

“It's not that I don't have problems, I'm just not putting them on Facebook”: Challenges and Opportunities in Using Online Social Networks for Health

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ABSTRACT

To understand why and how people share health information online, we interviewed fourteen people with significant health concerns who participate in both online health communities and Facebook. Qualitative analysis of these interviews highlighted the ways that people think about *with whom* and *how* to share different types of information as they pursue social goals related to their personal health, including emotional support, motivation, accountability, and advice. Our study suggests that success in these goals depends on how well they develop their social networks and how effectively they communicate within those networks. Effective communication is made more challenging by the need to strike a balance between sharing information related to specific needs and the desire to manage self-presentation. Based on these observations, we outline a set of design opportunities for future systems to support health-oriented social interactions online, including tools to help users shape their social networks and communicate effectively within those.

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GENERAL TERMS

Human Factors

KEYWORDS

Online health communities, social support, Facebook

INTRODUCTION

People are increasingly connecting with online health communities (OHCs) such as SparkPeople

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(<http://sparkpeople.com>) and dLife (<http://www.dlife.com>), for support around health-related goals. At the same time, vast numbers of people connect with friends and acquaintances online via social networking sites such as Facebook, and there is increasing evidence that they want to leverage those existing connections to further their health goals (e.g., [22]). A substantial body of prior research has looked at specific online health communities and characterized what makes them effective and valuable for their members (e.g., [18,23]). Less research has been done to understand *how* people choose where to share different types of information from among the variety of options available to them, including OHCs, generic online communities, social networking sites, and direct contact with offline friends and loved ones, and *why* they make those choices.

To understand how and why people share information with others online regarding health, we interviewed fourteen individuals struggling with weight loss and diabetes management who use both online health communities and Facebook. In relation to health concerns, our participants reached out to others for emotional support, motivation, accountability, and advice. It was not surprising to observe that people think carefully about which pieces of information to share with which groups of people, and that they form mental representations of the audiences in each of the different venues in which they communicate. It was more surprising to observe, however, the degree of effort devoted to building and maintaining the networks with which they interact. Our study also sheds new light on the ways that people navigate the tension between sharing vulnerability, needs, and health status information and the desire to convey positive images of themselves.

Focusing on the two challenges that derive from these observations—building and maintaining multiple networks and managing the tension between impression management and sharing information related to a health concern—provides us with a novel perspective from which to explore new design directions. From this viewpoint, we outline a set of design opportunities for future systems to support health-oriented social interactions online, including tools to help users build and shape health-enhancing social

networks and tools to help people express health related needs and information while managing social impressions

The contributions of this paper include:

1. Identification of people's considerations regarding *with whom* and *how* they share information as they engage in health-related social interactions.
2. Identification of two key challenges faced by users: 1) building, shaping, and selectively accessing a support network and 2) managing the tension between impression management and pursuit of other health goals.
3. Articulation of a new design perspective that focuses on helping users build and shape their networks for particular goals and manage goal-related communication more effectively.

BACKGROUND

Online Health Communities

Online health communities (OHCs) are online environments in which users interact with one another around a set of common interests or shared purpose related to health [20] using a variety of tools including discussion boards, chat, virtual environments, and direct messaging.

A key benefit of OHCs is that they provide members with access to other people with similar experiences, including people with more experience dealing with relevant health issues. Individuals can meet several goals in such environments. Previous research has found that OHCs offer patients opportunities for emotional support when dealing with difficult health issues [7,18]. Through sharing and sometimes competition, online health community members are able to serve as motivation for each other and can engage in mutual accountability [11]. In addition, such communities provide access to experience-based information about particular treatments or behavioral strategies, which many users find more relevant or accessible than information obtained from professionals [8,17,19]. Online spaces can help people connect with others in similar circumstances even when these people are not locally available or already in their social network, can be more convenient than in person groups, allow people to communicate anonymously, allow people to reciprocate the support they receive, and offer non-judgmental spaces in which to share [11]

Most studies of OHCs have sought to either evaluate their effectiveness from a health outcomes or patient satisfaction perspective, or have sought to explain aspects of how and why they operate. A less explored perspective has been to ask what people's social support needs are and to what extent different types of social software can support those needs. In this latter vein, Skeels et al [21] found that four types of information help make breast cancer patients' support networks valuable: health information, information

about the patient's status, knowledge about patient's interests and emotional state, and information about living through cancer; thus, is it helpful for patients' networks to include people who are knowledgeable about, and have experience with, the condition and who are knowledgeable about the patient as a person.

