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## Collaborative Help in Chronic Disease Management: Supporting Individualized Problems

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### Abstract

Coping with chronic illness disease is a long and lonely journey, because the burden of managing the illness on a daily basis is placed upon the patients themselves. In this paper, we present our findings for how diabetes patient support groups help one another find individualized strategies for managing diabetes. Through field observations of face-to-face diabetes support groups, content analysis of an online diabetes community, and interviews, we found several help interactions that are critical in helping patients in finding individualized solutions. Those are: (1) patients *operationalize* their experiences to easily contextualize and share executable strategies; (2) operationalization has to be done within the larger context of *sharing illness trajectories*; and (3) the support groups develop common understanding towards diabetes management. We further discuss how our findings translate into design implications for supporting chronic illness patients in online community settings.

### Author Keywords

Individualized; diabetes; chronic illness; support groups; online health community; collaborative help

## INTRODUCTION

Molly is a 65-year-old female who has been controlling diabetes for the last twenty years. She recently found she is developing liver disease. The new diet plan suggested by her doctor was opposite to what she should eat as a diabetes patient. Molly became frustrated. She scheduled an appointment with a dietitian in two weeks, but until then she wanted to know what other people did in her situation.

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Coping with chronic disease is challenging because not only it is a daily problem but also the burden of managing the disease is placed upon the patients themselves. Diabetes, like many chronic diseases, generates *individualized* problems. Molly's example illustrates how chronic illness patients constantly encounter unexpected challenges, uncertainty about the future, and specific problems that do not have easy answers.

Getting professional help from health care providers is costly. Accordingly, hospitals offer support groups to help patients improve and maintain daily health management. But many patients also turn to online; as a recent study showed, 61% percent of Americans search for health information on the Web [1]. Current collaborative help systems such as online message forums and Q&A sites highlight popular, frequently asked questions, and active topics. Getting help to uncommon and individualized problems is still one of the biggest design challenges in collaborative help [14].

Our aim is to address how collaborative help—sharing help among peer-patients—can better support finding individualized solutions. We studied current practices in how patients in support groups help one another solve individualized problems. We found that in order to help solve individualized problems, (1) patients operationalize experiences for easy transfer of knowledge, (2) and the operationalization takes place within the larger context of sharing illness trajectories. Furthermore, (3) operationalization and sharing illness trajectories result in building the community's common understanding towards diabetes management, which helps each member to better generate individualized diabetes management strategies. We end with translating these findings into design implications.

## BACKGROUND

We build on prior work that addressed online health community systems, elicitation of experiential knowledge, and information reuse in collaborative help to further discuss what could be done to address better serving patients find individualized solutions. Largely, we build on the discussions around work coordination, information flow, and awareness in CSCW.

The medical community has acknowledged the importance of providing patients with individualized (personalized) health care at the levels of disease, environment, medication, genes, healthcare, and information [9]. Among many aspects of work that facilitate personalized medicine is the information management of personalized medicine—namely through the patient-driven health care model [27]. The use of Health 2.0 technologies, such as online health communities, bookmarks, blogs, and Internet-based applications, serves to personalize medicine and support individualized solutions in health management.

Websites such as Patientslikeme and Curetogether<sup>1</sup> support patients to find similar patients, support one another, and share doctors' opinions. Patientslikeme was shown to be effective in improving psychological experience of living with their conditions and perceived control over their condition [30]. However, integrating health data with conversations, clarifying

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<sup>1</sup>Patientslikeme.com; curetogether.com

presentation of health information, and matching of people in similar situations still remains as critical challenges in the field [10].

Allowing patients to share experiential knowledge is a unique opportunity that support groups provide for patients, as noted in the literature [5, 6, 8]. However, transferring such situated experiences from one person to another is often challenging. Accordingly, studies have examined how this tacit knowledge could be elicited. Nonaka and Krogh [15] in their knowledge creation theory discuss “knowledge conversion” as the process by which tacit knowledge becomes explicit knowledge. Knowledge conversion is described as an iterative process of experimenting with words, drawings, models, and language. Ambrosini and Bowman [4] studied how to “operationalize” tacit knowledge in organizational settings through causal maps, interviews, and storytelling. Schatzki et al.’s [23] “practice turn” explained how tightly-knit groups operating in socially stable organizational contexts allow for individuals to acquire tacit knowledge through socialization, similar to the view of Communities of Practice [29].

Even in cases where knowledge is explicitly available for others to adopt, reusing it to make it work for one’s settings brings challenges. Issues of information reuse have been extensively discussed in collaborative help literature [2, 12] and this is where patients’ sharing experiential knowledge essentially becomes a collaborative help problem.

