Using Collective Intelligence for Supporting Diabetes Patients

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ABSTRACT
Research has shown that online health communities have become places with increasing potential for getting emotional as well as informational support through interactions with peer patients. However, further work is needed to support the specialized problems that many patients have. In this paper, we present our qualitative study on diabetes patients’ face-to-face support groups and online communities. Our preliminary results show four patient needs in controlling diabetes: understanding uncommon symptoms; finding where one stands; understanding the effectiveness of new interventions; and knowing patient profiles. These needs point to design implications that could greatly benefit from using techniques in collective intelligence (CI) both in further analyzing the needs among online community users as well as in assisting patients in fulfilling their needs.

INTRODUCTION
As Internet and information technologies become part of people’s everyday lives, new and exciting opportunities arose in leveraging collective knowledge and experience as a form of help. Accordingly, online communities became popular for supporting a variety of domains including end-user technical support, special interest groups, or personal health.[8] Especially for personal health management, research has shown that online health communities have become a place with increasing potential in getting emotional as well as informational support through the interaction with peer patients. However, while common problems can relatively be easily solved through FAQs and Q&A, further work is needed in supporting the uncommon needs of patients.

Diabetes is a complex disease that requires individualized care for each patient. Moreover, diabetes is becoming more prevalent in the United States. According to the American Diabetes Association, 23.6 million children and adults in the United States—7.8% of the population—had diabetes in 2007 [1]. Diabetes was the seventh leading cause of death listed on U.S. death certificates in 2008. Complications of diabetes include heart disease and stroke, high blood pressure, blindness, kidney disease, nervous system disease, and amputation. Diabetes is a progressive disease, thus controlling and maintaining diabetes is crucial in prolonging good health and reducing possibilities of contracting complications that diabetes can bring.

Accordingly, many health care systems in the United States offer support groups, educational resources, and trainers in diet and exercises for diabetes patients to continue to self-control their blood sugar and other complications, which is the key in managing diabetes.

For many patients in certain health care environments, however, lack of local resources for support groups and educational programs, especially for those with special conditions, keep patients from easily learning how to maintain their health and from becoming motivated to do so. Accordingly, many patients turn to online communities to make up for the necessary health care resources they do not have in their towns and communities. Even if one has good local resources, online communities can still provide benefit in giving greater access to the peer-generated knowledge.

What is challenging in supporting diabetes through online communities is that each patient is unique in terms of knowing what is safe, what works and what does not work in managing his or her diabetes. Depending on age, gender, which type of diabetes, the level of average glucose level in the blood stream over three months (A1C), and other complications that one may have, the treatment and diabetes management practices may need to be personalized. Accordingly, most of the newly diagnosed patients go through iterative testing period of finding the right drug and treatment plans. In addition, diabetes can be a progressive disease, meaning that it can change over time. Accordingly, patients and doctors need to continuously monitor what is changing and continuously adapt treatment plans and disease management practices.

The specialized need of each diabetes patient calls for better help mechanisms beyond current ways in which patients and experts share knowledge. In order to examine what the needs are and how we can design to better support individualized problems in diabetes, we studied both face-to-face support groups as well as online communities of diabetes patients. Interviews were also conducted with those who participated either in the support groups or the diabetes online communities.

Our preliminary results that showed four patient needs in controlling diabetes with specialized needs: understanding uncommon symptoms; finding where one stands; understanding the effectiveness of new interventions; and
knowing patient profiles. These needs pointed to design implications, which could greatly benefit from using techniques in collective intelligence (CI) both in further analyzing the need among the online community users as well as in assisting patients for fulfilling their needs.

In the following, we first describe related work and the method that was used, followed by our preliminary findings and design implications.

**RELATED WORK**

Websites such as PatientsLikeMe [12], CureTogether [3], and online communities of just about any disease are allowing patients to share their experiences with treatments and symptoms, and to emotionally support each other by helping to find others with similar conditions. Such openness philosophy is working well, as studies showed [7] that patients are increasingly sharing their personal health information (PHI) online. Accordingly, in order to better understand what is happening in Health 2.0 tools and whether there are any challenges that need to be resolved, prior work examined the effectiveness of patients’ online forums [4, 10], how patients utilize online forums [2], and effectiveness of various features of online forums such as sharing stories and profile information about patients’ health [5, 11].