In our study, we share Skeels et al's focus on individual needs and perspectives. However, where they focused on individuals' information needs with regards to supportive communications, we focus on the considerations that people weigh when deciding how to share information.

Facebook

Online social networking sites such as Facebook are typically used to support pre-existing social relationships [6] and activity on such sites is dominated by surveying the status and activities of friends and managing one's self-presentation through status updates and the information on one's profile [12].

Social networking sites such as Facebook help users create and maintain large, diverse networks of weak ties and thus can increase the bridging social capital upon which one draw for resources [5]. Additionally, Facebook supports the accumulation and maintenance of social capital, by allowing users to build, invest and maintain social ties with distant, geographically dispersed friends [6]. While a good deal of work has been done to link social capital with health in broad terms [13], the details of how different types of ties actually provide help needs further exploration.

Online social networks have also been studied in terms of privacy and information disclosure concerns. Many Facebook users experience "collapsed contexts", or the collision of multiple social groups and types of relationships in one environment [1]. Users often mediate this conflict by developing self-presentation strategies [16] and using privacy controls to limit sharing [24].

While these studies shine light on how people are using Facebook for general social interactions, little has been said so far about how Facebook is used in the context of health. Examining the use and potential of Facebook for health is one of the goals of this study.

STUDY DESIGN

Participant recruitment

Our participants included 14 adult individuals who were members of at least one OHC and Facebook and who had posted at least five messages to each in the past month. Participants were trying to lose weight and/or manage Type II diabetes. Recruiting participants who used both Facebook and at least one other OHC allowed us to learn strategies and tensions from individuals who had learned to successfully leverage these different resources, though it also limited our ability to learn from individuals who were struggling to figure out how to best use OHCs or Facebook

Table 1. Summary of study participants.

	Gender	Health concern(s)	Primary OHC	Time in OHC
P01	F	Lose weight	FatSecret	1 mo
P02	F	Maintain weight	Personal Blog	1 yr
P03	F	Type II diabetes	DiabetesDaily	2.5 yr
P04	M	Type II diabetes	DiabetesDaily	3 yr
P05	M	Lose weight	SparkPeople	4 yr
P06	F	Maintain weight	SparkPeople	3.5 yr
P07	M	Maintain weight	SparkPeople	8 mo
P08	F	Lose weight	SparkPeople	1.5 yr
P09	F	Lose weight	FatSecret	1 mo
P10	F	Lose weight	SparkPeople	1 yr
P11	F	Maintain weight	SparkPeople	2.5 yr
P12	F	Lose weight	SparkPeople	2 yr
P13	F	Lose weight	SparkPeople	1 yr
P14	F	Type II diabetes	TuDiabetes	2 yr

in pursuit of their goals. We recruited participants by asking moderators to post advertisements on discussion boards within several of the most popular OHCs at the time of our study, namely SparkPeople, LiveStrong, FatSecret, dLife, DiabetesDaily, TuDiabetes, and DiabeticConnect. We also posted recruiting ads on several Facebook groups for diabetes and the discussion forums for diet and fitness-related Facebook applications.

Procedure

Individuals who met the study criteria were contacted to set up a 90-minute interview. They received \$25 gift cards upon completion of their interviews. The semi-structured interviews centered around participants' experiences with their primary OHC and with Facebook, a history of health concerns, concerns about sharing and privacy, decisions about what to post on OHCs and Facebook, and their experiences obtaining support offline. All interviews were conducted over the phone and, during the interview, the participant shared his or her computer screen with the interviewer using GoToMeeting (<http://www.gotomeeting.com>) in order to show specific examples of how they used OHCs and Facebook and information they had shared. The audio and video of the sessions were recorded and the audio was transcribed. Transcript analysis consisted of inductive coding performed by the second author followed by group discussion including all authors to iteratively generate and refine themes and probing to challenge and find further evidence for emerging themes. Iterative generation and refinement of themes continued until a sense of closure was achieved.

Participants

Of our 14 participants, three were male and eleven were female; we did not ask for their ages. As shown in Table 1, our participants used four different online communities as their 'primary' online community; most had also joined other communities, but had chosen to invest their time into just one. The communities represented in our study were SparkPeople, FatSecret, DiabetesDaily, and TuDiabetes. In addition, one participant (P02) had created a personal blog where she and a friend followed a practice of posting daily about their eating and exercise and were hoping to attract other members. While this person was not an active OHC member at the time of our study, she was included because she had found her experiences with OHCs lacking, leading her to create her own solution.

