# Collaborative Help for Individualized Problems: Learning from the MythTV User Community and Diabetes Patient Support Groups

by

Jina Huh

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### **Doctoral Committee:**

Professor Mark Steven Ackerman, Chair Associate Professor Barry Jay Fishman Assistant Professor Mark W. Newman Assistant Professor Kai Zheng Research Associate Professor Stephanie D. Teasley © Jina Huh 2011 To Daniel, Willow, and Mom and Dad

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**Abstract** 

Collaborative Help for Individualized Problems: Learning from the MythTV User Community and Diabetes Patient Support Groups

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Chair: Mark S. Ackerman

As information technology increasingly becomes part of everyday life, new opportunities arise for aggregating people's experiences and knowledge.

Collaborative help can utilize collective experience and knowledge to benefit everyday problem solving activities. However, current help systems often limit their focus to common and active problems (e.g., Frequently Asked Questions), making it difficult for users to find answers to the problems that are uncommon and individualized. In my dissertation, I address how individualized problems can be better supported through collaborative help. My dissertation contributes to existing

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conversations around collaborative help, especially challenges in information reuse and contextualization. I further expand discussions around the role of temporal information during expertise sharing for finding solutions to individualized problems.

In order to study this, I examined two research sites using an interpretivist approach (Strauss & Corbin, 1990): the MythTV user community and diabetes patient support groups. Because problems are often individualized for members of both communities, these sites serve as excellent places to examine the research problem of how to better solve individualized problems through collaborative help.

I discuss three key findings that are critical for understanding how individualized problems are solved in community-based collaborative help systems. First, operationalizing experiences is critical for sharing executable solutions and context. Operationalized experiences are not only about the objectification of tacit knowledge (Ambrosini & Bowman, 2002), but are further operationalized so that the knowledge can be directly re-used. Operationalization process amplifies the material aspects of information and knowledge to become inscribed, transported, and affixed to items (Bowker & Star, 1999). Accordingly, operationalized strategies and their material characteristics make it easy to share and transfer knowledge.

Second, the process of operationalization inevitably breaks down. However, the breakdown of operationalization process serves as an opportunity to understand and handle individual differences. Operationalization process fails to

capture practices "simultaneously embedded in various processes" (Ackerman & Halverson, 2000) during maintenance activities, be it maintaining MythTV or diabetes. The breakdown of operationalization process helps each community member learn how to manage individualized situations as they occur, as suggested by Bowker and Star's (1999) argument about multiplicity and its role in making information visible.

Lastly, operationalization process needs to take place within the larger context of sharing trajectories. By comparing, connecting, aligning, and collaging pieces of individual trajectories, community members collectively expand their knowledge about maintaining MythTV and managing diabetes over time. The community members are able to further understand the individual differences in those experiences and continue to build negotiated understandings about the problem space. Through continual sharing of use and illness trajectories, members reduce uncertainty about the future, take preventative actions, and reflect on the past to revise their practices.

My dissertation concludes with discussing how these findings translate into design implications for collaborative help systems.

# Chapter 1

#### Introduction

As information technology increasingly becomes part of everyday life, new opportunities arise for aggregating people's experiences and knowledge. Collaborative help can utilize collective experience and knowledge to benefit enduser technical support or personal problems such as health management. However, current help systems often limit their focus to common problems (e.g., Frequently Asked Questions), making it difficult for users to find answers to the problems that are uncommon or individualized. I define individualized problems as uncommon problems for which answers are not readily available through documented forms such as FAQs, previous forum messages, or how-to pages. I also define individualized problems to include situations where answers appear to exist, but the suggested answers do not solve the problem. For individualized problems, answers would either have to be constructed from scratch, or existing solutions would have to be modified to work for the particular problem. The following two scenarios illustrate examples of individualized problems in technical and healthrelated areas.

#### Scenario 1. Kyle and His AppleTV

Kyle recently purchased an Apple TV. One of the things he wanted to do with the Apple TV was to see the photos on his computer on the large TV screen. However, when he tried to sync his photo files from his PC computer, it took almost one hour to sync his 25,000 photos. If this had only occurred once, it would have been fine. However, the problem persisted each time he synced his photos. Also, there was an issue where Apple TV tried to merge all folders into one folder while putting an artificial cap on syncing only 20,000 photos maximum. He called Apple but the response he received was "Too bad, we cannot help you."

He then started searching Google and read posts in various user forums. The design of the online forums made it difficult for Kyle to find the exact solution he wanted. He had to go through each topic and read the threads to figure out that the problem was not the same as his. He eventually posted the problem on an online forum and he received several responses. One suggestion was to check his home network. Kyle had no problem with his Netflix so he knew this was not a networking problem. The second suggestion was to not use to iPhoto and instead use Aperture. Kyle was using a PC, so this suggestion was also not helpful. Kyle did not find a solution to his problem, so he lived with the problems he had with his Apple TV.

Kyle's scenario illustrates how he encountered a technical problem that he wanted to solve but was not able to because there were no existing solutions. His process of trying to find the answer for an uncommon problem shows current shortcomings in collaborative help systems design. Kyle received suggestions that may apply to his situation, but none of them actually worked. In order to find the solution, Kyle would have to continue to share his particular circumstance with people who had the proper expertise to build solutions from scratch or modify existing cases.

Individualized problems can happen in many domains. The following scenario demonstrates an individualized problem in personal health management.

#### Scenario 2. Molly's Finding the Right Diet Regime

Molly is a 65-year-old female who has successfully managed her diabetes for the last twenty years. In a recent visit to her doctor, she heard that she might be developing liver disease. The doctor suggested a diet plan that was the exact opposite to what she should be eating as a diabetes patient. The new diet plan recommended high-calorie food, reduced protein, increased intake of carbohydrates, and white bread instead of whole grain bread. As a diabetes patient, she should be eating low calorie, high protein, reduced carbohydrates, and whole grain products instead of bleached ones.

Molly became frustrated. She scheduled an appointment with a dietitian in two weeks, but wanted to know what other people did in her situation until then. She also wanted to avoid dialysis and wanted to know what she could do to delay this as long as possible.

Molly's case describes well how people encounter uncommon situations as they maintain health over time. Also, because each patient is different, any given solution may not work immediately. Working with a dietitian, Molly would have to go through several iterative processes to find the right diet regime. She has her own personal preferences for foods and restrictions. While professional help may be ideal, the scenario describes patients' needs in wanting to understand other similar cases. Based on knowledge from others' experiences, Molly will be able to attempt to anticipate the future and make informed decisions.

In Kyle's case, the main problem is he could not find existing solutions that would help him directly solve the problem. Finding people with the right expertise can help him solve his problem by modifying and inferring from existing solutions.

In Molly's case, there may be diet regimes readily available for diabetic patients with liver problems, but it is unknown whether the regimes would be successful. Both cases are individualized problems because Kyle and Molly could not find solutions that would work immediately. Solutions would have to be modified, inferred, and tested in order to determine whether the solution would work. Current collaborative help systems are better at finding existing solutions than modifying or adapting solutions (thus helping individualized problems be solved).

Studying individualized problems brings out two important challenges from the perspective of collaborative help: tailoring and re-contextualizing existing solutions and dealing with long-term issues. First, because individualized problems are uncommon and rare, existing solutions do not (or only partially) address the problems. People need to find ways to tailor and re-contextualize existing solutions to fit one's specific case. Re-contextualization of existing solutions and finding the right solution to reuse (Ackerman & Halverson, 1999; Civan, McDonald, Unruh, & Pratt, 2009) are critical challenges themselves in collaborative help. As noted in "customization and appropriation gulf," (Huh, Newman, & Ackerman, 2011) individualized problems pose extra challenges for those who do not have expertise, do not know where to go for this expertise, or do not understand how to tailor possible solutions. Thus for collaborative help, how people with varying expertise can collectively generate individualized solutions becomes a key challenge.

Another important aspect of individualized problems is their time duration.

Many acute problems, such as fixing a broken wireless connection or learning how

to deal with nose-bleeds, do not require understanding historical context or anticipating long-term consequences. Solving problems coming from the long-term maintenance of things (such as maintaining outdated computers or dealing with a chronic disease) requires knowledge of the historical context and an anticipation of the future. The importance of the temporal context of the problem space has been widely examined in theories that attempt to understand how people learn to act and perform everyday lives (Strauss, 1993; Vygotsky, 1987). Building on existing conversations around the concept of trajectory in studying people's information work (Ackerman & Halverson, 1999) and health management practices (Brashers, Neidigb, Reynoldsa, & Haas, 1998; Wiener & Dodd, 1993), I further examine how historical aspect in individualized problems could be solved through collaborative help.

In order to solve the two challenges in individualized problems, in this dissertation I identify the critical processes found in existing individualized help systems and discuss the design implications of those processes. I examined two research sites using an interpretivist approach (Strauss & Corbin, 1990): the MythTV user community and diabetes patient support groups. These sites serve as excellent places to examine the research problem of how to better solve individualized problems through collaborative help.

