for affirmation, empathy and sympathy. The participants often felt overwhelmed by the amount of information in the forum and wanted to distinguish opinions of members deemed trusted and reliable. At the same time, equal footing between members and welcoming and embracing culture that values members regardless of their contributions was of great importance to many participants and something that in their eyes distinguished TuDiabetes from other online diabetes communities.

Attention to Contributions Versus Attention to the Authors

Finally, we found that participants had different degrees of interest in learning more about other members and their identity outside of the community, in contrast to focusing only on their contributions to TuDiabetes.

For some participants, the most important characteristics of a member that rendered them credible and reliable were this member's contributions to the forum. For these individuals, such characteristics as frequency of a member's posts, the diversity of topics they discussed, and clarity and insightfulness of their contributions were defining factors in establishing an individual's credibility.

S1.P1 (community manager [3 years], type 1 [lifetime]): *"…after all you have to see well, this person replies a lot and also see how other people respond to this opinion"*

For these individuals, the actual identity of the authors of posts was less important than their contributions. Consequently, these participants often wished for features that could make levels of members' activity within the forum more explicit, but did not expect to learn much about the authors' lives and identity outside of the forum.

Moreover, many participants also acknowledged that different members have different perceptions of privacy and of how much personal data they were willing to share on the forum:

S1.P4 (regular [5 years], type 1 [7years]): *"There is one guy on there that we think very similarly and he said, it's so scary how much we think alike, but he is a very private person and I have been aware of the fact that I have no idea and I know how old he is, he has mentioned that, but I have no idea if he is married, if he is retired, what he did for a living, he is just a private person.. I know about his diabetes, and that's a personal choice."*

These considerations further reinforced these members' desire to focus exclusively on members' contributions to the forum. They felt that requirements to share personal experience could present barriers for more privacy-conscious individuals and prevent them from becoming more active participants in the forum.

Other participants, however, paid particular attention to the personal characteristics of individuals who authored the posts they were reading, and not just the posts themselves.

S1.P3 (regular [8 years], type 1 [40 years]): *"Yeah, if I know the person I will have a – I will have great weight on what they might be saying… And the more I know a person, then the more credibility I add to that."*

For example, seeing sense of humor, positive attitude towards life in general and disease in particular, played a role in determining whose opinions to rely on.

S1.P5 (regular [9 months], type 1 [20 years]): *"I think the humor and the clarity, and the…everybody obviously deals with a chronic situation differently and I find some people to be much more stalwart and have humor about it, and kind of take things as they come which is more of my style, and I think some people, it is much more of a burden and their writing tends to be a little darker or a little more problematic."*

These individuals tried to learn more about the authors of posts they found interesting by looking at these authors' profiles. This was particularly the case for posts whose authors were new members of the community.

S1.P4 (regular [5 years], type 1 [7years]): *"…when I am responding to someone I do like to know a little bit about them because sometimes people will just say, I am new, I don't know how to handle my diabetes and it's the best way they can post their question but it's not enough information. So I will go to their page and I will look and see, are you type 1 or are you type 2? how long ago were you diagnosed? What is your A1c?"*

As a result, we propose that there is a tension between the need for accuracy, reliability and utility in the information and the socio-emotional need for privacy. While some members wished to focus on individuals' contributions to the forum, regardless of who the authors of the posts really are, others were interested in the identity of the contributors. Moreover, there were varying degrees of sensitivity to disclosure of personal information with some individuals being more private about their lives outside of TuDiabetes than others.

DISCUSSION

In this study we examined perceptions and attitudes of members of an online community dedicated to diabetes self-management, TuDiabetes, with a particular focus on the interplay between informational and socio-emotional needs of its members. Overall, the study suggested that there exist different perceptions regarding the purpose of the community and important differences in what its members considered a positive and desirable experience. Some placed upmost importance on the social ties and emotional support among its members, and valued the community mostly for its warm and welcoming character. Others were primarily concerned with their ability to effectively and efficiently search for information and considered everything else a distraction from their primary purpose.