Online Community Characteristics

Each of the four OHCs present a range of interaction options to users. In particular, all four communities support personal profiles, the ability to add "friends," personal blogs, topic-oriented discussion boards, and the ability to join dedicated groups (which, in turn, had dedicated discussion boards for the group). In addition, all four of the communities provide health tracking tools that allow members to enter, for example, calories consumed, exercise performed, current weight, and blood glucose readings. Each OHC provides a large amount of produced content as well, including articles, videos, meal plans and so forth that are provided by the curators of the sites. Our participants reported taking advantage of many of the features offered by OHCs including personal tracking, updating profile and status information, direct messaging, and participation in discussion boards and groups. Most participants indicated that they log in to their preferred OHC at least once every few days and several logged in daily.

Facebook is currently the largest online social networking site in the world, having reached 500 million users in July 2010. The average Facebook user is connected to 130 friends and, while we did not collect the number of connections for our participants it was clear in all cases that their friend lists were large enough to include both strong and weak ties, which is typical for Facebook users [6]. Our participants reported typical usage patterns for interacting with Facebook, including keeping tabs on family and friends (including geographically distant friends from earlier chapters of their lives), sharing pictures, posting status updates, and playing games. As with the OHCs, most participants indicated that they log in to Facebook at least once every few days or daily.

FINDINGS

Our participants used Facebook and OHC in pursuit of emotional support, motivation, accountability, and advice in relation to weight loss and diabetes management. As noted earlier, these goals are consistent with previously identified goals for participating in OHCs

[8,11,15,17,18,19]. Our study extends prior work by highlighting *the ways* that people share in order to meet these goals.

Moreover, our findings reveal that these goals often conflict with the goal of impression management. For example, the need to express a need for support can run at odds with the need to present oneself as a positive, appealing member of the community. People naturally wanted others to view their health status and activities favorably and also did not want to overload or bore them with inappropriate communications. In addition, we found that people put considerable effort into building and shaping their networks to more effectively pursue their health-related goals and to reduce the conflicts between those goals and impression management goals.

In this section, we examine each goal in turn, focusing on *with whom* our participants share information and *what strategies* they employ in order to share effectively and meet their goals. We then discuss the concerns people have about impression management and the strategies they pursue to maintain control over their self-presentation. Finally, we describe the work participants do to build and maintain their networks.

Emotional Support

Receiving and providing emotional support was the most commonly cited goal for interacting with others around health among our participants in their struggles to lose weight and manage diabetes. When considering where to go for emotional support, participants cited a number of characteristics that made OHCs a good venue and noted that the absence of those characteristics that prevented them from seeking support on Facebook. Specifically, OHCs were seen as good because they were filled with people who were going through the same struggles, provided positive and encouraging responses, and could be counted on for a rapid response at any time of day or night.

Connecting with people who share one's struggles was seen as important because others wouldn't understand or be sympathetic. One participant explicitly compared the advantages of sharing with an online community to the potential disadvantages of sharing with friends outside the OHC in terms of her health "journey:"

Most women won't say, "Hey I weigh 158 pounds..." But when you start out over 240 pounds and you get down to something as little as 158..., that's huge! And just some of the people that I am friends with they have not had that journey, so they don't quite understand." –P08

Feeling that others would receive a request for support with positivity and encouragement was also seen as critical. One participant explicitly compared SparkPeople to Facebook in terms of positivity versus sarcasm:

"Everybody feeds off everybody's positivity [on SparkPeople]. There's no sarcasm on here. Like if you said, 'I feel fat today' people would be like, 'Don't think that, you're not fat...' Whereas, if you put that on Facebook it would probably be like, 'Why don't you go run,' or they'll say something sarcastic and negative." –P07

P05 related a story about how some of his friends were unhelpful in supporting him when he quit smoking:

"Like for instance, many years ago I quit smoking. And every time I told someone I was going to quit, they were like "Are you having cravings, how you doing with the cigarette smoke? Hey, are you having a hard time? Does this make you want to have a cigarette?" So, when I finally quit I didn't tell anybody, I just quit." –P05

Another key advantage of online communities is that they are always available, and generally quite responsive. When emotional needs are acute, the availability of a place to connect with sympathetic others is seen as valuable:

"[If] I am going through a rough patch, and I post it up I can see immediately someone respond...the replies actually mean quite a bit for those." –P03

However, online communities did not serve all of the emotional support needs of our participants. In some cases, this was due to the personal preferences of the individuals. For example, P04, a professor with diabetes, sought emotional support from his wife when he struggled with his condition. He cited his private personality as a reason why he did not wish to discuss personal struggles online. He felt comfortable advising others online, consistent with his identity as a teacher, but not seeking support and exposing vulnerability. Others stressed the possibility of physical contact as being important. As P08 noted, "There is nothing that can replace that physical pat on the back or the hug or that smile."