How patients align with others’ experiences for better health management can be seen also as part of the heavily studied theme in CSCW concerning connecting activity, coordination, and information flows. For example, ethno-methodologically-inspired work has viewed this problem from the vantage of awareness and enactment [13], while symbolic interaction work has viewed it from the vantage of articulation work [11] and temporal sequences [24]. Over the last several years, more and more CSCW research has examined coordination and information flows over and within time. For example, Paul et al. [19] examined sensemaking in emergency rooms through information and communication displays. Reddy et al. [22] characterized the medical work in surgical intensive care unit as organized around temporality.

Our work contributes to this CSCW research theme, situating it in health informatics, by examining the interpersonal and interactional work involved in health over time. Our participants, of course, engaged in many of the previously uncovered kinds of interactional work involved in everyday behavior. However, we found several supplemental kinds of work we believe are critical for understanding how people deal with long-term, heavily situated (and therefore individualized) information and health needs. To our knowledge the work which we will describe as *operationalization* and *trajectory alignment work* below, have been previously detailed in the CSCW, HCI, or health informatics literature for diabetes or other chronic conditions.

## METHOD

We examined both face-to-face diabetes support groups and an online community for diabetes (dLife.com). We wished to have the findings from the two spaces to inform each

other. The two settings largely differed in terms of the role of professionals and demographics. Patients largely led the dLife forum, and health professionals in dLife mainly interacted with patients through the expert Q&A section. In face-to-face support groups (F2F), however, nurses and dietitians led discussions and clarified biomedical concepts. F2F mainly consisted of geriatric patients, whereas dLife had younger members that were recent college graduates, young professionals, and those in their mid-careers. Attitudes towards Internet environment for support also differed. F2F members often distrusted information produced from online communities, whereas dLife members actively utilized information on the Web, such as research articles and patients' forum posts. In both cases, the people we observed had adopted the medicalized view of their condition and were attempting to take control of their diabetes; we follow this viewpoint in this paper. While there are alternative views, these remain controversial. More importantly, there were common activities of members in both settings that helped one another solve individualized problems in diabetes management. We plan to focus our discussions around these common activities.

We conducted field observations of four face-to-face support groups for eleven months and did content analysis of 1,400 threads randomly collected from dLife. At any given session, each face-to-face support group had eight to twenty patients participating. We also conducted 20 semi-structured interviews from both F2F (13) and dLife (7). We studied Type 2 diabetes patients to simplify our analysis. In order to learn peer-help mechanisms among patients, we studied F2F that encourage peer-to-peer discussions among patients over lecture-based support groups. Field notes were taken during the observations; we were not able to audio or video record, because of privacy concerns.

dLife.com was chosen because it has the largest number of members (87,999 as of April 17, 2010) among the diabetes forums and because the conversations in dLife involved practical information sharing rather than giving emotional support like many other communities. We chose to study only the community forum section because our research purpose was to study peer help interactions. We randomly selected threads from the "Type 2 clubhouse" topic for the analysis.

Interviews were recruited through flyers in F2F and messages in the community forum. Interviews were done on the phone, email, or face-to-face depending on the participants' preferences and lasted from thirty minutes to one hour. The interviews were recorded and fully transcribed. We asked the interviewees about what they felt was helpful or not helpful about the support groups, their personal strategies in maintaining diabetes, and their perceptions towards the support group members and support groups in general.

Analysis was done in conjunction with the observations and data collection. The data were analyzed using iterative open coding [25]. We began with descriptive coding for each observation. As our data accumulated, the focus of our analysis continued to evolve. Codes were revised, merged, and broken down as the analysis evolved and more data were collected. We also used findings from the analysis to revise where to focus during field observations. In the end, we aggregated analysis in the form of codes and notes from both F2F and online community studies. These codes were again analyzed using an affinity

diagram to find any emerging themes, similarities, and differences for the final report of findings.

Next, we discuss findings about two major help interactions that were taking place in the support groups. One is *operationalization*, a process by which members easily transferred context, directly usable strategies, and ways to modify strategies. Second is *illness trajectory alignment work*, which allowed historical context to be shared as members were helping one another through operationalization. Operationalized experiences and illness trajectories are intertwined in practice. Operationalized experiences provide ways for an individual to understand his or her illness (and thus trajectory), while illness trajectories are part of the context for understanding one's own or others' operationalized experiences. We later discuss how the findings together contribute to design implications.

## FINDING 1: OPERATIONALIZING EXPERIENCES

We will first present cases in which operationalizing experiences works well for giving information for contextualizing problems or suggesting solutions. Participants not only objectified tacit knowledge [4], but further operationalized it so that the knowledge could be directly re-used. Operationalization amplifies the material aspect of information and knowledge to become inscribed, transported, and affixed to items [7]. Accordingly, the material characteristics of operationalized strategies makes it easy to share and transfer knowledge.

### Operationalizing Context

In collaborative help, (re)contextualization is one of the classic challenges in information reuse [2, 3]. In the support groups we examined, patients carry out operationalizations to contextualize their diabetic conditions and convey various experiences to others. Below, we discuss several forms of operationalized diabetic experiences that are used to connect with others, inspire others, contextualize individualized situations, and understand individual differences from interventions.