I will discuss three key findings that are critical for understanding how individualized problems can be solved in community-based collaborative help systems. First, to address the first challenge of information reuse, operationalizing

experiences is critical for sharing executable solutions and context. An operationalization process amplifies the material aspects of information and knowledge to become inscribed, transported, and affixed to items (Bowker & Star, 1999). Accordingly, operationalized strategies and their material characteristics make it easy to share and transfer knowledge. The findings will further show how operationalizing experiences can allow knowledge to be directly re-used.

Second, the process of operationalization inevitably breaks down. However, the breakdown of operationalization serves as an opportunity to understand and handle individual differences. The operationalization process fails to capture practices "simultaneously embedded in various processes" (Ackerman & Halverson, 2000) during maintenance activities, be it maintaining MythTV or diabetes. Similar challenges of failing to capture context have been discussed by standardization efforts in information systems. Standards do not remain for long, and "one person's standard is another's confusion and mess" (Gasser, 1986; Star, Han, Bouyambib, & Matre, 1991). The breakdown of operationalization helps each community member learn how to manage individualized situations as they occur, as Bowker and Star (1999) argue about multiplicity and its role in making information visible.

Lastly, the process of operationalization needs to take place within the larger context of sharing trajectories. This addresses the second challenge in individualized problems—the temporal aspects of long-term issues. By comparing, connecting, aligning, and collaging pieces of individual trajectories, community

members collectively expand their knowledge about maintaining MythTV and managing diabetes over time. The community members are able to further understand the individual differences in those experiences and continue to build negotiated understandings about the problem space. Through continual sharing of use and illness trajectories, members reduce uncertainty about the future, take preventative actions, and reflect on the past to revise their practices. Unlike Bowker and Star (1999), which viewed the trajectory of boundary objects as something that would continue to lose its context and history over time through routinization, use and illness trajectories continue to reveal their context attributed by the regular emergence of new challenges that the community members encounter over time.

## Overview of the Chapters

In Chapter 2, I further clarify the term "individualized problems" and examine areas—collaborative tailoring (in software engineering) and personalized medicine—that attempt to solve individualized problems. I then discuss two major areas of research that my dissertation builds upon, collaborative help and patient expertise sharing. I discuss how knowledge transfer and information reuse problems have been addressed in the collaborative help literature and further detail how patient expertise sharing systems are a collaborative help problem. I conclude the chapter by discussing how social constructivism and symbolic interactionism serve as the lenses through which I viewed, understood, and interpreted findings.

In Chapter 3, I discuss the methods used for studying the MythTV user community and diabetes patient support groups. I characterize the members of each community and describe specific research methods used to collect and analyze data. I describe the symbolic interactionist ethnographic research that shaped data collection, analysis, and interpretation of findings.

In Chapter 4, I describe findings from the MythTV user community. I focus on how configuration artifacts in the form of scripts, error messages, and files allow easy transfer of knowledge and context, and how the community aligns use trajectories to get help. I discuss how configuration artifacts function as boundary objects that facilitate communication and the transfer of knowledge.

In Chapter 5, I discuss findings from diabetes patient support groups. I talk about how operationalized experiences in the forms of patient profiles and experiment results are employed to easily transfer context and experiences. I also examine how the process of operationalization is carried out within the larger context of sharing illness trajectories. Individual differences in illness trajectories are continually negotiated to elicit agreed-upon solutions. This develops the community's common understandings, which becomes the guidance and reference with which members can build individualized strategies for coping with diabetes over time.

In Chapter 6, I discuss common findings from the two studies and derive implications for understanding what is critical in providing individualized help. I further address the findings specific to each site—the MythTV user community and

diabetes patient support groups and proceed to discuss theoretical and design implications, using scenarios to illustrate the design implications. I also expand the discussion of boundary objects from Chapter 4 to examine transparency and temporal issues. The chapter concludes with a discussion of limitations and future work.

### Chapter 2

#### **Literature Review**

My dissertation builds upon existing work on collaborative help. More specifically, my dissertation further extends discussions around information reuse, knowledge transfer, and contextualization during help. Through my dissertation, I also discuss temporal properties in experiences as a critical resource in sharing experiences. Altogether, I address how collaborative help systems could further solve individualized problems.

The purpose of this chapter is to first clarify my research questions based on the existing literature on the topic, study the previous work that my dissertation builds upon, and lastly, examine relevant social theories that would help me build analytical tools suited for the particular questions I am asking. The chapter is divided into five parts. In Part I, I briefly clarify what I mean by "individualized problems" and examine how existing conversations in collaborative tailoring and personalized medicine have addressed individualized problems. Part II and Part III discuss existing efforts specifically around the issues of collaborative help in two domains—technical help and personal health. In Part II, I examine how researchers

in collaborative help deal with transferring tacit knowledge, information reuse, and informal communication as a knowledge resource, mostly in technical domains. Furthermore, I highlight the literature about learning in practice that allows collaborative help, specifically for individualized problems to be facilitated. In Part III, I reconnect personalized medicine, as discussed in Part I, with socio-technical systems supporting patient expertise sharing, such as support groups and online health communities. I discuss how online health communities are in the end a collaborative help problem. Lastly, in Part IV, I describe the fundamental building blocks that I used as analytical tools in my study. I talk about social constructivist and symbolic interactionist perspectives, specifically around the concepts of communities of practice, social worlds, trajectory, and boundary objects as critical analytical components to the findings in Chapters 4 and 5.

#### Part I. Individualized Problems

In this part, I walk through various literatures and show how they are related (or not related) and what findings they offer for my problem, "Individualized problems." The term "individualized" may be confused with "personalized," "customized," and "appropriated." However, these concepts have slightly different connotations in terms of their purpose, the field in which they are used, and the implications for how existing solutions are used to find solutions to the problem. To avoid confusion stemming from various connotations involved in the fields of

research that have differing methods and goals, I settled on the term "individualized."

For instance, "personalized search" refers to smart systems that understand user needs and preferences and present documents accordingly (Pretschner & Gauch, 1999; Shen, Tan, & Zhai, 2005; Speretta & Gauch, 2005). Successful personalized search depends on well-structured user profiles (Pretschner & Gauch, 1999) and good algorithms that would help systems find better results to users' queries (Shen et al., 2005). On the other hand, I am more interested in solutions that emerge out of social interaction (Ackerman, Pipek, & Wulf, 2002), rather than controlled documents filtered through user preferences and needs. More on knowledge emerging out of situated social interaction will be further discussed in the "Informal Communication as Help" section in this chapter.

Another example that offers similar meaning to the term "individualized" is "appropriation," which often refers to the use of technical systems in unexpected and creative ways. Studying appropriation has been used to examine the coevolutionary relationship between users and technical systems (Ackerman, Halverson, Erickson, & Kellogg, 2007), personal expression and mastery in technology use (Akah & Bardzell, 2010; Voida, Erickson, Kellogg, & Mynatt, 2004), use discourse and negotiated use of groupware systems (Pipek, 2005), and design toward sustainable practices in computer use (Huh, Blevis, et al., 2010; Huh, Nam, & Sharma, 2010). Accordingly, studies in appropriation help me understand how individuals struggle to make technologies part of their individualized work

practices and everyday activities. However, the connotation of the term, appropriation, is of a personally meaningful activity to the users as opposed to a challenge to be overcome as in the cases of individualized problems.

#### **COLLABORATIVE TAILORING**

Another term tailored has a similar purpose and meanings to my use of the term individualized problems in this dissertation. It is similar in that the act of tailoring refers to how solutions can be customized to an individual's specific problems and account for an individual's context, constraints, preferences, and configuration, and collaborative tailoring is a research area that explores the issue of individualized problems.

As part of the development of systems to support individualized context, tailorability is extensively explored in software engineering. The tailoring activity described in the literature addresses several solutions for individualized problems: sharing executable artifacts, tailoring as an activity to support individualized context, and the collaborative nature of tailoring work.

Nardi and Miller (1990a; 1991) studied how users from various communities share tailored artifacts to help one another with tailoring activities. In their ethnographic study of spreadsheet users in work environments, they found how the spreadsheets used are mostly the result of collaborative work among users with differing levels of programming and domain expertise. Similarly, "component-based tailorability" (Wulf, Pipek, & Won, 2008) allows users in their run-time

environment the flexibility to tailor software to work for their particular use through sharing component structures created by the users. The cooperative tailoring activity around easily sharable artifacts such as macros, templates, and component structures in various user groups with differing expertise allows knowledge to be shared through mobilizable forms of information. What is still under-addressed, however, is how much the shared artifacts can be directly used as solutions and how the artifacts embed historical context that could help facilitate with contextualization during problem solving process.

Further work in this area found that tailoring is often a collaborative process shows the relationship between the developers and the users (Mørch & Mehandjiev, 2000). Tailoring is shown as a cooperative work process of different user groups, such as user-designers, tinkerers, or gardeners, who customize and tailor software to user needs and share their work through "standards" such as macros and forms (Trigg & Bødker, 1994; Nardi & Miller, 1990). Pipek (2005) contributes to the technical issues of tailorability by further bringing in a holistic perspective on "appropriation work," "a social process among technology users that helps producing a fit between technology and work tasks." From two prototypes that each supports configuration of an event notification service of a groupware and configuration of an inter-organizational software, he arrived at several implications for supporting community-based appropriation work. An example includes "quoting," where experiences in different representations of technology and use context are collected to further understand "use discourse."