Some participants were explicit about the calculation regarding what information to share on their OHC as opposed to Facebook. This was most clear when participants used posting mechanisms that forced them to make an explicit decision about where to share their updates. P06, for example, was one of several participants who used a feature of SparkPeople that let them cross-post their status updates to both SparkPeople and Facebook, however she was selective about how she used this feature. While she posted about her runs on Facebook, she explicitly chose *not* to cross-post messages about her struggles, instead posting these only to SparkPeople:

"[I do post about my runs, but...] See, yes. I did not put that on [Facebook] because I didn't want everybody on Facebook knowing that my butt muscle hurt today." –P06

Another strategy used was to reframe posts for each community by, for example, tuning the content to include more or less detail. For example, while P03 was open about

sharing details about her diabetes on Facebook, her posts on Facebook tended to be short and less personal, while the same messages on Diabetes Daily were much longer and went into detail about her frustrations.

Accountability

Social accountability has been proposed as a key mechanism for supporting the maintenance of healthy behaviors (e.g., [3]), and we observed that it is a significant goal in driving people's health-related interactions online. Many participants sought to engage with others in order to remain accountable for making progress on their health goals. Accountability-related interactions were seen as being about sharing one's progress in sticking to a plan in a way that was visible to others.

Different participants preferred to be accountable to different kinds of people. Variation stemmed from differences regarding desire for privacy, importance of personal connection with the people providing accountability, fear of abandonment, and preference for engaging with those seeking to implement the same behavior changes.

P09, for example, avoided publicly posting goals and progress online because of privacy concerns, and instead relied on one 'workout buddy' in person. Another participant, P02, was more concerned about the reliability of the people she counted on for accountability. Rather than turn to an OHC for accountability, she sought to recruit some of her friends to join a weight loss 'accountability group' she had created on a personal blog. She felt strongly that having friends keep her accountable would be more effective than getting support from people she knew only online and with whom she may not have an ongoing relationship:

"They're strangers, and so you don't know that you're going to see them again the next day...you're not going to get direct feedback daily from the same people. So, the accountability doesn't quite work because you don't know the people." -P02

Though she wasn't able to recruit as many friends as she hoped, P02 and one other friend had been keeping each other accountable for over a year by posting about their diet and exercise daily. She used Facebook to remind her friend to post when she had not done so for several days.

Other participants found that forming strong relationships with other members of the OHC was critical to success. When P07 did not post for several days, his "SparkFriends" checked in on him:

"They were checking on me making sure everything's okay. None of us wants each other to fall off the ladder. They all want me to be successful and stay fit." -P07

Motivation

While accountability provided strong motivation for several participants, there were other means that participants employed to keep themselves motivated to maintain healthy behaviors.

Some participants sought motivation and inspiration from specific role models, others who had achieved their weight loss goals or had successfully managed their diabetes. For example, P06 looked to a friend who was older than her but had recently run a marathon. The advice and friendship from this person gave her motivation to reach her own running goals.

On the flip side, some participants maintained their motivation by avoiding people who would bring them down—usually people who shared frustrations too often.

"You get some folks that all of their posts are negative things. And you spend so much time trying to build those people up. And it can be draining. Kind of brings down your personal spirit a little bit. I try not to see the world that way." -P08

Another group that served as motivation for many was similar others: those in the same situation of losing weight or managing diabetes, and with similar goals. One participant even set up a competition with a friend on his OHC so they could motivate each other. Their knowledge of each other and perceived similarity was key to making the competition work. The two of them had become friends after finding out they shared similar interests and both started at the same weight.