**Patient Profiles**—The most frequently observed indicators for patient profiles include A1C<sup>2</sup>, fasting blood sugar (FB)<sup>3</sup>, weight, and the dates and times that these indicators were measured. In addition, medication information, date of diagnosis, type of diabetes, age, diet and exercise regimes used, and complications are also important pieces of information for contextualizing one's diabetes.

The patient profiles assumed many forms across dLife and the F2F we observed. In all of the F2F meetings we attended, at the beginning of the sessions patients introduced themselves with patient profile information. This process helped familiarize group members with one another so that they could later ask for help. A typical introduction phase proceeds as follows:

<sup>2</sup>A measurement showing the average plasma glucose concentration over prolonged periods of time.

<sup>3</sup>Blood sugar taken at bed time, before meal, or after 12 hours of fasting.

Patient #1: John. Diagnosed in 1980. Give 4 shots of insulin a day. Mainly watch diet and exercise. I passed out 4 times in the last 20 years.

Patient #2: Was diagnosed in January of 2010. I have heart problems, so I can't take the pills. I check my sugar 3 times a day, and most of the time I get sugars below 100.

Patient #3: I've been diabetic for 2 years. The support group has been helping me in reading labels and such. I take meds 2 times a day.

Patient #4: Was diagnosed in 2005. I am on insulin, but other than that I am fine. (July, 2010. FF5)

As shown, a typical face-to-face support group consists of patients at diverse stages, ranging from one that has been diagnosed a few months ago to those who have been managing diabetes for more than a decade. They each have different complications, regimes for controlling their diabetes, genders, and age. Patients are then able to share experiences about the domains that each is more familiar with. John, patient #1, who mentioned that he had passed out several times, indicated that he has problems with low blood sugar. The nurse who was leading the group asked John about his strategies in getting over low blood sugar. In other groups as well, patients with similar complications, such as an organ transplant, were able to connect through simple introductions, and then members understood with whom to talk when there were specific issues at hand (such as thinking about adopting an insulin pump). In dLife, members used simple textual descriptions and visualizations in their signatures to provide patient profile history, with which members could connect with one another and share strategies from successful cases.

**Informal Experiments**—Patients also attempted to systematically share their situated experiences through various casual experiment results, such as testing blood sugar changes before and after various diet and exercise regimes. Members also conducted experiments collectively, where they coordinated protocols for the experiments and shared the findings together. Through this collective activity, members were able to collect real life experiences and understand individual differences regarding various interventions for controlling diabetes.

At one F2F meeting (FF1), the group performed a quick five-minute arm exercise together. Blood sugar changes before and after the exercise were significant for some patients and not so much for others. The lesson that the members received was not only to understand how such exercises could change their blood sugar levels, thus motivating patients to exercise even for a short amount of time, but also to help patients understand the individual differences from the interventions.

An interviewee was able to understand from an online forum ([diabeticconnect.com](http://diabeticconnect.com)) how variations of a pizza slice, such as being whole wheat or having tomato sauce, can affect blood sugar differently. This helped the interviewee to get a sense of how to choose what to eat:

I read twenty posts and a lot of people were saying they have horrible blood sugar readings even if they had just one piece [of pizza].... It seems like it affects people in different ways, but I've got some ideas on how to eat pizza occasionally. (I, FF2\_P12)

Collectively sharing small findings from personal experiments with food helps other members make informed decisions, at least in an informal fashion. Conveying context through a standardized form of information makes it easier for patients to interpret and compare shared experiences. A patient shared the value of sharing experiment results of various interventions with other support group members:

It's sharing, sharing, sharing, it doesn't matter what it is but you need to share (I, FF4\_P9)

### Operationalizing Strategies

Over the course of attempting to control diabetes for many years, patients develop their own individualized coping mechanisms for maintaining control of their diabetes. The members operationalize strategies and daily routines to a form that could easily be adopted, tried out, and tweaked. The forms of operationalization include step-by-step instructions, bullet points of lessons, rules of thumb, blogs, and lists of links, books, and recipes. Such information was especially helpful for newcomers who needed concrete guidelines. At the same time, because not all solutions would work for everyone, the members also help others to learn how to operationalize, deal with exceptions, and find the right individualized solutions. Below, we describe several cases illustrating how members operationalize strategies and share how to generate individualized solutions.

**Start Up Solution Kit**—A representative set of examples of operationalized strategies is part of the basic knowledge about managing diabetes that is taught at diabetes education classes. It is often useful for newcomers or those who have had diabetes for many years but never knew how to manage it. In dLife, members share what we call a “startup solution kit” for newcomers who ask where to start. The startup solution kit comes with links to blog articles that teach patients about basic diabetes management strategies, simple descriptions of how strategies should be performed, and book recommendations. The solution kit is free of heavy context or verbatim stories, and thus is easy to replicate or post for a variety of situations. The concrete solutions, well-polished through repetitive use, help newcomers who are dealing with extreme ambiguity and do not know where to start.