Through this work, Pipek further pushed how software can incorporate collaborative efforts in reshaping technology "in use." The work in collaborative tailoring then uniquely describes the intricate relationship between social process and individual activity during tailored use. Sharing standards, artifacts, and use context as discussed above give implications for how individualized use can be socially shared in order to help one another's individualized problems.

The work in tailoring activity, however, still has several areas that need further exploration. Transferring one's knowledge and re-contextualizing existing solutions for individualized situations is a known challenge in the help literature (Ackerman & Halverson, 1998). To make the problem even more difficult, long-term maintenance of computing devices is not just troubleshooting problems at hand. Rather, users need help in understanding long-term consequences that any intervention may cause, plan according to their ongoing needs, and easily share with others what one has learned from the past.

Technical use is not the only domain that suffers from individualized problems. Personal health is another space in need of finding solutions for individualized problems, especially with its issues related to time. A person's health problem has to be understood within the larger context of the environment in which the person is living, particular genetic problems the person may have, life style, personal preferences, and health history. Furthermore, patients constantly deal with anticipating the uncertain future. As will be discussed below, the field of

personalized medicine attempts to address the issue of providing patients with individualized care.

#### PERSONALIZED MEDICINE: PATIENT-DRIVEN HEALTH CARE

The act of individualizing (or personalizing1) occurs not only in the fields of software engineering but also in personal health in the name of personalized medicine (other similar efforts include participatory medicine and patient-driven health care). In the case of personal health, health care is personalized to meet the various needs of patients. However, as Fierz (2004) addresses in the quote below, personalized medicine is a broad concept with many component areas.

We now know that a 'one fits all' type of treatment has its limits. Medicine needs to be (re-)personalized. [...] Privacy, protection of minorities, and prevention of discrimination are at stake. Regulations are required. The health-care process needs redesigning to render personalized medicine effective. Information and communication management is challenged to handle the wealth of personal information and link to global medical knowledge.

The six dimensions of personalized medicine can be conceptualized as disease, environment, gene, medication, healthcare, and information (Ginsburg & McCarthy, 2001; Jain, 2002; Meyer & Ginsburg, 2002; Ross & Ginsburg, 2003). That is, patients carry different susceptibilities and predisposing factors for disease. They are affected by geographical and seasonal factors and their life style and sexual behavior can influence the prevalence of particular microbes. Particular

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<sup>&</sup>lt;sup>1</sup> In the field of medicine, "personalized" is used to denote providing health care tailored for each patient's biomedical, social, and personal needs.

individualized molecular traits and mechanisms are expressed in a patient's actual mRNA, protein (Gerling, Solomon, & Bryer-Ash, 2003; Tyers & Mann, 2003), and cell levels (Valet & Tarnok, 2003). It is one of many challenges in personalized medicine to better understand genetically identifiable subgroups of the population with individual factors that influence drug absorption, distribution, metabolism, and excretion.

Giving personalized health care involves extensive lists of activities, such as genetic counseling, patient education, and evaluating risk profiles. One of the ultimate goals in personalized health care is to have electronic health records that contain personal information about the patient, so that personal health information can be used in connection with knowledge-based information (e.g., evidence-based medicine) to support personalized medicine (Fierz, 2004). Personalized medicine, then, becomes a huge project that involves numerous stakeholders; incredible amounts of coordination and information management; and the delicate meshing of social, ethical and regulatory issues that all need to be tackled at the same time.

Among many strands of work that facilitate personalized medicine is patient empowerment—namely through the patient-driven health care model (Swan, 2009). This model is deeply tied with Health 2.0, embracing many of the ideas behind Web 2.0 for health care, where the patients become active producers and consumers of health information through social media and the Internet in general. The term medicine 2.0 has also been used to denote "better health systems" that

"emphasize collaboration, participation, apomediation, and openness, as opposed to the traditional, hierarchical, closed structures within health care and medicine" (Eysenbach, 2008). Eysenbach further argued new healthcare systems should move away from hospital-based medicine, focus on promoting health, and empower patients to take their own responsibility for health. Examples of recent developments include personally controlled health record (PCHR) and personal health applications (PHA) such as Google Health, Microsoft HealthVault, and Dossia, which help pull health data from various sources for patients.

Consequently, "tectonic shifts in the health information economy" (Mandl, Szolovits & Kohane, 2001) have been observed, moving away from the notion of health care providers as the sole custodian of medical data.

Providing patients with increased control in managing medical data can further personalize health care and promote ongoing patient education. While the potential inaccuracy of end-user-generated content has been raised as a concern (Hughes, Joshi, & Wareham, 2008), to promote health, a number of studies examined patient-generated data on the Web, such as their health status shared through social networking websites. For instance, Bonander (2008) explored tailored health promoting messages for increased awareness of wellness utilizing publicly available MySpace (myspace.com) profiles, such as smoking and drinking status, mood, and ethnicity. A similar attempt was made in integrating wellness applications to Facebook (Munson, Lauterback, Newman, & Resnick, 2010). The authors found that, by allowing users to share on Facebook three good things that

they did, it is possible to deliver wellness benefits to users. Some privacy issues emerged, where the users did not want to share their status with everyone but only with specific group of friends. Accordingly, tailoring how information is broadcasted and received for individuals is an important design implication in promoting health through social networks.

As such, increased patient empowerment and use of Health 2.0 technologies, such as online health communities, bookmarks, blogs, and Internetbased applications, serve to support individualized problems in health management by allowing patients to have access to information and experience gathered from other patients. As will be further discussed later in Part III, health social networks such as PatientsLikeMe (patientslikeme) or CureTogether (Curetogether) allow new kinds of patient learning experiences to emerge. One example is collaborative filtering—a way to identify patients in similar situations by matching various reported conditions and quantified self-tracking data. Collaborative filtering was found to give critical aid in allowing patient information-seeking and trust-building in health models on the Web (Eysenbach, 2008). This study found that a patient driven model realized by patients' social networks not only helps increase information flow for patients in empowered selfcare, but also helps advance medical research. Even patient driven self-experiments are being done to understand various interventions. For instance, a PatientLikeMe member gathered 250 patients to test the effect of lithium in delaying disease progression of amyotrophic lateral sclerosis (ALS) (Arnst, 2008). The result showed

lithium does not slow disease progression. These examples highlight the new power and role of patients, and their increased individual ownership in health care as personalized medicine further incorporates patient driven health care model.

However, the field of Health 2.0 technologies is still in its early stages. More work needs to be done in helping patients to find the right information they need, distinguish valid information, and deal with long-term issues. Furthermore, researchers are just beginning to understand consequences of increased use of Health 2.0 technologies within the larger context of health care. In Part III, I discuss further how patients share experiential knowledge through online health communities and what design challenges have emerged in supporting personalized health care.

#### **SUMMARY**

In Part I, I clarified my use of the term "individualized problems" and discussed how collaborative tailoring and personalized medicine have addressed supporting individualized solutions. Both areas have several open issues that could be further examined. First, while getting help from peer-to-peer sharing of experiential knowledge is a promising area, finding, transferring, and reusing knowledge need further work. Second, few studies have addressed the temporal issues that emerge in looking at problems from a long-term perspective. Next in Part II and Part III, I further discuss how studies in collaborative help and patient

expertise sharing address issues in information reuse and domain specific challenges.

## Part II. Studies on Collaborative Help

In Part II, I examine how researchers studying collaborative help have explored the challenges of knowledge exchange among people and have considered informal communication as a critical source of knowledge. I discuss how one-shot-inquiry continues to be challenged, emphasizing de-centralized knowledge transfer and negotiated knowledge generation in collaborative help.

#### TRANSFERRING KNOWLEDGE AND ISSUES OF INFORMATION REUSE

Ongoing challenges in collaborative help include gaining access to information that may be embedded in a tacit dimension (Nonaka & von Krogh, 2009; Polanyi & Sen, 1966), recording shared information as a collective memory (Ackerman, 1993b), and confronting the issues of information reuse. In reusing information, how knowledge sharing gets influenced by status implications and how knowledge gathered from one context could be re-contextualized to work in another setting (Ackerman & Halverson, 2000) become increasingly challenging.

Polayni described tacit knowledge by saying "I shall consider human knowledge by starting from the fact that we can know more than we can tell."

(Polanyi & Sen, 1966)[pg.4] Researchers in the area characterized unrecognized knowledge or tacit knowledge in several ways: as difficult to write down or

formalize (Nonaka, Toyama, & Konno, 2000), as deeply embedded in individual mental models that tend to be taken for granted (Nonaka, 1991; Sternberg, 1994), as practical knowledge or "know-how" (Kogut & Zander, 1992; Sternberg, 1994), and as context specific and "deeply rooted in action and in an individual's commitment to a specific context—a craft or a profession, a particular technology or product market, or the activities of a work group or team" (Nonaka, 1991, p. 98).

Because of its context-specific, implicit, and ambiguous nature, tacit knowledge is recognized as a powerful resource that adds to an organization's competitive advantage. Barney (1991) suggested that the role of tacit knowledge in organizations is to provide resources that are "simultaneously valuable, rare, imperfectly imitable and imperfectly substitutable." Because tacit knowledge is ingrained in people or organizations, the knowledge is implicit and can be taken for granted (Nelson & Winter, 1982), making it difficult for outsiders to imitate or copy them. (Sobol & Lei, 1994) Badaracco (1991) states that, "unlike knowledge of a computer code or a chemical formula, it cannot be a clearly and completely communicated to someone else through words or other symbols" (p.82).