"If you know the person, you know what their struggles are, you know what their challenges are on a day to day basis. I guess if I don't know the person then for all I know that person has a reason why... Maybe they have thyroid problems and I don't consider if fair to challenge myself against someone that has a thyroid problem." -P07

Competing with someone perceived as similar was especially motivating because it was possible to imagine how they might handle a particular situation,

"...I was like, 'I'm not feeling well today, I don't wanna run 3 miles, I'll just run one'. But then I would be literally thinking "Oh, what would [my friend] do. Would he give up? No. He'd push." -P07

Some participants found that a good way to receive motivation was to motivate others. On SparkPeople, giving 'goodies' (little virtual gifts that could be sent to any friend) helped create a reciprocal system of encouragement, since there were points associated with the goodies that could be redeemed to send goodies to other friends:

"People send you little goodies, saying you did a good job, saying that they noticed you've lost a couple of pounds this week or that you've been extra encouraging. These can be spent ... to buy the treats you send to other people." -P08

Advice

Of the four goals that our participants discussed, advice was the least commonly mentioned. Information and advice have been previously described as critical components of online interactions around health (e.g., [18]), and it may have been less prominent among our participants because most of our users were managing diet- and fitness-related health concerns and felt that the other concerns discussed here—emotional support, accountability, and motivation—were of primary importance.

However, the need for advice did come up in a few cases—especially among the participants who were managing diabetes. All of the participants with diabetes reported joining diabetes online communities soon after being diagnosed with the condition. In this initial period, obtaining information was the most important thing to them. These participants recognized, however, that they needed to share information in order to receive information. For P04, asking questions had the additional benefit of helping him find a mentor:

“Early on I was having a hard time with my numbers; they were very high and one person... It's very interesting; she kind of adopted me, mentored me, and sent me recipes, with regard to how to talk to my doctor about getting him to prescribe insulin. We talked to each other quite a bit about our doctors and frustration and how to get what we want, how to present our problems to our doctors.” –P04

Impression Management

Impression management is known to be a central concern of users when interacting with others online [1,4], and thus it was not surprising to find that participants in our study discussed this as a major issue. Impression management interacted with the motivation to improve one's health in two ways. First, impression management could act as a health-enhancing goal in its own right. In some cases participants broadcast an image of themselves that emphasized their identity as a healthy person. Second, concerns about self-presentation often acted as a constraint on sharing information to further other goals. To address these challenges, most of our participants developed different strategies for sharing information in Facebook and in OHCs. Broadly speaking, the two venues mapped onto the front stage and back stage of Goffman's analogy [10]: Facebook was the front stage where participants wanted to communicate the impression of being interesting people who were in control, positive, and not struggling; the OHC was the back stage where they could be more open about their struggles, and need for help.

The notion of Facebook as a “front stage” was captured by P02 who noted that her writing is “almost like a stand up comedy routine.” She went on to note that her performance on Facebook was successful because she restricted the information she shared:

“I have had people send me a private message of, ‘Wow your life is so great! You know you do this, this and this and all these fun things happen.’ And I tend to think, ‘you know, you're only seeing what I want you to see.’ ... It's that I'm a better writer and my content is very select. It's not that I don't have problems, I'm just not putting them on Facebook.” –P02

For some participants, Facebook was a place where they could express a new, healthier identity. For example, P06 was aware that her old high school friends were part of her audience on Facebook. However, unlike the others participants for whom having high school friends on Facebook dissuaded them from posting, P06 was proud of her new identity as a runner and wanted her high school friends to know about it. She had even changed her profile picture to be of a medal she had earned in a race. For her, posting about her running was a way to impress those who used to know her in the past as someone else:

“On Facebook I am not afraid to post anything about my running because I never... I have a lot of high school friends on here. And in high school I was always the band nerd and I was really overweight back then. And so I kind of like to “out” my running ability now. ...I like to really talk about my running on Facebook. Because I'm so darn proud of it...” –P06

She particularly likes getting comments from these friends, and is motivated by the positive feedback that she had never received from them during high school:

“They're just so surprised that I'm running and they'll say like “fantastic” and “when are you going to run?” ...And so yeah I'm getting the feedback that I want. I'm finally getting... some positive feelings from those people that I couldn't get back in high school.” –P06

On the other hand, the desire to portray a positive image to one's Facebook friends limited the sharing of some information that was needed for emotional support or accountability. To get emotional support, participants needed to report on difficulties, not just successes, and that would not create positive impressions. Three participants specifically mentioned high school friends as being a part of their audience that gave them pause when posting about their health to Facebook; for them, ‘high school friends’ seemed to serve as shorthand for ‘weak tie’. For most, having these connections in their network was a reason not to share about their health issues on Facebook:

“There are some people I wouldn't care about if they saw [posts I might make about health on Facebook] but I got people, you know, from my high school that I am friends with that I haven't talked to in 25 years. And I have no desire for them to know about my weight issues or weight status.” –P09

The ability to keep OHC content unlinked to one's real-world identity made some participants more comfortable

posting about struggles on OHCs than on Facebook. P02, who had used a variety of online health communities as accountability tools, said “I don't want them on my Facebook wall or on a status setting... I want everyone to think I'm perfect.” To use Facebook for health interactions, P02 would want to be sure that the health information would be seen only by strangers and would never be posted to her wall or be seen by her friends.