**Collecting Diverse Strategies**—As the patients progress with their diabetes treatment, they encounter new problems that are not addressed initially or explicitly by diabetes education materials. By sharing one another's experiential knowledge, patients are able to get solutions for newly encountered problems. For instance, a recently diagnosed patient was unable to check her blood sugar because her blood did not come out well. She had to squeeze her finger in order for the blood to come out. She was not sure whether squeezing was the best thing to do. Instead of answering her question right away, the nurse who led the group asked other group members to share how they checked their blood sugar.



Patients share various strategies of their own, which then lead to a collection of operationalized strategies that the patient herself could try out to see what works better for her. One male patient in F2F said he has been diabetic for so long he developed a callous so he had to get a longer needle to get it working. He then physically demonstrated how he could get the blood monitoring device to work better. Other patients told him to try poking the needle in different areas (other than fingers), to try different fingers, or to run it under hot water. Another patient shared that her doctor had told her to take a baby aspirin before taking her blood sugar. Then the group started talking about a gadget that allowed blood sugar to be checked from the arms.

**Solving Unexpected Problems**—Problems become more complicated when patients go past the initial learning curve and encounter unexpected problems that are specific to their own situation. In this case, unlike with the startup solution kit or collectively gathering diverse strategies, helpers have to consider the particular individualized situation that the asker is in to provide appropriate solutions.

The following example shows how the operationalization process happens not only in identifying procedural steps of the strategy but also in interpreting the results and applying them to everyday practices. A member, Gary, in dLife encountered unexpected lab results that conflicted with his own readings taken personally at home. Jule assumed there might have been problems resulting from when and how the asker was taking his blood sugar readings at home. Jule suggested a specific blood sugar reading strategy called ‘bookend testing,’ which would help Gary measure his blood sugar at the right time and to find the glycemic index—how much the food elevates one’s blood sugar—of foods that Gary commonly eats:

You need to do bookend testing. [...] Bookend testing is as follows. Take the reading before first bite, then exactly two hours afterwards (Use an alarm, I like to use the one on my phone.) You should be around 40 points difference. So, if you were 103 before lunch, then you should be around 143 post. If NOT, then that means you went way higher and are still coming down from a high. [gives example from Gary’s case] (August, 2010. OC. Jule)

Here, Jule not only gave step-by-step instructions for how to do bookend testing, but also provided numbers that would help Gary identify whether the results were normal.

Operationalization is done in a way that others could not only follow the instructions but also learn how to interpret the results and construct individualized strategies.

### Breaking of Operationalization

While the operationalization process makes knowledge exchange efficient, it also unnecessarily simplifies the solution, making it difficult for patients to apply the solution for individualized settings. Operationalization breaks down when the context behind solutions is missing, individual differences are detected, and standards and definitions vary, making it difficult to settle down on a solution. At the same time, the breaking of operationalization works as an opportunity for people to further understand individual differences and learn how to better deal with individualized problems. The conflict, individual differences, and



exceptions that challenge existing understandings in the community further facilitates the community's generation of shared understanding about appropriate solutions, which is critical for the long-term understanding of both the community and individuals.

**Individualized Problems and Conflicting Philosophies**—Each patient has differing personal beliefs and expectations about what constitutes a good strategy. Suggested solutions often go through a negotiation process among the members to arrive at an agreement about what are appropriate solutions for various individualized settings. Through the process of agreement, the community as a whole develops enriched understanding towards the problem where individual differences and exceptional cases are recognized.

As an example, we describe below how sharing personal strategies through operationalized solutions breaks down because of patients' failure to adequately share their personal histories, individual differences, and conflicts in what patients believe are appropriate diabetes management strategies. The members then attempt to come to an agreement about what was an appropriate strategy for checking blood sugar. In the following, the initial asker had been diabetic for 16 years, but still had not found a strategy that would help him choose the right meal plan. David replied with simplified information about a step-by-step procedure that included measuring blood glucose (BG). The asker could follow this procedure in order to find the right food to eat for himself:

Take a pre meal BG write it down, write down how many carbs you eat, eat, take your BG 1 hour after eating, take your BG 2 hour after eating, take your BG 3 hour after eating. Now you know how many carbs you ate and you know how much your BG went up. Adjust one or the other until you get numbers similar to your before food BG. (October, 2010. OC. David)

While David's suggestion was simple and easy to follow, this post triggered others to discuss how frequent one should check blood sugar. Adam questioned whether checking blood sugar every hour was necessary. Checking blood sugar two hours after the meal is a standard procedure that most diabetes educators suggest, because that is when blood sugar peaks. Adam thought checking blood sugar 2 hours after the meal was sufficient to determine meal adjustments, and checking blood sugar every hour would hurt one's finger tips and waste test strips. This belief indicated his personal preferences towards resources. Others might prefer to waste their test strips than be in danger of going hyper- or hypoglycemic.