Researchers in organizational studies examined how tacit knowledge could be translated into objective knowledge—knowledge that is "readily written down, encoded, explained, or understood" (Sobol & Lei, 1994, p. 170). "Objective knowledge can be shared with others and is not specific or idiosyncratic to the firm or person possessing it" (Sobol & Lei, 1994, p. 170). This term grew out of the

recognition that tacit knowledge in the form of organizational resources could become "competency traps" (Levitt & March, 1988) or "core rigidities" (Leonard-Barton, 1992). From this perspective, tacit knowledge acts as hindrance to adaptation and innovation in the work environment.

On the other hand, Nonaka and Krogh (2009) discussed "knowledge conversion" as a process that allows tacit knowledge to become explicit, and explicit knowledge to become tacit. They discussed participation in social practices as a primary way in which tacit knowledge can be acquired by others.

Communities of practice (Wenger, 1999) is one example, where, as members continue to engage in social practices in a community setting, members will come to acquire shared practices that the community members learned and coconstructed over time. Tsoukas (2003) and Lave (1991) also suggested how one could acquire tacit knowledge through engaging in social practices under the guidance of more experienced people. As members participate in the social practice of, for instance, "piano playing," members come to "learn the "rules" of the performance, skills, values, belief, and norms that constitute their virtuous behavior and that shape their work" (Nonaka & von Krogh, 2009, p. 644).

While participating in a social practice may be the ideal way to transfer tacit knowledge, it may not be the most efficient way. Collaborative help systems might need more efficient ways, while organizational researchers have argued that research on knowledge management has overemphasized the codification of explicit knowledge, appropriate for databases and other traditional information

system solutions (Tuomi, 1999). Stenmark's (2001) work showed that tacit knowledge is not beyond the reach of information technologies. Stenmark demonstrated how intranet documents can make tacit organizational knowledge tangible and shared among organizational members while retaining its elusive nature.

Members' abstract concepts that lack explicit articulation can be translated into easily recognizable, adoptable, and mobile form of information through the process of step-by-step instructions, a set of numbers, or executable files that members can share. For instance, one of the findings in Nardi and Miller's (1990) work is how the visual format of spreadsheets for structuring and presenting data supports sharing domain knowledge among co-workers. Similarly, Ambrosini and Bowman (2002) showed how tacit knowledge of organizational members can be elicited through causal mapping and storytelling. Through the representation of tacit knowledge into visual and literary forms, they argued knowledge can be translated into tacit skills that can be imitated, substituted, and transferred. Furthermore, Friedrich et al. (2007) showed how tacit domain knowledge transfer can be facilitated through Joint Application Development workshops (Hughes & Cotterell 2006). In software development environments, clients' tacit domain knowledge is often not appropriately transferred to software developers, thereby generating faulty software products. The authors examined how workshops where developers get introduced to the clients' working environments to jointly extract requirements as well as develop new solutions to the proposed system can facilitate eliciting tacit domain knowledge. While the developers did not feel comfortable working outside of their own domain, the authors saw that the workshop can facilitate clients and developers to easily share tacit domain knowledge and together build common body of knowledge.

As such, converting tacit knowledge into various reusable forms of information helps to easily transfer knowledge. At the same time, objectification of tacit knowledge in itself would not fully address how elicited knowledge could be recorded for reuse and how recontextualization for individualized problems can happen. For instance, Ackerman (1993b) developed a system called Answer Garden (AG) for users to collaboratively gather and distill knowledge from various communication channels, such as email, Q&A threads, and online chat, to augment organizational memory. His later study on the use of AG (1996) illustrated an important issue around context. In order to have answers recorded and reused by more generalized audience, the detailed context has to be removed. This process of formalization produced repercussions for both authors and readers. This recontextualization problem was also observed during hotline help (Ackerman & Halverson, 1999). Sufficient amount of decontextualization had to happen in order for information to become a boundary object (Star and Griesemer, 1989) that could then be reused later. In order to reuse the memory, however, help agents had to combine memories of their own, other members of the group, and the organization as a whole. As long as some formalization processes and recording knowledge for later use are involved in sharing knowledge, the issue of decontextualization and

recontextualization observed from AG and hotline will continue to be a challenge for collaborative help systems.

Community-based help environment poses a new problem in information reuse, namely status implications (Sproull & Kiesler, 1991). While Sproull and Kiesler (1991) have suggested that computer mediated groups may equalize status differences due to reduced social cues, status maintenance has shown to be an important factor during collaborative help systems use. For instance, from a field study of AG, Ackerman (1998) revealed that the specifics of using AG were often governed by status implications in the interaction between experts and novices. Experts formalized their answers in order to maintain their "face" in the organization, which went against AG's original purpose of providing users with a place for quick and informal sharing of answers. Even though novices were given opportunities to access experts, novices did not want to bother experts. Ackerman suspected that the clear-cut separation between the roles of experts and novices in AG is leading to operational difficulties. This study shows the intricate connection between social implications and help interaction in organizational settings. This study further poses how collaborative help systems can utilize status maintenance practices, anonymity, re-categorization of expert levels, and organizational incentives as affordances for enhanced system use. The important lesson is: how knowledge is shared, captured, and reused relies on various social implications emerging from differentiated member roles.

One way to improve status implications problems is supporting users to discover appropriate expertise in community settings. In a field study of a mid-sized software company, McDonald and Ackerman (1998) observed how participants identified and selected expertise. Through one of the core concepts developed from the study, "escalation," the authors described finding expertise as a fluid and interwoven process of breakdowns in expert identification and selection, as well as repairs of the breakdowns. An implication here is that systems need to be able to support multiple iteration of tracking a problem and its state, both social and informational. Systems should remember what a user has previously attempted and give feedback accordingly. Then, supporting escalation, as a design implication, suggests ways to break apart expert levels depending on user preferences and situational needs, addressing challenges posed by Ackerman (1998) about expertnovice dichotomy.

Status implication can also work as positive incentives, as discussed in Ackerman's AG study (1998). In order to further examine how people can be motivated to give answers to help systems, Nam et al. (Nam, Ackerman, & Adamic, 2009) studied a Korean Q&A Website called Naver Knowledge-iN (KiN). There were a number of reasons why KiN users answered others' questions. One reason that KiN responders wanted to help others was because they do not have the knowledge, which is deeply rooted in Korean culture of helping others without expecting anything in return. Another reason why KiN responders responded to others was to promote their business or maintain their current understanding of a

topic. The finding that connects with status implication is that the responders wanted to maintain celebrity-like reputation by building up scores by providing high quality answers. Furthermore, KiN users had expectations for particular expertise that KiN responders would be able to give when asked, namely commonsense knowledge and current events. While the findings from this study pertain to situations where the level of expertise is low, challenges posed by the AG study about how to motivate people to answer questions still remain as topics that require a high level of expertise.

How people come to share their knowledge, ask for knowledge, and reuse knowledge is highly influenced by social dynamics that exist in each community. As seen from the research mentioned above, incentives to answer can vary greatly due to different categories of expertise existing in communities, levels of complexity in the topic, and cultural implications. Accordingly, in developing community-based help systems, research shows the importance of defining expert levels, rules for social interaction, and incorporation of cultural and topical differences for each community.

As seen from previous work in information reuse, knowledge sharing often happens during informal conversations. Below, I examine the "informal" component in communication playing out in collaborative help systems.

#### INFORMAL COMMUNICATION AS HELP

Informal communication is known as an important factor in productive work (Kraut, Fish, Root, & Chalfonte, 1990; Orr, 1996; Whittaker, Frolich, & Daly-Jones, 1994) and instruction in end-user computing (Cole, 1984; Lee, 1986; Scharer, 1983). It is helpful to share expertise with a small group of peers with similar organizational roles and connections to central help resources (Eveland, Blanchard, Brown, & Mattocks, 1994). Novices use information communication to get help that minimize the use of experts' scarce time (Berlin & Jeffries 1992).

Recognizing informal interactions as important part of help-giving, Bannon (1986) raised the issue of informal user help. His use of the term "over-the-shoulder" stressed the need for the examination of informal social interactions, such as the hints on computer use that new employees learn from sharing an office with an experienced employee (Bannon, 1986, p.403). Similarly, Twidale (2005) explored over-the-shoulder-learning (OTSL) as an informal way to learn computer use. By examining informal and spontaneous workplace help-giving interactions, Twidale made several design suggestions for integrating OTSL as a feature in software design. For example, he suggested capturing the historical context of novice interactions, supporting shared input devices, and adjusting screen resolutions to give more than one user an easier view of a computer screen. Over-the-shoulder learning. It attempts to couple informal learning by embedding informal learning features as part of computer systems. Such informal learning may

not only be pertinent to work environments. Forum discussions largely involve informal interactions, and Bannon and Twidale's work give implications to how observation of others' practices through informal conversations can potentially work as a help mechanism in other areas, such as patient support groups.