Impression management can be at odds with accountability when accountability requires sharing the often detailed and repetitive information required for reporting progress towards a goal. While OHCs explicitly encourage this through the availability of tracking tools and established norms around sharing their output, such sharing was seen as taboo on Facebook. Key concerns included “boring my friends,” cluttering their friends’ news feeds, and coming across as boastful. Indeed, some participants had even reacted negatively to others who tried to share health-related status information. For example, P02 had a friend who posted status messages nearly every day about his running. Not realizing at first that he was using an application to automatically post these messages, P02 said she “for the longest time thought he was just bragging”, and that she had hidden his posts from appearing in her News Feed.

Building and Shaping the Network

The foregoing discussion highlights the factors considered by people when deciding with whom to interact around health concerns. These considerations in turn drove a set of activities that participants engaged in to build and shape their support networks in order to make sure that they had access to the “right” set of people to help them pursue different types of goals. These activities can be seen as a kind of maintenance work that people must engage in to lay the groundwork for pursuing other goals through day-to-day communication around health. The activities we observed in this area included actively seeking out new supportive contacts through interactions on OHCs; honing in on existing clusters of individuals they anticipated would be most helpful; using OHCs and Facebook in conjunction to strengthen supportive relationships; and nudging existing contacts to be healthier.

For several participants, an explicit reason for joining an OHC was to “make friends” that would be supportive around health. Some realized that making their posts public and “putting oneself out there” was a necessary step:

“My page was never private. ...To me if I'm new I'm not going to have any friends—because I don't know anybody. And if I'm new and I'm private on top of that, my chances of having friends is low.” – P05

Once a relationship had started on an OHC, a number of the participants used Facebook as a way to deepen their connections with their new “health buddies.” They did this

by adding a subset of these OHC contacts to their networks on Facebook. Doing so served to make the connections stronger, as they were able to see more details and updates about the friends’ lives than what was shared on the online health communities:

“With some of these [people from SparkPeople] that I see on Facebook too, our friendships are tighter because we communicate both ways. So you know the more you communicate with somebody the closer you get.” –P06

Adding OHC connections on Facebook allowed participants to reach these friends more easily. P04 used Facebook to still communicate with friends from Diabetes Daily who had stopped using that community. P06 sensed when a friend was posting more often on Facebook than SparkPeople that she would be easier to reach through a private message on Facebook.

While, as noted earlier, most participants avoided posting health status information on Facebook, those who did found it to be a useful way to stay in contact with health-related connections that they would have otherwise lost touch with. For example, P08 had once worked at a company that provided free enrollment to a Weight Watchers support group. However, since changing jobs, she no longer participated in Weight Watchers, but did stay in touch with her old Weight Watchers friends via Facebook. Her practice of cross-posting “all her stuff” from SparkPeople to Facebook was unusual among our participants, but allowed her to maintain those connections:

“I post all of my stuff [from SparkPeople] to Facebook and then I have friends that I used to work with that I did Weight Watchers with and they are like ‘yay’ or they'll make comments about, ‘I really need to get to the gym, thanks for a reminder.’ So... It encourages us in both directions.” –P08

Finally, several participants also used Facebook as a way to deepen their engagement with the online health communities. Most of these communities had a presence on Facebook, through Facebook applications or pages. By adding these applications or pages, participants then could receive updates from the community in their Facebook News Feeds and feel more connected to the community even when outside it. One participant even found his friends from DiabetesDaily on Facebook by seeing who else was a fan of the DiabetesDaily page.

Some participants sought to reinforce the supportive role of their existing networks by “nudging” friends to adopt healthier behavior. This was typically not their primary motivation for sharing, but an added bonus that might reinforce their own efforts. For example, P06 found that posting about her exercise on Facebook reminded her friends to exercise also. It was a lightweight way to nudge her friends without specifically targeting them.