Current Health 2.0 tools that allow patients to log their activities and share them with other people such as PatientsLikeMe provide aggregated results of the treatments, symptoms, and experiences with drugs of the members of the community, in conjunction with profile information such as age, gender, and years of diagnosis. Members of the site can browse these data to learn about different treatments that other members use and the members’ experiences with those treatments. Furthermore, members can see how elements of logged activities (e.g., taking certain amount of medicine) affect other elements (e.g., viral load of HIV).

The aggregated form of logged activities provides good understanding of top X – top symptoms or top treatments, for instance. However, top Xs are most of the time already well known. Difficult problems occur among the things that are not well articulated and experienced by others – the information that may become hidden during the process of highlighting the more popular instances. The interesting design challenge then as designers of Health 2.0 tools using collective intelligence is to ask how we could support the more specialized problems out of the socially aggregated data.

The aim of this paper is to explore first the kinds of specialized problems and needs that patients encounter that could not be easily solved through the existing tools. The continuing work then will examine how patients attempt to solve the specialized problems through face-to-face support groups and online community forums.

**METHOD**

In order to understand the problem space of specialized needs in managing diabetes as well as any challenges or things that are working well in the current community-based help mechanisms, the first author is observing face-to-face diabetes patient support groups, analyzing patients’ messages posted on online communities for diabetes patients (diabeticconnect.com and dlife.com), and interviewing those who participate in online and face-to-face diabetes support groups. Observing monthly support groups began in March, 2010, and is still ongoing (current date: October, 2010). Three support groups are being observed monthly.

Interviewees were recruited both from the face-to-face support groups that we attended, and from the two online communities. Twenty interviews were conducted, 13 from face-to-face support groups.

Content analysis of the online communities is still ongoing. The findings from the observations and interviews were analyzed using open coding analysis. Our preliminary analysis resulted in four categories that showed the needs in accommodating individual differences in diabetes.

**FINDINGS**

In the following, we report our preliminary findings on four patient needs in solving problems on individualized diabetes.

**Understanding uncommon symptoms**

Because each patient has a unique profile of his own, a symptom can be caused by a variety of things, and one may experience uncommon symptoms. In both cases, finding the cause, knowing how to manage those symptoms, and incorporating appropriate treatment into the daily diabetes management practices is crucial.

We were able to observe patients’ attempts to find other people’s similar experiences in order to learn possible causes or solutions. For example, Doug used to have a high blood sugar in the morning. He tried eating dinner that contained less carbohydrates the day before and getting rid of snacking before bed, which all did not work. His doctor told him that it was in fact a rare condition called Dawn phenomenon, which happens when the liver produces excess glucose during the night because it detected that the blood sugar was too low. His doctor suggested several natural methods such as eating a snack before bed. Doug asked other members in the support group who used to have high blood sugar in the morning about what they did. The feedback Doug received was to eat a small amount with higher carbohydrates. However, this did not work, and he had to iteratively try different foods to eat before bed. Eventually nuts worked best for Doug.

Doug could not find people from the support group who were diagnosed with Dawn phenomenon, but was able to find people with similar symptoms. While it helped to get
ideas on what natural methods he could try out in lowering his blood sugar in the morning, the method needed to be personalized to fit his body through iterative trials. Also, currently in the diabetic online communities we observed, there are discussion threads about Dawn phenomenon where the members discussed different methods that worked well for them. However, the information is scattered in different threads across different communities, and often times people who tried out a number of interventions to get rid of the symptom did not report back.

These experiences suggest better mechanisms are needed in identifying associated symptoms. That is, people who do not have Dawn phenomenon could still give advices to a person with Dawn phenomenon through their experiences in dealing with sweating at night, high blood sugar in the morning, or switching to different medications. In this case, the question is how we could provide a tool that could learn associated elements for a problem and aggregate information from the associated elements when necessary.

Finding where one stands

In addition to solving sporadic conditions such as Dawn phenomenon, diabetes patients constantly need to monitor and maintain their diabetes. Managing diabetes is all about maintaining the appropriate level of a variety of things: blood sugar level, A1C, vitamin D, cholesterol, etc. However, knowing whether one is in good standing for any of the measurements above can often become a challenge due to mismatched standards among different hospitals and health care providers. Also, not being informed about how good or bad lab results often frustrated the patients.