In order to explain how he came to the strategy, David provided historical context and personal background. David believed that every time blood sugar spikes, bodies would be damaged. Also, he stated that his body did not do a good job of regulating blood sugar so he had to initially check as frequently as he could until he found a solution that would help him keep his blood sugar levels down. Adam, however, was opposed to David's assumptions about the severe consequences of having acutely high BGs, since his wife who was not diabetic had blood sugar readings of 180 to 200 when she ate high-carbohydrate food.

Bringing in official information put an end to the negotiation about whether taking blood sugar readings at random times is considered important, but the members of the thread

continued to discuss what is considered dangerous, citing what their doctors had told them, what they had read, and what they believe to be true. The thread ended with collaboratively coming to understand what is considered severe or normal depends on individual differences such as how high the initial blood glucose was.

Such as this, the key to working around the breakdown of an operationalization is coming to an agreement. The process of agreement helps members to generate shared understandings towards dealing with exceptions and individual differences. During this agreement process, patients' personal understanding of standards and definitions is often discussed. These standards and definitions vary between the patients, creating yet another conflict—a point for negotiation.

**Varying Standards and Definitions, Coming to an Agreement**—This section will discuss how even standards and definitions are subject to negotiation. For operationalized guidelines and advice that patients will follow, having consistent standards and definitions is important. Inconsistency in standards and definitions, however, was observed both in the information patients gathered from different doctors as well as in varying beliefs among the patients. Below, we will describe two examples that demonstrate how patients are challenged by inconsistency in information given to them. The first is a case where a patient could not get consistent advice from his doctors for what his A1C level should be, and the second is a situation where standards given by lab reports are inconsistent. In both cases, members accept standards that make the most sense to them amongst health professionals or shared interpretations of other members.

FF4\_P4 is a geriatrics patient who needs to be extra cautious with hypoglycemia, especially because he uses an insulin pump. He needed to know whether to maintain his current management practice or to try to lower his blood sugar or increase his consumption of carbohydrates so that he would not go too low. Determining this became difficult because the advice given from his doctor, a nurse at one diabetes meeting, and another nurse at another diabetes meeting all suggested different target levels of A1C:

I: What is your target A1C that you want to get?

FF4\_P4: Well, three months ago I was 5.5, now I'm 5.6. I would like to be around 6. But then that Linda Evans at Domino's says you should be 6.5. And then this new lady at the diabetes meeting, she said to stay in 7~7.2.(I, FF4\_P4)

The lack of consistency in the standard for FF4\_P4 and his A1C level, even among health care providers, made it difficult for him to operationalize what he needed to do to achieve his goal in controlling diabetes because the goal itself was ambiguous. Not only standards—such as what was considered low, high, good, or bad—were difficult to define, but the definitions themselves were often challenged and negotiated. Because there was no unified answer, FF4\_P4 just had to pick what made most sense to him.

Varying and conflicting standards were often observed in the support group discussions, and the members handled such conflicts by adopting standards that “made sense” to them. In the following example, a member in dLife found out about a newly changed standard in A1C from his recent lab result. In the ensuing discussion, members negotiated common grounds

for what were considered “normal” versus “optimal” numbers, and how interpretations for such terms could change.

I got a copy of my labs today, and I noticed that they have new standards on it. It is reflective of the AACE recommendations. (By the way, this is from Quest Diagnostics Labs...other labs may have different standards, I just thought I would let you know that my lab had changed. Other labs may be different.) (August, 2010. OC. Fang)

When Fang introduced the new lab standard that supposedly differed from the previous standard, another member introduced varying standards that were present across diverse lab testing companies and explained how their standards changed over time. Members then discussed their interpretations for what can be considered ‘normal’ and ‘optimal’ numbers for A1C:

When I was first diagnosed, the lab said under 6% was normal, and nothing else.... You are correct, the change is more reflective of what it should be. (August, 2010. OC. Jule)

There is a vast difference between what is ‘normal’ and what is ‘optimal’. there is a lot of evidence that it’s better to be under 5 than under 6. (August, 2010. OC. Nguyen)

As seen from the case of conflicting standards referenced above, because members often rely on their own interpretations of standards, definitions, and guidelines, they regularly conflict with the terms and definitions that guide diabetes management practices. This conflict becomes a placeholder for members to understand the individual differences and gauge what subjective measurements such as ‘normal’ or ‘optimal’ could mean.

In order to discuss personal interpretations and go through negotiation process, members have to reveal their illness histories--historical context of how they maintain diabetes over time. As members reveal their illness trajectories, new kinds of help process also emerge.