Others nudged more directly; P02 deliberately contacted friends in her personal network to recruit them to her ‘weight loss accountability group’. She targeted those who she felt most needed to lose weight:

“I know some of [my friends] need to lose weight. A lot of them very seriously need to lose weight and I was hoping to motivate them in the process... There's a few that, I think I should recruit that could lose a hundred pounds.” –P02

Others nudged their friends to join their OHC. For example, SparkPeople’s feature for posting messages to Facebook marks these messages as being from SparkPeople. Several participants explained that they used this feature as a way to ‘spread the Spark’ to their friends on Facebook. The fact that they also received points in SparkPeople for Facebook posts was a further motivation.

“I've got friends on Facebook, real life friends, who need to lose weight and be more healthy and some of them have read my blogs [that I post from SparkPeople to Facebook] that way. So I can recruit them that way. "Spreading the Spark, we call it.” –P11

DISCUSSION

As we have just described, participants articulated a set of different goals that they pursued through interactions with others. For each of these goals, participants described *with whom* they wanted to share information as well as *how* they wanted to share and present that information in order to maximize the benefits and minimize the drawbacks. Persistent concerns about self-presentation were seen to inhibit the pursuit of support and accountability, but offered an opportunity for enhancing self-efficacy by projecting a healthy self-image and getting positive feedback about it. In addition, participants described work that they did to build and maintain multi-faceted support networks online and to control their self-presentation across multiple audiences. These observations highlight a pair of challenges that face individuals who seek to engage with others online around health concerns, and the challenges lead in turn to a set of design opportunities that can guide the evolution of online tools. First, people would benefit from having support in building, shaping, and selectively accessing the network. Second, people would benefit from assistance managing the tension between impression management and other health-related goals.

Challenge: Building, Shaping, and Selectively Accessing One’s Network

As discussed above, different individuals wish to engage with different types of people in regards to their health, and preferences for whom to engage with will often vary according to the foremost goal being pursued in the interaction. For these participants, considerable thought and effort goes into making sure they have access to the right people to support their goals and selecting the right channels to direct their communication to just the right

people. While existing OHCs provide some of the capabilities desired by users, there were several places where they fall short.

Some participants felt that goals such as emotional support and accountability were best served by people who knew them personally as opposed to only through their online identity. This is consistent with findings that suggest that knowledge about someone’s personality, emotional state, and interests help people to give more effective support [21]. Such knowledge may require a good deal of interaction that takes place over time, and thus existing relations are more likely to possess this knowledge than new connections made through online social sites.

In principle, each of these shortcomings could be overcome or at least mitigated by systems such as Facebook that make it easier to interact with existing friends and family members. In our study, however, we found that Facebook was not an effective venue for interacting around health. The disadvantages articulated by users included the lack of a supportive community norm, the lack of anonymity, and the prevalence of weak ties with whom people did not feel comfortable sharing health related information coupled with tools that best support and default to sharing broadly.

Design Opportunities

To help people shape and access their support networks, social software should provide users with greater control over their communication partners. While both Facebook and health community sites offer some degree of control over the sets of people with whom communication is shared, these controls are generally hidden and cumbersome to use. A possible area for improvement, then, would be to explore lightweight ways to increase the precision of one’s communication. Allowing people to define egocentric *custom groups* for particular communication patterns would be one way to accomplish this. Ideally, groups would consist of individuals that a user selects for the particular goal she has in mind, for example emotional support around a difficult issue. A variant of this approach would be to provide support for *custom lenses*, which would allow users to filter messages from certain people to support certain goals, in particular supporting their motivation by selecting people and messages that would be inspiring. Such groups may consist of friends and family as well as health-specific connections and therefore may span networks.

While the notion of custom groups or lenses is not inherently novel (indeed “groups” for controlling the recipients of outgoing messages is a feature supported by Facebook), a challenge with implementing groups and lenses will be reducing the overhead required to construct and disband groups. Moreover, such a facility would be far more powerful if combined with suggestions of people that one might find beneficial. The notion of automatically creating lists based on relationship characteristics has been

explored by Gilbert and Karahalios [9], though it is not clear that their approach of partitioning contacts into “strong” and “weak” ties will be adequate for supporting health-related communication, which our study suggests would require partitions along multiple dimensions. Thus our next recommendation focuses on suggesting groups and individuals for focused communication.