#### DE-CENTRALIZED KNOWLEDGE SHARING: LEARNING IN PRACTICE

Central to informal learning is reinterpretation of where expertise lies. Although the traditional means of knowledge transfer between experts and novices is helpful in certain contexts, the notions that knowledge can be easily transferred and that experts are at the center of the knowledge repository began to be challenged (Ackerman & Palen, 1996). Fischer (1999) discussed the case of multiple community-based knowledge systems (such as groups of citizen experts in urban planning and programmers) converging to collectively address a design problem. Each knowledge system possessed an incomplete understanding of different parts of the problem. He used Rittel's (1984) term "symmetry of ignorance" to explain mutual teaching and learning as the most important activities in resolving design problems. Brown and Duguid (1991) similarly criticized the separation between knowledge and practice and called for connecting working, learning, and innovating as a way to facilitate the transfer of tacit knowledge and practices. Thus, organizational members could become practitioners rather than making them learn about practices.

Additionally, prior work pointed at that expertise is dynamically and socially constructed. From a field study of Answer Garden, Ackerman (1994) found the dichotomy of experts and users problematic, because people's expertise and skills vary in many ways in different fields of knowledge. Accordingly, Ackerman and McDonald (1996) developed mechanisms that facilitate getting help from local helpers, such as colleagues, rather than directly routing unanswered questions to experts. Ackerman and Mandel (1999) also developed an application called ASSIST, which combines organizational memory with task performance for astrophysicists. They discussed the importance of "memory in the small" generated through tasks, allowing researchers to think beyond large-scale institutional memories in organizational support. Ackerman et al. (Ackerman, Pipek, & Wulf, 2002) contrasted memory-in-the-small and expertise sharing as part of socially situated processes with "information-in-the-large"—information that could be anticipated, documented, and controlled by management. Similarly, Bobrow and Whalen (2002) discussed generating knowledge from the "frontlines" with their stories on implementing Eureka, a knowledge aggregating application for technicians. The importance of the ability to gather knowledge emerging from the front lines, or customer knowledge, again emphasized the importance of embedded knowledge in practice. Together with the role of informal communication in expertise sharing, as discussed in the previous section, prior work in knowledge and information management continues to point to the

assertion that expertise sharing and practice cannot be separated and that expertise is dynamically and socially constructed.

As discussed so far, studies have examined ways in which learning happens as an ongoing and embedded social process rather than a one-shot dialogue (Ackerman & Palen, 1996; Fischer, Giaccardi, Eden, Sugimoto, & Ye, 2005; Twidale, 2005). This is especially important for supporting individualized situations where there are no one-size-fits-all solutions. Individualized problems require helpers to fully understand the context around the problem and suggest tailored solutions accordingly. Both helpers and those needing help may not be experts but have useful expertise, which can be uncovered in information communication, sharing of practices, or perhaps shared operationalized artifacts. Operationalized artifacts, mainly discussed as objectified tacit knowledge in the literature, can help facilitate information to be transferred and reused for various problem settings. The literature also points at that contextualization and tailoring are interactive processes between helpers and askers; thus, the learning process is an ongoing socially negotiated process. During this process, operationalized forms of experiences help to easily transfer context as well. My dissertation then builds on existing conversations around how learning happens with informal communication and help embedded within practice. This aligns well with Nonaka and von Krogh's (2009) discussion on knowledge conversion and communities of practice. The challenge however is how collaborative gathering of experiences can address individualized problems.

So far I examined collaborative help activities in the context of technical domains. As discussed previously in personalized medicine in Part I, such tailoring activity of solutions occurs not only in software engineering and technology use, but also in personal health. I will now discuss how collaborative help is used in the context of personal health, specifically in patients' sharing expertise. As I further examine how self-help groups and support groups can be implemented in online health communities, I show that patients' expertise sharing also is increasingly a collaborative help problem.

## Part III. Patient Expertise Sharing

In this part, I discuss what has been done in facilitating patients' experiential knowledge sharing through support groups, be they face-to-face or online, and what is left to be done. As seen from personalized medicine, health problems are increasingly individualized resulting in efforts being focused on how patients could receive more personalized health care (Fierz, 2004). In the medical community, information management approaches have also gained increased attention. For example, Tate et al. (Tate, Wing, & Winett, 2001) studied effectiveness of the Internet for delivering a behavioral weight loss program; Bacon et al. (Bacon, Condon, & Fernsler, 2000) studied how young widows receive support through Internet self-help groups; Ablon (1981) studied how social identity in being an outsider of the society is cured through support groups; and Preece et al. (Preece,

Ghozati, Rice, & Katz, 2001) discussed the importance of shared empathy in online communities.

As such, studies of self-help groups and support groups have often focused on empathic and emotional aspects of patient health, although with some notable exceptions. While empathy is known to provide critical basis for support in self-help groups, advise sharing among peer members produced clinically positive results. For instance, Edmunson et al. (Edmunson, Bedell, Archer, & Gordon, 1982) compared two support groups—patient-led versus professionally supervised—of psychiatric patients. They found patient-led group had much shorter average hospital stays (seven days versus 25 days) than professionally supervised group and a higher percentage of members than non-members could function with no help with the mental health system. This finding can also be explained by a study that examined a resident run advice sharing center (McGrath, 1975). One of the reasons the author found why the resident run advice sharing center was successful was because of the informal and friendly atmosphere that non-professionals could freely share relevant life experience to one another.

Despite such argued importance in peer-based experiential knowledge sharing (Borkman, 1976), researchers are dealing with ongoing debates on validity of patient-generated health information, especially those shared online (Eysenbach, 2002; Eysenbach & Jadad, 2001; Murray et al., 2003). Only recently researchers are actively beginning to examine how patient expertise sharing could be

facilitated (Ancker et al., 2009; Civan, 2009). Below, I discuss existing work on patient expertise as help and what further work needs to be done.

#### RECOGNIZING PATIENT EXPERTISE AS HELP

In her dissertation work, Civan (2009) distinguished patient expertise from clinical expertise in that the former is gained from coping with day-to-day personal health issues and trial and error within one's own life experiences. Patients offer expertise and advice on managing responsibilities and activities associated with work, friends, family, and the home, while clinical expertise focuses on the delivery system of healthcare, bio-medical research, and the work of health professionals. Civan builds upon Borkman's (1976) analysis of self-help groups as a method of gaining experiential knowledge as opposed to professional knowledge. Borkman defined self-help groups as "a human service-oriented voluntary association made up of persons who share a common problem and who band together to resolve the problem through their mutual efforts" (p. 445).

Even before the age of online social media, self-help groups played a critical role in helping patients share experiential knowledge. Borkman (1976) defined experiential knowledge as "truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others." Borkman's distinction between experiential knowledge and expert (professional) knowledge can be seen in the current concerns in online health communities about the lack of professionalism

(Yablonsky, 1965), and the validity of the information being shared. Wisdom and know-how are gained from personal participation in a group rather than as "isolated, unorganized bits of facts and feelings upon which a person has not reflected" (Borkman, 1976). Borkman then made the distinction between "experiential expertise" and "experiential knowledge" in that experiential expertise refers to "competence or skill in handling or resolving a problem through the use of one's own experience," whereas experiential knowledge refers to "truth based on personal experience with a phenomenon."

Due to the role of self-help groups as a way to share the experiential knowledge and expertise of patients, self-help groups were discussed as sources of patient empowerment. Humphries and Rappaport (1994) noted that "one of the empowering features of self-help groups is that members experience autonomy, control of the group, and a sense that they are experts on their problem." The success of face-to-face support groups can be seen in the creation of Alcoholics Anonymous (Burnett & Buerkle, 2004). The success of this group led to support groups on the topics of weight, overeating, and sexual addiction. Self-help communities for addictions and other diseases evolve on the Internet as well (Frost & Massagli, 2008; Maloney-Krichmar & Preece, 2005). Online support groups offer the advantages of anonymity and privacy, immediate/delayed response, and recording of transmissions as compared to physical support groups (Sparks, 1992).

support and self-disclosure for persons who are not likely to use traditional forms of helping (Salem, Bogat, & Reid, 1997).

Despite the known success of support groups as aids to patient empowerment, online support groups have been criticized on the basis of the credibility of the information being shared. This is similar to Borkman's observation about self-help groups and their reputation of lacking professionalism. One study found that the accuracy of information in medical support groups is inaccurate and misleading (Culver, Gerr, & Frumkin, 1997). This negative view of online medical support groups can be seen in other studies on the credibility of medical information online (Bates, Romina, Ahmed, & Hopson, 2006; Lebow, 1998; Rains & Karmikel, 2009; Sundin & Francke, 2009).

Whether medical information presented online by support groups is credible ignores an important aspect of the role online support groups play. As discussed by Civan (2009), patients develop significant expertise when encountering day-to-day problems. For example, finding the best place to use a testing site for a glucose meter can affect the accuracy of meter readings. Patients can share experiential knowledge (or expertise), for instance, about strategies for using glucose meters to achieve the most accurate results, especially when talking to peer patients who have used the meter for a long period of time. This type of knowledge exchange between newcomers and veterans has been addressed as the most critical element in the learning process of newcomers (Powell, 1990). As a result, more and more patients turn to online communities for health information and social support

offered those with experiential knowledge (Fox & Jones, 2009; Rimer et al., 2005). Studies found that an online support community functions as a place of support, compassion, and trust (Preece & Ghozati, 2001; Preece & Maloney-Krichmar, 2005). Newman et al. (Newman, Lauterbach, Munson, Resnick, & Morris, 2011) studied how people can use online health communities and existing social network sites, such as Facebook, to meet their health needs. They found that people receive emotional support, motivation, accountability, and advice from people in these spaces, but that the need to balance sharing information with the desire to manage one's impression can make meeting these goals challenging.