## FINDING 2: ILLNESS TRAJECTORY ALIGNMENT WORK

Sharing illness trajectories is critical in members’ negotiating conflict and individual differences. At the same time, sharing illness trajectories generates interactional work that we call, *Illness trajectory alignment work*. We follow the symbolic interactions in examining “work” as interactional work—one’s continuous efforts to act, especially among people within situations that contain socially constructed meanings as well as negotiated senses of order. We use the term “alignment work” not necessarily to denote that patients are trying to have a unified illness trajectory, but to explain how, through the act of comparing and contrasting one another’s experiences, patients derive personal meanings out of one another’s illness trajectories. The temporal component in the shared stories allows patients to deal the uncertain future inherent to chronic illness, to understand that the sequence of events could be different depending on the individual, and to be aware of unexpected consequences that might arise at any point.

We will describe illness trajectory alignment work in two ways. First, members attempt to project one's future trajectory through others' trajectories. More experienced patients also share how they deal with a situation in the past that a newly diagnosed patient is currently struggling with, give warnings, and offer reassurances about the likelihood of positive consequences. Through the alignment work of one's future and past trajectories, one can reduce uncertainty about the future, learn shortcuts to problems, and be warned about possible danger to come.

Second, *re-assembling illness trajectories* describes the collective work of the members to build a coherent story about how one might experience a particular problem or intervention over time. Whether the topic is medications, diet regimes, or any number of other subjects, members at different stages share stories about their illness trajectories. These stories are then re-assembled together to construct something the community could use to understand individual differences.

Before we discuss illness trajectory alignment work, we first briefly introduce the Chronic Illness Trajectory Framework (CITF), upon which our analysis builds.

### Chronic Illness Trajectory Framework

We use Strauss and Fagerhaugh's [26] Chronic Illness Trajectory Framework (CITF) to borrow terms and analytical tools for understanding how the patients share their stories about managing diabetes over time. In "Social Organization of Medical Work," [26] Strauss defined trajectory as:

- (1) the course of any experienced phenomenon as it evolves over time (an engineering project, a chronic illness, dying ...) and (2) the actions and interactions contributing to this evolution.

In our use of the framework, CITF describes what patients share with peers—the experience of having diabetes over time: how they got diagnosed, what medications are being used, what symptoms and side effects are there, how patients communicate with doctors, what challenges are there in working with the health care providers, and how the patients are dealing with insurance companies. These various stakeholders had to all be considered in order to holistically understand patients' experiences.

The role of the patients today is not limited to attempting to better detect symptoms or to more effectively communicate experiences with the doctors as described in CITF. The patients' work has become diversified and empowered through experiential knowledge gathered from peers, creating a new facet in the illness trajectory framework—the work that is being done among the patients. We next discuss how patients share their illness trajectories as a way to convey their experiences, reduce uncertainty, and help to anticipate possible consequences.

### Projecting into the Future and Past

This section will discuss how members share and compare their illness trajectories to help one another project into the future. Not being able to anticipate the timing or severity of things that might happen in the future produces anxiety and stress, and diminishes

empowerment for patients [20]. Hearing from experienced patients about how they overcame similar challenges helps to reduce uncertainty about the future. Experienced patients warn less experienced patients about critical events they might encounter and help them become more proactive about problems that might not otherwise have been anticipated.

The following example illustrates a new insulin user attempting to project her future through others' experiences. Sharing past experiences, present struggles, and expectations about the future enables members to encourage one another, find solutions, and reduce uncertainty. The thread began with Tina sharing her excitement about the effectiveness of the insulin, such that she thought she could now eat however she wanted and still enjoy lowered blood sugar levels. However, she was still interested in hearing from experienced patients whether insulin was something she could rely on for a long period:

I think I just might be in love with insulin!...I feel like I have the freedom to eat the way I want to again without the guilt of high blood sugars. Last night I had spaghetti and garlic bread and 2 hours later a sugar of 99!! [...] My only concern is whether or not [...] a year of insulin hurt my body in anyway? (Oct, 2010. OC. Tina)

Several patients replied to this, including a patient who also had a positive experience with insulin. Other members expressed concern about Tina's possible weight gain due to the increased use of insulin and the possibility that she might ultimately develop insulin resistance. Members who replied to this thread included several who had experienced gestational diabetes and who enjoyed insulin in the beginning as Tina did—but their recommendations were to start thinking about incorporating appropriate diet change and exercise instead of relying solely on insulin.

As illustrated in Tina's case, patients often cannot anticipate side effects that they might suffer over the years, since little information is given at the time of diagnosis. Accordingly, hospitals arrange support groups to educate patients and to help them become self-sustainable after the acute treatment. Those who choose to engage in support group discussions either F2F or online can get such advice—often from the successful peer patients—and potentially identify negative outcomes that they might have overlooked otherwise.