For instance, the standard for how much A1C one should have in order to be considered as in “good standing” varies a lot depending on which health care provider you talk to. Paul, an 80-year-old, who has been managing diabetes for 40 years could not get his insulin pump because his doctor said his A1C was too low for using the pump. His A1C was 6.5 most of the time, which instead needed to be at least 7.0 in order to be considered for getting a pump. Especially because of Paul’s age, his doctor did not want to risk possible strokes that could be a danger to his health because he was at the borderline of becoming low on blood sugar. He has been fighting for a pump for years, and he finally went to see another doctor at another hospital. In this hospital, having A1C of 6.5 was considered “good,” and he was able to finally get his pump.

Paul was always confused about this mismatch in standards between the two hospitals that were located in the same city. He wanted to know the A1Cs of other patients with pumps, maybe for the entire country. Is Paul’s A1C really low for his age? How low compared to others?

Grace had a similar need; she wanted to know how bad or good her vitamin D level was. She knew that she had her vitamin D level checked when she went to the hospital for a regular check-up. However, she had no idea whether it was good or bad, which might help her to make an effort in making sure her current vitamin D supplement is properly absorbed and knowing how much supplement to take:

*Is there a way I could check how other people’s vitamin D levels are so that I know how I am doing?* (September support group A, Grace)

While HIPAA rules and patient privacy may be hindrances, a useful help mechanism might be gathering patients’ health information to inform the patients where they stand,
and providing any nation-wide data that may be available from government resources. This could help the patients to take proactive efforts or at least monitor how they are doing in terms of managing diabetes.

**Understanding the effectiveness of new interventions**

Diabetes patients we observed continuously sought better treatments and methods to improve their diabetes. Rather than an individual trying out all possible remedies that are available, hearing other people talking about how different remedies worked for their particular situation helped the patients assess which new interventions they should try out to see whether they could better control their diabetes. However, not having a systematic mechanism to share the experiences made it difficult to learn how the methods worked or did not work. For example, in one session at a support group, the group leader, a registered nurse, brought a box of gluten-free pasta (uncooked) that is supposedly good for diabetes. Giving a pasta sample for each patient, she asked the group members to try out and check blood sugar before and after eating the pasta so that the next month the group could share how the pasta worked for different people. A month later, when the group reconvened, only a few had tried out the pasta and shared that the pasta indeed gave lower blood sugar readings than other pasta. They also shared recipes on how to cook gluten-free pasta so that it would not taste like cardboard. The members were all curious to know how tasty the pasta was and how much it worked for other people, but they often forgot to perform the simple experiment with the pasta.

As shown in figure 1, members of a support group were trying out how a 10 minute simple exercise can lower their blood sugars. Two members who brought their meters were able to perform the small experiment. Both had lowered reading of more than 3 points after a simple exercise. The results of this small group experiment could then motivate the members to try more extensive exercises later on.

As seen from the pasta and exercise cases, often experiments were not performed by all of the group members because of various constraints (e.g., forgetting to do it, not having the right device in front of them), although the members wanted to know the results. Current tools do not provide systematic ways to share within a group of people user-defined parameters that the members can log. A help mechanism that asks users to directly input their daily experiments in trying out different interventions when they can at home and showing aggregate results to participants can be useful.

**Knowing patient profiles**

For all needs discussed above, understanding one another’s patient profiles served as an important context in understanding and applying collected knowledge. Knowing a patient’s profile was a way to contextualize, compare and contrast some given information in order to understand how applicable that information would be. Also, knowing patient profiles allowed members to understand the situational context of how the information would work differently for different individuals and of any exceptional cases that patients needed to be aware.

One of the interviewees, Joy, who was an active participant in diabeticconnect.com and then later a website staff member, confessed that because she had type 2 diabetes, she tried not to give advice for type 1 patients. Similarly, Sally, who was the youngest person in one of the support groups always had in mind profiles of others when hearing experiences and applying them to her situation. She thought twice about advice that an 80-year-old male was giving to her, because she might have been going through menopause. The sweating at night for the 80-year-old male could come from Dawn phenomenon, whereas for Sally it could have been from her menopause. Profile descriptions were more explicit in the online communities. When asking questions or giving advice, they tried to give the background context about their profiles, just like Perez who gave detailed information on when he was diagnosed, with which type, the changes of his A1C over time beginning with the diagnosis, when he felt numbed sensations, and which pills he was taking:

*I have been diagnosed as type 2 on Sep/09. My A1C was 11.5. Only some days after my diagnosis, I developed neuropathy in my legs. Since Feb/10 my A1C has been under 6.2 (the last one was 5.2), and I’m controlling my diabetes with diet and exercise. But my neuropathy is still there. I took Bedoyecta injections (B vitamin), used Alpha Lipoic Acid and Neurobion pills (more B vitamin). Nothing worked. I have heard that having a good blood glucose control you can eliminate or at least reduce neuropathy. How long does it take? I’m so frustrated. I’m tired of the pain and numbness. Any help will be welcome. (September 21, 2010, Perez)*

For any given information that is disseminated, knowing the profiles of where the knowledge originated from, and comparing and contrasting between experiences from different profiles would help patients to be informed in greater depth about a problem. Accordingly, close coupling of the patients’ profiles and their posts would help contextualize the conversations happening in the forums.

**DESIGN IMPLICATIONS USING COLLECTIVE INTELLIGENCE**

As discussed briefly after each finding, collective intelligence could greatly help in supporting individualized problems of diabetes patients. Current tools such as Patientslikeme [12] and Curetogether [3] support crowd-sourcing patients’ profiles and presenting the data through simple statistics or histories of individuals. However, more work is necessary in integrating patients’ Q&A.
conversations, experimental results, and associations among profile elements (e.g., associated symptoms for a complication) with patient profiles. This integration will better inform patients who are encountering uncommon symptoms, help patients to understand how they are doing in controlling their diabetes, and help patients to find better interventions for improving their diabetes. A system that we envision will do the following:

- The system has a database of patient profiles: the time of diagnosis, A1C at the time of the diagnosis, blood sugar readings on a daily basis, foods eaten, exercise regimes, medications, complications, family history, and any other relevant information that may affect one’s diabetes.
- The profile records historical changes, which can inform patients about which medications did or did not work well for patients with certain profiles; which exercise regime was most helpful in reducing blood sugar; and which diet regime was most helpful in losing weight without lowering blood sugar, to give a few examples.
- The profile would be used to help patients know where they stand, by allowing patients to pick each element of the profile database (e.g., vitamin D level, A1C, blood sugar readings in the morning), which then can be further analyzed by seeing whether there are any patterns that may contribute to the result for other people with a similar profile. For example, what are the profiles of those who have A1Cs that are lower than 5.0? What about those with over 10.0?
- The system learns associated elements among profile elements such as symptoms, treatments, and interventions to expand the definition of “similar” and identify members who may give helpful advices even though they do not seem related on the outset.
- The system aggregates threads across a number of online diabetes communities clustered around keywords of the message content as a way to make visible popular conversations as well as those that are at the margin. This could also work to distill information that has been scattered inside and across the communities.
- The system allows a group of users to enter results from small experiments, in a manner similar to voting features, and to share the results amongst the system users. This can be utilized to test new interventions in terms of different food or recipes, exercise regimes, vitamin supplements, or medications.

So far we discussed how CI could help diabetes patients with needs occurring in their daily diabetes management practices. CI can also be used for analyzing online community content to understand individualized problems and learn when solutions to the problems work or do not work. For example, tools such as many eyes [9] could be used to compare the question message content between those who receive no replies versus those that receive over the average number of replies. What are the common patterns of those that receive more replies? Is there better phrasing of questions that attracts better answers? Also, for those who mentioned neuropathy in their posts, what are other frequently mentioned words? How is the community clustered in terms of the frequency of interaction between the askers and the answerers?

**CONCLUSION**

Current forms of collective intelligence in patient health information are restricted to patients’ manual inputs of pre-defined parameters. A mechanism that allows user-defined parameters for sharing small experiments and uncommon problems would support patients to share less common problems. Furthermore, it would be helpful for systems to learn associations among profile elements as the system analyzes both profile elements as well as content of questions and answers that patients upload. Google Health [6] provides a mechanism to automatically download health history from various drug stores, insurance companies and hospitals. However, the data is only open to the individual and is not shared among people. It would be important to have an infrastructure that patients would be able to easily allow or disallow their health history to be part of the collective data and protect patients from any unanticipated future risks that the patients did not sign up for. Collective intelligence in healthcare is relatively a new area, thus health policy and patient privacy issues for these CI mechanisms still need to be worked out. However, as much as the benefit for CI in healthcare is projected to be high, exploring how CI can get around current health related policies or suggesting interventions for the impediments of current health policies would be important future work.

**REFERENCE**

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