The particular focus in the literature so far has been on patient-generated information and the social relationships of patients. There are various other research opportunities in patient-driven health care, such as health social networks and consumer personalized medicine (Swan, 2009), and quantified self-tracking (Li, Dey, & Forlizzi, 2010). These all serve the purpose of improving information flow, transparency, customization, collaboration, and patient choice. This literature has shown that support groups and online communities are important opportunities for patient empowerment and personalized health care. Support groups and online health communities are places that allow patients to share experiences and information, grow social networks, and collaborate with other patients to build emotional and practical support. In this way, patient health communities become a place that deals with problems in collaborative help.

# ONLINE HEALTH COMMUNITIES DEALING WITH COLLABORATIVE HELP PROBLEMS

As online health communities grow, canonical challenges in collaborative help, such as information overload and finding the right expertise (Ackerman, 1993a; Ackerman & Halverson, 2004; Ackerman, Pipek, & Wulf, 2002; Zhang et al., 2007) arise as important research questions in patient expertise sharing as well. For instance, systems designed to help patients find professional medical expertise have benefited from getting information about health status or treatment options from gathering peer patients' experiences (Johannsen & Kensing, 2005). However, ways that systems help patients share expertise can be improved are still underexplored areas, especially since it has not been long since the recognition of the importance of sharing among patients for empowerment.

The emphasis on de-centralized expertise sharing—like the bootstrapping process or the process of sharing bottom-up expertise process in the collaborative help processes of organizations (Ackerman, Pipek, Wulf, & Fitzpatrick, 2002)—continues to evolve in the area of personal health. Internet-based tools, such as blogs, wikis, online communities, and web forums provide avenues for patients to share experiential knowledge and expertise about the practical management of side effects of medication and treatment experiences (Civan & Pratt, 2007). Despite the increasing community-based health information systems (Adams, 2010; Elkin, 2008; Sarasohn-Kahn, 2008), in peer-based help systems, little has been explored about canonical collaborative help problems, such as finding the right expertise,

recording information, and organizing and managing information in knowledge repositories.

Civan et al. (Civan et al., 2009) studied where patients find their help in everyday life – friends, family, clinic waiting rooms, internet, etc.--and how this finding can be applied to redesigning online communities for patients' expertise sharing. More specifically, they studied design implications for locating the right patient expertise so that patients can reduce the time that they spend during a bricolage learning process (Levi-Strauss, 1966; Turkle & Papert, 1992). The bricolage learning approach refers to the lengthy and iterative process of making gathered expertise one's own. This approach is portrayed as a time consuming process that produces incomplete knowledge. However, at the same time it can be seen as a critical process in finding useful personalized knowledge. Like general collaborative help problems, the ways of facilitating individualized help solutions in health-related experiences are also an under-explored area.

To address the need expressed in the literature about incorporating what we know about collaborative help to patient expertise sharing, my dissertation examines how the daily practices, experiences, and skills of patients can be shared with others to support individualized solutions to problems. This examination requires an understanding of the process by which people learn from one another. That is, how knowledge is constructed through social interaction, what kinds of social interaction facilitate the learning process, and how information gets shared need to be understood. Social constructivism and symbolic interactionism, the

fields that attempt to understand how people create meanings in their everyday lives through social interaction, are most suited for examining these questions.

# Part IV. Building Blocks: Social Constructivism and Symbolic Interactionism

In this section, I discuss my perspectives, and tools for analysis. I chose to use social constructivism and symbolic interactionism to form the theoretical framework for a number of reasons. Their perspectives allow me to see the learner as an active constructor of knowledge, rather than as a passive individual that receives structured information. These theories share perspectives on social interaction as utmost activities from which people gain knowledge. Both theories influenced the development of "communities of practice" (Wenger, 1999), "trajectory" (Strauss, 1993), and "boundary objects" (Star & Griesemer, 1989), which have been essential for me in my understanding of the formation of communities and the knowledge generation process, and in how information gets reused. Accordingly, these theories provide firm theoretical ground for my examination of peer-to-peer help in user communities and patient-driven health care in self-help support groups. I use these building blocks for the chapters to come.

I begin with a discussion of Vygotskian social constructivism, the basis of communities of practice. Social constructivism is similar to symbolic interactionism in that people's actions are decided by the meanings resulting from social

interaction. The symbolic interactionist perspective is also helpful to understand the social phenomena of learning processes in social activity. I discuss three main concepts from Vygotskian social constructivism: material objects embedded in cultural activities, historical analysis as a critical process for understanding human activity, and that cultural-historical context is embedded in people's everyday lives. I continue the discussion on social constructivism with an examination of the community of practice model, which provides a practical background for an analysis of communities.

My discussion on symbolic interactionism will focus on the concept of Strauss' trajectory (1993) and Bowker and Star's boundary objects (1999). While communities of practice as a theory provides the background for understanding members' community interactions, trajectory and boundary objects present an understanding of collaborative activities on information sharing, knowledge transfer, and communication.

SOCIAL CONSTRUCTIVISM: MATERIAL OBJECTS, HISTORY, AND CULTURAL-HISTORICAL CONTEXT IN EVERYDAY LIVES

In this section, I briefly describe the social constructivist viewpoint regarding how people learn to act the way they do. I describe how social constructivists view the interaction of the individual with the external world and how the cultural and the historical environment affect the generation of internalized knowledge. I conclude the section with a discussion of material objects, history, and cultural-

historical context in everyday lives—that will build the theoretical framework for the analysis to come in later chapters.

Social constructivism (Vygotski , Cole, & John-Steiner, 1978) views the learner as an active constructor of knowledge. Representative research in this field would be the work on communities of practice (CoP), in which members share interests and collaboratively construct knowledge (Wenger, 1999). This constructivist view aligns well with the role that peer collaborative help plays in adaptive practices in that it provides a framework of thought for how learning is an iterative and diverging/converging process.

Rooted in education and psychology, the origin of social constructivism lies in Vygotsky's work<sup>3</sup>. Vygotsky (1987) attempted to explain higher psychological processes that influenced international scholars from various fields. His basic idea is that individuals' minds develop through social interaction and mediated activities that are centered on the use of speech. Vygotsky gave an example of how a child, through the interactions with her caregiver, develops the use of pointing gesture to convey meaning by grasping an object. When the child tries to grasp an object out of her reach, her hands stretch forward toward the object. At this initial stage, the pointing gesture is nothing more than pointing to an object for the child. However, once the caregiver interprets the gesture (which is also largely influenced by the

<sup>&</sup>lt;sup>3</sup> Also known as social learning theory, sociocultural theory, socio-cultural theory, cultural-historical theory, socio-cultural-historical theory: see (Wertsch, Rio, & Alvarez, 1995) for further discussions on the terminology used to describe the Vygotskian approach.

society she is in) and reacts accordingly, the child starts to learn the meaning of the pointing gesture. In this way, the meaning that society has given to a gesture is internalized by the child. This idea contests the idea that behaviors develop solely out of an individual's mental processes (Vygotsky, 1987).

Vygotsky further discussed the process of internalization in learning with the concept of the zone of proximal development (ZPD). This concept introduced a new understanding of the relationship between learning and development. He defined ZPD as "the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance or in collaboration with more capable peers" (Vygotsky, 1987). ZPD helped to develop the idea of scaffolding in education, a way to scale a problem to an appropriate zone so that a child will be able to solve problem. Also, Vygotsky explained the process of gradual accumulation of knowledge through the continuous exchange between existing knowledge and new knowledge to be learned.

Peer scaffolding has been discussed in various domains, specifically in giving implications to designing technologies that would help people learn from one another. Examples include Fishman's (2003, 2007) work on linking on-line video and curriculum to leverage community knowledge; Teasley et al.'s (Teasley et al., 2008) discussion of "cognitive convergence" as a concept that describes various underlying mechanisms that determine successful collaboration and individual learning outcomes; Lave and Wenger's (1991) community of practice,

widely utilized for studies in computer supported collaborative learning (Koschmann, 1996).

Vygotsky and his followers in cultural-historical activity theory accepted three core values in social learning, which provide insights into supporting better collaborative help. First is the centrality of mediation (Cole, 2005). In examining how a child adapts to the external world, Luria and Wertsch (1981) noted that "humans modify material objects as a means of regulating their interactions with each other and the world." The material objects here can be interpreted as tools for collaborative help that allow learners and helpers share expertise, and thus adapt to their changing environments. I further discuss these material objects through the configuration artifacts and operationalized experiences of the MythTV user community and the diabetes patient support groups. The second core value is the importance of genetic (historical) analysis. Dnilchenko (1993) said that, "to understand behavior, one must understand the history of behavior." As discussed earlier, one of the challenges in supporting collaborative help in emerging environments is making help an ongoing and embedded social process rather than a one-time dialogue. The support of historical understanding about one's experience is a critical challenge in allowing situated knowledge to be shared amongst helpers and learners. This is discussed in my analysis of the trajectory alignment work in both the MythTV user community and the diabetes patient support groups. The last core value is the grounding of culturally-organized activity. Leontiev (1981) noted that "from a cultural-historical perspective, the

natural laboratory for the study of the role of culture in human development is in the everyday activities of people." Dealing with emerging problems in individualized environments is an everyday activity, in which current practices are maintained while solution to new problems are developed through ad-hoc workarounds. The capture of such day-to-day activities is yet another challenge in supporting collaborative help for individualized problems.