These findings are consistent with previous studies that pointed out a similar dichotomy in members' perceptions. For example, Brzozowski et al., explored public Google+ communities and found that these communities were perceived as "plazas" to meet new people by some, and as "topic boards" to discuss common interests by others [7]. Similarly, studies of Twitter posts found two major modes of behavior: an information-driven one, and one based on reciprocated social ties, where the prevalence of the two depends on the age of the user's account [57].

In our work we further build upon these previous findings, and not only suggest that there exist tensions between informational and emotional needs of community members, but also identify several different dimensions for how these tensions manifest themselves in individuals' expectations from the forum. Below we discuss these dimensions in further detail, and draw implications for the design of future platforms for online health communities. While few of the studies referenced below specifically focus on OHCs, their findings are consistent with our observations and, as such, are of high relevance for our claims.

Staying focused and going off-topic

The first of the tensions identified in our study focused on the contrast between the desire for focused discussion and free socializing. Given the focus of TuDiabetes, it is not surprising that diabetes and its self-management are the glue that connects the members and keeps the community together. Many participants of our studies placed particular importance on keeping the discussions focused and were less supportive of topics that could increase information overload and, consequently, make finding desired information more challenging. Yet for others, discussions about wine, coffee, and movies were just as valuable as those related to diabetes self-management, because they helped them build social relationships with other members and increase the sense of belonging to the community.

These findings are consistent with previous studies that examined the dichotomy between focused and broad discussion topics and their impact on member engagement. For example, studies of Twitter showed that users who have narrow focus of topics in their early tweets, ultimately attract higher number and more tightly knit followers [78]. On the other hand, Postmes et al. showed that restricting conversations to specific domains makes a community less appealing to people who want to learn more about other members, whereas a policy of encouraging off-topic conversation can undercut identity-based attachment [71]. To overcome this tension, Kraut and Resnick proposed the notion of "going off-topic together"—a situation where something that is normally considered off-topic becomes on-topic, at least temporarily. They suggested that "going off-topic together" can increase both identity based commitment and bonds-based commitment [47]. Moreover, off-topic conversations can help members discover additional common interests and share personal information, thus enhancing interpersonal bonds [47].

In regards to computational solutions for addressing focused and broad discussion, many of them use computational methods that automatically match discussion initiators' needs with the comments provided by others [76,77]. Others distinguish between factual and conversational discussions [33] and detect evolution and semantical distance between topics over time [19,80]. However, few of these solutions provide recommendations as to how to handle conversational and off-topic conversations once they are identified.

Homogeneity and Diversity

The second tension contrasted members' interest in diversity and their desire for homogeneity and belonging to a group. TuDiabetes has a highly diverse international membership with over 30,000 participants from all over the world who have diverse experiences and knowledge in regards to diabetes and its self-management. Many of its members considered this diversity to be one of the forum's most valuable assets. Yet others felt overwhelmed by the multiplicity of opinions and felt the need to find a smaller group of members they could identify with. As these participants pointed out, it is human nature to trust those whose perspectives and life experiences are similar to one's own, and to be suspicious of opinions of strangers.

Previous research depicts the positive and negative sides of both perspectives. For example, past studies identified correlations between profile similarity, shared interests and trust [29]. However, restricting one's interactions to a small circle of similar friends may introduce bias in interpretation of the information and distort true credibility [79], prevent users from exposure to diversity in perspectives [62] and opinions that can have important benefits like triangulation for validity, power of cooperation [63] and lateral thinking which is known to contribute to creativity in problem solving [65]. Additionally, this approach of recommending similar users may further reinforce existing cliques and lead to new members feeling excluded and disenfranchised. Moreover, while it may promote development of strong ties between few members, it may prevent development of weak ties among larger groups that could be instrumental to dissemination of novel approaches to self-management of diabetes. Granovert suggested that social networks with weak ties among individuals who share fewer common characteristics are more conducive to diffusion of information than more homogeneous groups with stronger ties among their members [30]. Many participants in our study were aware of the importance of diversity of opinions in exposing one to new ideas and original approaches to the management of diabetes.