Mechanisms that help people find communication partners could help people meet their goals more effectively. As noted, the ideal partner may differ depending on which goal a user is pursuing at a given time and so for specific goals, different suggestions might be offered. As an example, to support motivation, the degree of positivity of a person’s messages or a group’s conversation could be estimated using automated methods, along the lines of [14]. In principle, similar techniques could be applied to other attributes, guiding users towards others who will provide helpful support, accountability, and information or advice, though automated techniques for detecting appropriate text patterns have not been as well explored. A fruitful direction for future work, then, will be to determine the factors and mechanisms that will produce valuable suggestions or partners for furthering different health goals.

Challenge: Managing Impression while Meeting Health Needs

Many of our participants had developed sophisticated strategies to deal with the tension between impression management and other health-related goals. However, the most common strategy developed by our participants was based on selectively accessing different components of their networks using fairly blunt categories—namely deciding whether to post information via an OHC or via Facebook. As a result, involving offline contacts in one’s online health interactions was not a feasible option in most cases, and this could be a drawback for certain types of desirable interactions.

Design Opportunities

A possible approach to addressing this challenge lies in coaching users to help them strike a better balance between expressing needs and health status information and conveying their strengths and accomplishments. With a couple of exceptions, our participants tended to err on the side of conservatism when estimating the response their information sharing would elicit from recipients. Instead of finding a way to share potentially sensitive information with acquaintances online, they often avoided identity-linked sharing completely. In some cases, participants selectively shared health-related information, either by selecting only the positive bits or reframing updates to render them more positively. This reflects a desire to share health information with personal networks and also the possibility of strategies that would support at least limited sharing.

To coach on people on effective communication we can build on analysis of online rhetorical patterns [2]. While this earlier work focused on identifying the types and forms of questions that elicit the most informative responses in online discussion, more work will be needed to understand how to advise people how to communicate to receive other types of responses. An analysis of communication patterns could reveal more and less effective strategies, which could be used to guide people towards meeting their communication goals. Moreover, allowing users to mark responses as supportive, motivational, helpful as well as, perhaps embarrassing or “spam” could lay the groundwork for machine learning approaches that would map characteristics of posts with desired and undesired responses, which could in turn provide assistance to users.

Coaching could also be directed towards those who receive messages and can choose to respond with either critical or supportive comments. Previous literature has identified the value of OHCs in creating nonjudgmental spaces [11]. Our participants similarly trusted OHC members but not Facebook contacts to provide positive support rather than sarcasm or criticism. If social network sites such as Facebook provided proactive feedback, people could pause and revise comments in order to provide their friends with the help and support they are seeking. Such features might make Facebook and other networks more conducive to health communication.

Limitations and Future Research

Our study was limited by focusing on a small number of people who are already actively engaged in health-oriented online interactions. All were active members of at least one OHC, which implies they had found a satisfying ground for health interaction. It is likely that there exists a (possibly large) set of people who have tried to engage with one or more OHCs and failed to find one that worked for them. These people may have experienced some of the same issues that our participants did but reacted to them differently, and they may have experienced other issues as well. It would be interesting to complement this study with a study of OHC dropouts to find out what issues they had faced. Second, the fact that they had established a relationship with an OHC meant that they may not have been as motivated to find other means of connecting with others around health. In particular, they would not have been as motivated as others might be to find ways to use Facebook to meet their goals. Anecdotally, the authors of this paper have all witnessed health-related posts on Facebook which might indicate that some people have developed or are developing ways of interacting with Facebook that are helping them advance their own health goals. Our study did not shed light on these practices, if they exist, though we believe it would be a worthwhile area for further study.

CONCLUSION

The potential of online social interactions for health improvement is enormous, as is evidenced by the rapid growth of huge communities such as the ones discussed in this paper. To understand online health interactions, both inside and outside established online health communities, we interviewed fourteen individuals who are active members of online health communities and Facebook. Our study highlighted a set of goals that people pursue in order to enhance their health—emotional support, motivation, accountability, and advice—and identified the tension between the pursuit of these goals with impression management. We reviewed the strategies people use to build and shape their online support networks in order to ensure that they have access to the different people they need to interact with to advance their health goals. Based on these observations, we described a set of design opportunities for future systems to support health-oriented social interactions online, that address two key challenges faced by our participants: developing tools to help users build and shape networks to better serve these goals and developing tools to promote awareness of the impacts of their communication to support balancing between impression management and health-enhancing goals. The identified challenges can inform future online interaction tools to support health. Exploring the design opportunities remains a promising direction for future work, as does continuing to explore the issues faced by different groups of users when attempting to interact online in support of their health.

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