Having in mind the three major take-aways from social constructivist perspectives, I now turn to more recent development of social constructivist paradigm frequently used in computer supported collaborative work.

#### **COMMUNITIES OF PRACTICE**

The more contemporary concept that follows the social constructivist's line of research is communities of practice (CoP) (Lave & Wenger, 1998). Bjorke (2004) described how CoP is informed by Vygotsky's work, mainly ZPD, in that it fosters member-to-member learning in an informal setting and as part of everyday experiences. The experts scaffold the learning processes for the newcomers so that:

[...] learners can operate in the area beyond their immediate capability, in a context of guided practice. Having achieved mastery, they become able to operate independently and can take the next step forward, again into territory just beyond their immediate independent capability (Thorpe, 2002).

The newcomers bring their previous knowledge and experience (the foundational learning concept in Vygotsky's constructivism) and contribute to the development

of the community "in the so-called zones of proximal development, where the different participants in the community interact and learn" (Bjorke, 2004, p. 2).

Lave and Wenger's (1998) definition of CoP is "groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly." The core three elements that distinguish CoP from the general notion of communities include the domain, the community, and the practice.

A CoP is not merely a social network of people but members who share a common domain of interest. Membership implies a commitment to the domain and a shared competence that distinguishes members from other people. The domain may not necessarily have "expertise" that is recognized outside the community. Wenger (1999) gives an example of a youth gang, a group that survives on the streets through collective action, which may not be valued by people outside that community. The community in CoP is defined as a community that consists of members that engage in joint activities and discussions, share information, and help one another. It would not be a CoP if the members did not interact. Everyday interaction is not required as long as the members can learn together through interactions. The practice element of CoP is an important element that distinguishes a group of people, for example a group that likes Star Trek, from a group of people who develop a shared repertoire of resources such as experiences, stories, tools, and ways of addressing reoccurring problems.

A few examples of the ways CoPs develop include the following: problem solving, requests for information, experience seeking, asset reuse, coordination and

synergy, developments discussions, documentation projects, visits, mapping knowledge and gap identification (Wenger, McDermott, & Snyder, 2002). These examples were all observed in the MythTV user community and the diabetes support groups, often as a form of help in dealing with individualized problems.

The scope of fields to which CoP has been applied is quite large. The founding work on CoP began with Goan tailors and Yucatan midwives (Lave, 1991; Lave & Wenger, 1991, 1998). The application of CoP further expanded to studying groups of engineers and office workers at Xerox (Brown & Duguid, 1991; Orr, 1990; Orr, 1996; Suchman & Trigg, 1986), bread-making machine design at Matsushita Electrical Company (Nonaka & Takeuchi, 1995), and flute crafting (Cook & Brown, 1999; Cook & Yanow, 1993). Additionally, CoP has been discussed in health care domains as a way to facilitate continuing professional development for physicians (Parboosingh, 2002) and to help patients to be empowered (Winkelman & Choo, 2003). CoP has been also used as a guideline for building online support and learning communities (Hansen, 2007; Resnick, Levine, & Teasley, 1996).

Researchers have contributed a wide variety of interpretations of CoP as the terms "community" and "practice" can be ambiguous (Cox, 2005; Li et al., 2009; Swan, Scarbrough, & Robertson, 2002). Duguid (2005) pointed to the seductive character of the word community, which Williams (1976) described as a "warmly persuasive word" (p.66). As Osterlund and Carlile (2005) pointed out, most citations of Lave and Wenger have utilized CoP even in cases where practice was

not present. Duguid (2005) attempted to re-emphasize the role of social and tacit dimensions of knowledge in CoP while drawing the boundary of how far CoP could be applied.

The limitations of CoP have been discussed from various viewpoints. Brown and Duguid (2001) pointed out the incompleteness of CoP to support the knowledge flows across communities, which constrained innovation at the wider organizational level. This could be problematic for "cultivating radical innovations that often occur at the interstices across established groups and work activities" (Blackler, 1995). CoP has been portrayed as a plausible solution to many classic knowledge management problems (Cox, 2005; Papargyris & Poulymenakou, 2003) in that CoP groups act as a social instrument to create, share and steward knowledge. However, Cox (2005) also pointed out concerns with CoP for its inheritance of hierarchical relations from the wider organization and its likelihood of developing its own internal politics, its divergence into directions that may be unhelpful for the wider organization, its lack of immediate, predictable or measurable outcomes and the challenges it creates in the community.

As a result, CoP and its use in organizational knowledge management has been widely criticized for its multiple versions of interpretations and its applicability in cultivating innovation and appropriate management. Liedtka (2000), for example, viewed CoP as a way of empowering organizational members through deeper engagement in work and giving greater freedom. However, from

the management point of views CoP has been viewed as encouraging questions of control and empowerment in management (Watson, 2002).

In health domains, the inherent assumptions of CoP were that the members are "naturally collegial, honest, and respectful of each other, and that they put aside their personal agendas for the common good" (Li et al., 2009). In reality, in non-apprenticeship CoPs, members may not necessarily move beyond the position of peripheral participation to contributors and remain learners or observers. In this case, the learning and negotiation of meaning continues to be a reflection of the dominant source of power. As shown in Gabbay et al.'s report (Gabbay et al., 2003) on multi-stakeholder collaboration in the health sector that develops policies for elder care, the group discussion was often dominated by the opinion and agenda of only a few members of the group despite the best efforts of the facilitator (an experienced librarian).

In the MythTV user community and diabetes patient support groups, I discuss how the newcomers' roles are not confined to trainees or passive learners. Rather, they are active learners that produce exceptional cases and underaddressed problems that continue to challenge and revise dominant knowledge that is being negotiated by the regulars. Accordingly, unlike the existing model of CoP discussed through the concept of "legitimate peripheral participation," newcomers do not necessarily always participate at the periphery, but participate at the center of where the community knowledge is being built. Still, CoP will be useful to apply to my specific inquiry, namely for engaging in the questions on: the

social relations of the members that encourage learning; the common knowledge enterprise being built by the community; and the negotiation of meanings that result in the social construction of new knowledge toward emerging individualized problems.

As I acknowledge the traditions of the constructivist approach to learning, it is my goal to discover further social mechanisms (beyond transformation of memberships) that allow individualized problems to be interpreted, analyzed, and solved through negotiations between the members. In this work, concepts of social worlds, trajectory and boundary objects in symbolic interactionism are useful resources.

#### SYMBOLIC INTERACTIONISM: SOCIAL WORLDS AND TRAJECTORIES

"[W]e are confronting a universe marked by tremendous fluidity; it won't and can't stand still. It is a universe where fragmentation, splintering, and disappearance are the mirror images of appearance, emergence, and coalescence. This is a universe where nothing is strictly determined. Its phenomena should be partly determinable via naturalistic analysis, including the phenomenon of men [and women] participating in the construction of the structures which shape their lives." A. Strauss, "A Social World Perspective" (Strauss, 1978)

While constructivism is rooted in education as an explanation for how people learn, symbolic interactionism is rooted in sociology and social psychology. Symbolic interactionists focus on interaction in micro-social contexts as a method to analyze how people think and act (Blumer, 1986; Mead, 1934). Symbolic interactionists argue that meanings are created through social interaction. Based on

the meanings people ascribe to things or actions, people act accordingly. Mead (1934) and Blumer (1986) were mostly concerned with the sociology of the everyday experiences (as is Garfinkel (1984) and Goffman (1959), which is useful for uncovering important domains in designing everyday personal technology. Rather than focusing on examining an isolated event or task, Symbolic interactionism (SI) focuses on the discovery of how a problem is interwoven with the many aspects of everyday lives, such as who we are, what we do for a living, what tools we use, and how we use those tools. Most importantly, SI is concerned with whom we interact, how we interact, and what kinds of meanings we construct from interactactions with others.

Strauss (1993) described his "assumptions" that work as the basis for his theory of action, namely that "meanings are aspects of interaction, and are related to others within systems of meanings" (p. 26) and "the external world is a symbolic representation, a 'symbolic universe'" (p. 27). The central ideas of SI are that where external or internal influences affect the outcome of an action meaning is created through the social interaction of the members. He then discussed the central research problems or thrusts of the symbolic interactionists' sociological inquiry: the nature of work, the embodied character and temporality of action, symbolization and representation, the routine grounds of action, plurality and difference ("social worlds" and "arenas"), and the problem of social order (as "negotiated order" and "structural ordering").