### Re-assembling Illness Trajectories

Our analysis to this point has focused on following the linear trails of each illness trajectory as a form of help, where the transferring of experiential knowledge flowed from directly patient to patient. Now we will further analyze how pieces of illness trajectories from different temporal points on multiple members' trajectories are collected and re-assembled to understand how one might experience medications, diets or exercise regimes differently over time. Rather than attempting to find a solution that perfectly fit each member, awareness of individual differences helps members collectively understand various possibilities so they could adjust their expectations, practices, and decisions accordingly.

The following case illustrates how the community builds an understanding about long-term experiences from a medication. Peter started a thread in dLife after his doctor suggested him to start taking Victoza, a weight loss medication. Victoza was relatively new at the time, thus he wanted to hear about other patients' experiences with the medication so that he could assess whether it would be an appropriate medication for him and also to anticipate what might happen as he continued to use the medication. This thread became helpful not only for Peter, but the community in general.

27 different members replied to the thread, which ended up running for several months and resulted in 41 posts. Some participants had never heard of Victoza, some were thinking of switching to Victoza from other medications, some were about to use it, some had just started using it, and others had been using it for a week to a month. Some of them regularly updated their experiences with the medication. Personal beliefs, past medical history, other medications, and insurance providers varied among the posters of this thread, all factors affecting either the effectiveness of the medication or the consequences of choosing it.

For example, Rick replied to the thread after his third day of using Victoza. In this post, Rick informed readers what they might experience during the first few days of taking Victoza, such as gassiness, and initial fear of injections (Victoza is an injection drug):

I just began taking Victoza. Today is only day 3. So far, so good. It has brought my blood sugars down and I am pleased about that. No nausea so far [...] I have noticed more "gas". Hopefully this will pass (no pun intended) in a week or two. [...] I am very hopeful that Victoza will work for me. (Mar, 2010. OC. Rick)

Notice that Rick left it open for what might happen with more protracted use of Victoza. A month later, Rick offered information about how his Victoza experience changed over time. His blood sugar had returned to normal, his dosage had been increased to the normal dose of 1.2 ml, his weight decreased, and new medications were added to his medication plan without side effects. Updating his trajectory over time helped other members anticipate the longer use of Victoza. Hanraty was encouraged by Rick's update:

Thanks for your note. I was just given Victoza to try as well- gained 8 lbs and am feeling VERY not happy and reading your note actually gave me a tiny glimmer of hope... (Sep, 2010. OC. Hanraty)

Furthermore, the thread allowed eliciting individualized problems around Victoza. Victoza's possible connection with cancer was discussed and which alternative medication—Byetta—could be taken accordingly for those with cancer history. Peter not only had a history of cancer but also had stomach problems in using Byetta. Thus Peter tried controlling his blood sugar levels without the help of Victoza or Byetta for several months, but the risk was too high for him since his blood sugar level was not being controlled. Moreover, contracting pneumonia complicated the situation further. After several months, he was forced to think about how to better manage his use of Victoza—when to take it and where to inject it to minimize the stomach problems:

Have a question for those who use it - when do you take yours - morning, afternoon or evening - I know it should be the same time each day but what is the best time -

hoping to avoid stomach upset. Any other hints will be appreciated - site of injection (thigh okay?) (Aug, 2010. OC. Peter)

Through several months of discussions with other members of the community, Peter was able to develop a fuller understanding of Victoza and how it affected individuals differently. Through re-assembling partial stories from various points in time, members developed a rich picture of what taking the medication was like, and became aware of alternatives that might be pertinent to their own situations. Also, members came to better understand the use of Victoza over time, helping them to adjust their expectations and practices.

Similar activities were observed in F2F, such as their experiences with laser eye surgery, the shingles vaccine and its effects on diabetes, and the progress of the artificial pancreas. This discussion helps them to collectively assemble a more complete picture of what they might anticipate over time and to appreciate individual differences in the experience of various resources, activities, and events.

## DISCUSSION

In this section, we discuss how members ultimately involve in constructing common understanding towards diabetes management as they participate in the support groups. We then further examine the relationship between operationalization and illness trajectory alignment work, and how our findings translate into design implications.

### Community's Common-Enough Understanding Of Diabetes Management

Knowledge produced by being regular members in a community and all other help processes becomes a foundation for community members' constructing common understanding towards diabetes management. This understanding is common-enough (i.e., not complete) and negotiated [26]. This is similar to Weick's sensemaking [28] in that, during the times of ambiguous and uncertain situations, people collaboratively attempt to share understanding of individuals' perspectives and varied interests. While Weick's analyses largely involve ad-hoc and abrupt situations, the settings we examined involve sensemaking activities happening over years-long period of time. Over time, a community builds a conceptual pool of knowledge containing the community's agreed understanding about appropriate diabetes management strategies. The common understanding then affords members to tailor solutions for themselves or to help others generate solutions for individualized problems.