In regards to the computational solutions explored thus far, many of them focused on helping members of online communities to connect with others based on shared interests. Researchers worked on subdividing a larger community into clusters of participants who are similar to each other [34], discovering social circles in ego-networks [55] and predicting the strength of social ties [27]. Topic modeling techniques were used to identify the important themes in a discussion [9,44], and automatic methods for detecting opinion leaders [6] and comparing opinions [50] were developed. In addition, many mechanisms have been proposed for helping people stay connected with those they interacted with in the past, or with similarity in profiles, interests, and social proximity [13]. These are particularly common in social networks like Twitter for example [32], but are also present in OHCs, where PateintsLikeMe members can locate others with similar circumstances and with shared medical experiences based on manually entered detailed profiles [24]. Going one step further, researchers automatically extracted person-generated health data from posts and reconstructed profiles for peer mentor matching along three dimensions: health interests, language style and demographics [36].

Once again, while these proposed approaches provide novel solutions to the question of connecting members based on similarity and shared interests, it is not clear what impact they would have on promoting diversity of opinions, and promoting weak ties that can greatly enhance dissemination of information within the community.

Credibility without Undue Influence

The next tension identified in this study focused on the members' need to establish authority and credibility of information, and their desire for democracy, and for equal footing for all. TuDiabetes is a lively and active community; most of the questions posted by its members are answered within the first day [54]. Moreover, many questions receive a great variety of answers that may reflect deep differences in opinions among members. As a result, the participants of the studies who prioritized information needs often wished for an easy way to identify credible posts that came from trusted and authoritative members. Given that many members come to TuDiabetes to ask for advice on critical issues related to diabetes self-management, distinguishing between trusted sources and unsupported opinions was important. For some participants, a member's past contributions to the forum, their quality and whether others found these contributions useful were among the most important questions [68]. This information was often used to gauge credibility and trustworthiness of this member's future contributions. In addition, these individuals often wished for a better ability to see members' aggregate contributions to understand their views and opinions. However, other participants were highly skeptical of introducing any explicit cues as to the credibility and trustworthiness of members, because of their potential to give these members a higher degree of influence in the community. For example, they feared it may enable strong-willed and opinionated individuals to establish dominance within the community, and to help them "grow antlers", in the words of one of our participants.

These findings are consistent with previous research on the impact of competence on social influence, which showed that individuals perceived as more competent have a higher influence on judgment of others [21]. However, these authors were also concerned that creating highly competitive environment may inhibit less knowledgeable, experienced and vocal members from participating.

There exist emerging computational solutions relevant to this problem. For example, previous work proposed methods for computationally identifying credible posts [56], finding authorities [45] and experts [16,17] and estimating trust among members [29]. Yet, few previous studies examined the impact of these approaches on the power dynamics within the communities and on inclusion of novices.

Providing Context While Respecting Privacy

The final tension identified in this study focused on the members' desire to contextualize information in experiences and identity of its authors, and their need to maintain privacy. As is typical for many online communities, most members of TuDiabetes know each other only through the forum; few have any personal encounters in the real world, or communicated outside of the community. In these circumstances, the impressions members form of each other are mostly based on the information available within the forum [16,17,35]. For some participants, and similar to findings of other studies [35], additional information on contributors' life circumstances, specific diagnosis and disease trajectory, and other aspects of their lives that could show them the person behind the posts was of great importance. It could help them to build a closer relationship with the person, and construct more reliable and meaningful discussions around their questions and challenges. These participants wished for richer profiles that complement and expand what was manually entered in the members' profiles [35], which could include personal stories, photographs, and information on their disease history. Yet these desires were sometimes met with skepticism due to different attitudes in regards to privacy issues; while some were comfortable disclosing intimate personal details, others remained guarded about their life outside of TuDiabetes.

Both of these sides of the argument have their support in existing literature. For example, previous research argued that context is crucial in a quest for health-related information, for example when building a query [15] or asking a question [82]. Others suggested that search results should be personalized based on a user's medical history [15]. Other solutions in this area proposed incorporating searchable profiles that reflect an individual's treatments, side effects, lifestyle information, strength of social ties and their social roles, as well as type and level of health-related knowledge [16]. However, all types of information are not universally treated. A study showed that there is more willingness to share clinical information than other forms of demographic and daily life information [25] and that sharing is highly context-dependent on what type of information is shared, to whom, and for which purpose [60]. On the other hand, there is a body of research that promotes awareness of the potential harms due to the disclosure of personal information [4] and advocates the importance of privacy [23,75].

Existing solutions in this space focus around user modeling [83] for content recommendation in Twitter [1] and learning users interests from Facebook profiles and activities [5], formulating aggregated and multi-domain user profiles [61] extracting patients' personal information from the social web [23,51] and several categories of health interests: health problems, treatments, diagnostics and tests, and provider care [36]. A recent study in PatientsLikeMe showed that when such detailed profiles are made available for social use, they are often utilized for constructive purposes: asking advice of a user with a particular experience, offering advice to a user with a specific symptom or health problem, and fostering relationships based on shared attributes [24]. However, the implications of these new capabilities on the discourse and dynamics within the communities still remains poorly understood.

Designing for Balance: Urban Life of Online Health Communities

Given the seemingly irreconcilable nature of the tensions identified in this study, the question remains as to whether and how these tensions can be addressed in the design of new platforms for online health communities? While the review of the solutions provided in this paper is far from comprehensive, it suggests that new solutions increasingly favor informational needs and focus on optimizing effective and efficient access to information. From using novel topic modeling methods to flag "off-topic" discussions, to using computational methods to identify clusters of individuals based on shared interests, to automatically detecting trustworthiness of individual members, to automatically reconstructing individuals' profiles, these solutions can indeed address the challenge of information overload and make it easier to navigate the richness and complexity of the modern discussion forums.

However, these solutions may also lead to unintended consequences. In a way, the tensions identified in this study carry a resemblance with a long-standing argument in regards to the interplay between efficiency and community building in urban planning. In her book "The Death and Life of Great American Cities" Jane Jacobs [41] identified segregation of function and disproportional focus on purpose and efficiency as one of the root causes of the decline of urban life in the United States. Jacobs suggested that the desire for clean organization of neighborhoods by their purpose created cities that included residential quarters, business districts, and commercial zones, each with their dedicated purpose. However, such cities lacked places where people of different walks of life could mingle, socialize, and build a community. As a result, this segregation led to a degree of sterilization of urban life and to a large degree destroyed its vibrant spirit. Conversely, neighborhoods that managed to preserve a synergistic and at times chaotic mix of commerce, business, and residential life, maintained their resilience and community spirit even in the face of economic hardships. Jacobs describes the struggle between community activists in New York City (herself included) to prevent construction of a four-lane highway (a functional unit) through Washington Square Park (a social interaction unit), the cultural heart of progressive New York that gathered artists, musicians, activists, and protesters [86]. As a result of this movement the highway plans were abandoned; moreover the park was closed for all traffic, which helped preserve the vibrant Greenwich Village neighborhood.

The analogy with urban planning and Jacobs' characterization of urban life has several implications for the design of future online health forums. We envision that these platforms build upon the new technical innovation in automated text analysis and information retrieval, while at the same time promoting social engagement among community members. First, the analogy points to potential pitfalls of enabling customizable experiences for different individuals based on their identified needs and preferences. Given the differences in opinions between community members, customization may seem an attractive, if not inevitable option. However, while customization can meet individuals' needs in the short term, over time it may potentially lead to a growing disconnect between community members and reduced sense of common ground between them. If each person experienced a city in their own unique way, they would have fewer opportunities for community building. We envision that future platforms for OHCs can help their members meet their individual needs while at the same time reinforcing shared experiences. For example, they can further enhance members' ability to create and maintain personalized content collections by subscribing to particular authors or threads or by automatically detecting content of interest, while at the same time enabling easy traversing between the selected content and discussion threads it originated from.