The common understanding becomes a guideline, a reference, and trusted experiential knowledge repository that patients seek out for as ultimate source of help. The common understanding is not tangible in any way. Similar to what was observed from the workers in a hotline [3] and an emergency room [19], a community's common understanding is embedded in the processes of members' close awareness of one another, continuous negotiation of strategies, elicitation of exceptional cases, and challenges emerging out of operationalization, the breaking of operationalization, and illness trajectory alignment work.



## Operationalization and Illness Trajectory Alignment Work

Operationalized information and illness trajectories supplement each other. Operationalized knowledge becomes elements that comprise a more complete story of one's illness trajectory as members share their patient profiles, experiment findings, and current struggles as part of their interaction with the support groups. Still, the missing information between shared operationalized experiences, and the context that surrounds each shared operationalized experience, can only be filled with stories and anecdotes as they become necessary.

Each member's illness trajectory as presented to the support groups is never complete. Only the parts that the members willingly report are visible to the community. One's illness trajectory is in a constant state of progression, thus members need to be kept abreast of one another's illness trajectories over time in order to have a "complete" picture.

## Design Implications

We now go back to Molly's case introduced in the beginning. How could collaborative help systems support Molly's situation of finding solutions to conflicting diet plans? We discuss three implications.

**Facilitate Sharing of Operationalized Experiences**—With the advance of Internet technology and increased user participation, sharing operationalized patient profiles in the forms of personal health records (PHR), Microsoft HealthVault, Google Health, or manually reported is actively being explored [16–18]. Personal health information tools integrating above PHR related applications can help find relevant clinical trials for patients' health status, improve patient-doctor communication [16], and monitor one's health in a systematic way (e.g., [healthmanager.webmd.com](http://healthmanager.webmd.com)). In the context of support groups, our study found operationalized experiences help members easily [17] share context and strategies. To help further facilitate the process of operationalization, we can imagine a system with a repository of operationalized experiences that includes experimental results of various diet or medication regimes. Molly could then narrow down the pool of patients who have had diabetes for roughly 20 or more years like her and who have had liver disease at the same time. She could then compare diabetes management strategies of those who progressed to the later stages of liver disease more quickly than others versus those who did not. The results may not give her scientifically valid information, but for patients like Molly who are in need of relevant information this could help with the uncertainty of managing chronic illness.

## Support Challenging Operationalized Solutions to Elicit Individual Differences

—Existing patient networking sites have been critiqued for its disconnection between shared personal health information and narrative discussions [10]. Our findings show that breakdown of operationalization in fact helps members to understand individual differences of a given problem. When a dLife member challenged a strategy for checking blood sugar, the community was able to further understand the need for individualized strategies in checking blood sugars. A repository of operationalized experiences discussed above should not represent each experience as a finished and complete data point. Rather, each data point should be subject to change and the context in which the data point was challenged should

be recorded. Examples would include support for conversational threads for each shared data point in the repository. Any data point with long conversational threads could signal that the data point is controversial and is significant.

### **Facilitate Sharing Individual Trajectories and Help Community's Negotiated Experiences Become Visible**

—Sharing illness trajectories is critical in not only contextualizing but also generating information about one's future and take preventative measures. The importance of visualizing patient history has been recognized [21]. When Molly narrows the pool of patients diagnosed with liver disease, the ability to see the past history and future plans of those patients would greatly help her reduce uncertainty about the future. Molly could essentially align her future with those who have gone through a similar problem and she could see many cases and exceptions that would help her to anticipate her own future.

In order to support the visibility of the community's common understanding, we could also imagine a system where patients post their problems and the system suggests prior threads that are relevant to their posts. The patient could then link to relevant prior threads in their posts and explain the distinctions between their current problem and prior posts. This feature could not only help the poster learn about prior relevant posts but also help readers to learn about each poster's problem within the larger context of how the community attempts to solve problems.

## **CONCLUSION**

In this paper, we discussed how patient support groups give individualized help and derived design implications. Operationalization facilitates transferring executable experiential knowledge and context. However, operationalization inevitably breaks down due to members' individual and situated differences. Such breakdown in fact works as an opportunity for members to deepen understanding towards exceptions and individual differences, and generates negotiated understandings. The process of operationalization and reflecting upon operationalization breakdowns have to be done within the larger context of sharing illness trajectories. Members also use illness trajectories as resources to help one another anticipate about the uncertain future and understand individual differences. Ultimately, as members continue to participate in the community, they construct common understanding around an ideal way of maintaining diabetes over time.

There are several caveats and remaining questions to be discussed. First, our participants are the group of people who are actively attempting to control their diabetes. A new set of inquiries arises for how we can better support patients who are less proactive about their conditions. Second, our participants come from all around the world, and information they gather from their doctors can conflict. How members can use information they receive from dLife with their health care providers is another question that needs to be answered. Lastly, how our findings relate to online diabetes communities other than dLife and the face-to-face support groups in other parts of the United States is unknown. Devising appropriate environment fit for targeted patient group will become important as we design online communities for varying groups of patients.

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