Second, it advises against going too far in promoting efficiency in satisfying information needs at the expense of social interactions. For example, if a search engine focused only on informational needs of an individual and efficiently retrieved information that matches those needs, it may discourage this individual from posting to the forum and thus contributing to social interactions within it. Overtime, this may reduce the amount of new searchable content available to others. And while browsing through multiple discussions within a forum may seem inefficient, it could nonetheless expose an individual to unexpected perceptions and highlight the multitude of opinions. Moreover, if search results are presented in a way that disconnects them from the informational and social context in which they were created, it may have a negative impact on the individual's ability to fully understand the topic, and also to prevent them from contributing their own perspectives. Instead, we suggest that future platforms further reinforce the connection between the content and its authors and the social setting in which it was created and uses every information request as an opportunity to promote social interaction among members. Moreover, we suggest that these forums focus not only on addressing individuals' immediate informational needs, but also create opportunities for their members to be exposed to the breadth of perspectives within the community.

Finally, it suggests the need to complement research on optimizing information seeking in the online communities with research on new technical solutions to promoting social interactions and engagement. While many previous studies suggested the importance of community building for the survival of online communities, typically, such efforts fall into human domain. For example, a recent study of

StackOverflow highlighted the active role of this forum's founders in energizing the community, attracting new members, and maintaining its active functioning [53]. Similarly, in TuDiabetes, forum's founders and moderators work tirelessly on organizing new community-building activities. Yet computational solutions to promote and enhance these efforts are limited. We propose that new computational methods could be used to not only facilitate access to information, but also to monitor wellbeing and pulse of the community and for creating new opportunities for members to engage and socialize. For example, such increasingly popular methods as sentiment analysis could be used to detect emerging negative attitudes within a community towards a subject or between members, or identify members in distress and help community organizers and moderators better focus their efforts. However, all the design recommendations mentioned here need to be further examined and evaluated on their actual impact on the social dynamics within online health communities.

Taken together, the findings presented here paint a complex picture of highly divergent priorities and expectations expressed by different members of TuDiabetes, particularly in regards to whether they prioritized information needs as opposed to valuing an ability to socialize and build a community. These different priorities are not mutually exclusive but form complex intertwined relationships and have impact on each other in often unexpected ways. While perhaps not surprising, these findings highlight how challenging it is to strike the right balance between these competing priorities, and how easy it is to disrupt the social fabric of the community by favoring one set of needs over the other with focused technical solutions.

This research focused specifically on online health communities and examined forces that may contribute to their longevity or inadvertently disrupt them. The question remains, however, to what degree the phenomena uncovered in our study apply specifically to communities that focus on health and wellness, and to what degree they generalize to other online communities and social media platforms. In our previous work we examined an online question and answer forum for software developers, Stack Overflow, and found that these communities have somewhat different set of values and priorities [53]. For a professionally-oriented community that focuses on efficiency in finding the right information, features that promoted competition and rewarded expertise were highly successful and beneficial to the growth of the community's popularity. This suggests that different communities of practice may have different sets of values and priorities that may require different sets of features to reflect these values.

This study has a number of limitations. Most importantly, it only included a small fraction of members of TuDiabetes and as such may not generalize to all members. In addition, it relied on a convenience sample of volunteers who in their majority overrepresented experienced members of the community. As such, these findings may underrepresent the experiences and perceptions of new members and are not sensitive to possible differences in opinions among them and the more experienced members.

CONCLUSION

In this paper we conducted a secondary qualitative analysis of interviews with members of the TuDiabetes community to understand the role of interpersonal relationship among members and their perceptions of others in their appraisal and use of information within the forum. The study highlighted a number of tensions in members' expectations and priorities in regards to their experience with the community that have important implications for the design of social computing platforms that support OHCs. We propose that these tensions arise due to the different priorities in regards to members' information needs and their need to socialize and build a welcoming and nurturing community. As many pointed out before us, online health communities are complex social places with intricate social dynamics that can have a high impact on members' sense of belonging and on the overall wellbeing of the community. *It is important that the efforts to promote effective and efficient information retrieval do not disrupt the existing social connections and dynamics and serve to not only improve information seeking but to help members have richer and more fulfilling overall experiences*.

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