Social worlds, "a fundamental building block(s) of collective action" (Clarke, 1991, p. 131), are interactive units that emerge when a group of individuals strive to act in some collective way, often through coordination of separate perspectives and resources sharing. Social worlds have "at least one primary activity (along with related activities), ... sites where activities occur ... [and] technology (inherited or innovative means of carrying out the social world's activities)" (Strauss, 1978).

Social worlds share common ideas with CoP in that they are a unit in which members create shared meanings in the process of pursuing goals. The notion of sub-worlds and the ability for an individual to participate in multiple social worlds align well with membership in multiple CoPs. Membership in social worlds is bounded by effective communication or action rather than formal static structures such as geography. CoPs are also bounded not through formal structures, but rather malleable informal structures or common practices that can be anything from knitting sweaters to creating health care policies.

The social worlds perspective differs from CoP with regards to the concept of "arena." This new locus of analysis—arena—allows us not only to understand a single social world as an isolated unit, but also to engage in studying very different types of worlds simultaneously. In the essays in honor of Anselm Strauss, Clarke (1991) noted, "arena analysis permits the researcher to study relations within, between, and across the collective entities without having to make a priori judgment calls about the nature of their relationships (hierarchical, equal, dependent, independent, etc)" (p. 138). The concept of arena that explains

relationships between multiple social worlds is an answer to the critique made of CoPs for its lack of analysis about the intersections among CoPs as well as the intersections between a CoP and the external world. Within a CoP, legitimate peripheral participation (LPP) is described as a process of learning defined by how a newcomer learns what old-timers know. While both are ways for members to create order for how they interpret the world in which they are acting and how they maintain meaning, LPP seems less dynamic and structured than what negotiated order proposes.

Strauss (Strauss, 1993) also introduced the concept of "trajectory."

Trajectory explains the meaning creation process as a continual one that constantly reflects the learning process. It also describes how a newcomer becomes a member of a social world. This very process of the meaning making process, represented through a trajectory of one's being in a social world, becomes a useful analytical tool in understanding the interactants that participate in constructing the social order. For instance, Ackerman and Halverson (1999) examined trajectories as paths that helpers develop in making assumptions and projecting future consequences.

The authors examined how, during hotline workers' collaborative work practice, workers make incorrect future projection and how this results in workflow breakdown. Greenberg (2001) reviewed trajectories as part of context as a dynamic construct. He suggested practical implications for context-aware applications, mostly in emphasizing challenges in a given event's temporal context. In both

Ackerman and Halverson and Greenberg's studies, trajectories played as tools for work coordination and rich contextualization.

In the field of learning sciences, Strauss' trajectory is used to understand multiple social institutions responsible for shaping one's learning process and the historical context during the learning process. For instance, Mercer (2008) described learning as "not simply matter of accumulating information; it involves the gradual induction of students into new perspectives on the world, the development of new problem-solving skills and new ways of using language for representing knowledge and making sense of experience." Mercer then argued the importance of temporal analysis in classroom learning. Similarly, Gan and Zhu (2007) examined a learner's trajectory as a helpful resource to understand knowledge building process of virtual learning communities. The authors examined how social identification and academic learning are intertwined in study learners. Their notion of trajectory explains how contexts travel to other situations (from school into local micro-community and vice versa) during learners' knowledge building process. Similarly, Leander et al. (Leander, Phillips, & Taylor, 2010) discussed "place and learning trajectories" to inquire "how resources, people, and places are brought into relationships through networks and circulations." The authors further asked, as we live in a "networked society," (Castells, 2000) a question of how people and all manner of resources for learning get configured and reconfigured across space and time, creating opportunities for learning.

Strauss' original use of trajectories comes from the chronic illness trajectory framework (Strauss & Fagerhaugh, 1997). Illness trajectory framework goes beyond describing patients' illness trajectories as phases that lead to dying. The framework examines the role of various stakeholders and their coordination during the process of managing a patient's disease over time. Rather than limiting the use of trajectory as a concept to paths that describe historical and temporal changes of events, how one's trajectory meets others' trajectories and how multiple stakeholders do coordination work in one's trajectory (Ackerman & Halverson, 1999; Huh et al., 2011) are how I envision utilizing trajectory in my work.

While I take in constructivist approach of situated learning (such as CoP), Strauss' theory of action allows further observation of the more individualized and free-form social dynamics that govern how the MythTV users and diabetes patients solve individualized problems through communities' help. Social interaction occurs in a world that is "complex, often ambiguous, evincing constant change as well as periods of permanence, where action itself although routine today may be problematic tomorrow; where answers become questionable and questions produce ultimately questioned answers" (Strauss, 1978, p. 19). Strauss' theory of action helps me maneuver the space of individualized problems in technical environments where things change at a rapid pace and uncommon and rare problems emerge.

### **BOUNDARY OBJECTS**

Consequent developments in symbolic interactionism include Star and Griesemer's (1989) boundary objects. Boundary objects are defined as:

mobjects which are both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual-site use. They may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable means of translation. The creation and management of boundary objects is key in developing and maintaining coherence across intersecting social worlds (Star & Griesemer, 1989).

Boundary objects help to explain how communication is facilitated across multiple social worlds, how coordination of people's interpretations gets facilitated, and how conceptual or material objects embody multiple meanings that can adapt to various social environments.

The concept of boundary objects has been further developed by other researchers from various domains. Chrisman (1999) described how various stakeholders in geographic information systems used the concept of boundary object to help with inconsistent interpretations of wetland mapping. For his study participants, boundary objects served as a "common point of reference" for conversations that allowed the conclusion to "agree to disagree." Fischer and Reeves (1995) discussed people's use of boundary objects as "means of coordination and alignment," with an example of how story cards are used to align the needs of business experts with what programmers built. Furthermore, Fischer

and Reeves described how the story cards help to translate business operations and to smooth the process of explanation. Boundary objects were also shown to be ways to satisfy different concerns simultaneously. As noted in the quote by Star and Griesemer (1989), boundary objects are plastic enough to be adapted and adjusted as needed. Boundary objects are "working arrangements" that will not appeal as standards or static notions. Ackerman and Halverson (1999) also studied boundary objects as an aid to organizational memory. They saw employee records serving as boundary objects that help to organize work arrangements in hotline help.

Bowker and Star (1999) described several characteristics and roles of boundary objects: Boundary objects contain multiple meanings depending on who uses them; Boundary objects become aids for communication, work coordination, and alignment in understanding. They are supportive aids, not necessarily the main solution. This is because boundary objects are always incomplete as the meanings change dynamically and the context in which a boundary object was originally created would not surface or be found by its users: The role of boundary objects is to facilitate, but not necessarily to solve problems; The complete history of how it was used would not be found if it is not within the interest of its users.

Boundary objects are largely conceptual or material objects that transform their meaning based on a situation at a given point in time (Lutters & Ackerman, 2002). Their temporality has been under-explored. Other than Lutters and Ackerman (2002), I know of no other work discussing temporality or transparency in boundary objects. Below, through the analysis of how the MythTV user

community used configuration artifacts, I will extend boundary objects to include the notions of transparency and temporality. I want to further question how boundary objects and their historical meanings, in connection with Strauss' trajectory, play important roles in supporting individualized problems.

## Part V. Conclusion

In this chapter, I placed my research problem—supporting collaborative help for individualized problems—within the existing conversations in collaborative help and patient expertise sharing. I also discussed the theoretical foundations that my dissertation builds upon—social worlds, trajectories, and boundary objects. I discussed the challenges in transferring tacit knowledge, how informal communication becomes a source of knowledge, and how learning is happening in practice. I also discussed how patients' expertise sharing, supported by increasing interest in patient-driven health care in the medical community, is continuing to become a collaborative help problem. Through these conversations, I was able to examine various challenges in knowledge transfer, system solutions, and the remaining problems in the area of collaborative help both in technical and patient health areas. Reviewing the literature shows that more efforts are needed to support help interactions in communities as they seek to generate, through shared personal experiences, meaningful solutions to individualized problems. More importantly, I discussed the need for us to further examine temporal dimensions in

sharing experiences and how temporal dimensions can become helpful resource for community-based learning.

In order to support collaborative help systems to find solutions to individualized problems, the open questions are:

- How individuals' strategies for tailoring solutions for individualized problems can be easily transferred between people
- How rich descriptions of context can be conveyed during help interaction
- How existing solutions can be reused for individualized purposes.

Throughout the findings and discussion chapters, I describe how knowledge encapsulated in mobile forms of information and maintenance trajectories play important roles in addressing the issues of information reuse and contextualization.

Before I move onto the findings, I first explain how I studied the two communities—the MythTV user community and diabetes patient support groups.

## **Chapter 3**

## Method and More on the Research Sites

This chapter serves the purpose of describing the research design and method used to conduct research for the dissertation. I also focus on describing the research sites because the method and rationale for conducting research at each site is closely tied to the characteristics of each site. The site descriptions will help to contextualize the findings as we move through the next two chapters. My methods for studying the MythTV user community and diabetes patient support groups include interviews, field observations, and content analysis using an interpretivist approach (Strauss & Corbin, 1990). I further describe the interpretivist approach and how it influenced my research process. This chapter contains four sections: 1) Symbolic Interactionism and ethnography; 2) a research design rationale for how I came to my current research design; 3) the MythTV user community study and my methods for studying the community; 4) the Diabetes patient support groups study and my methods for studying the groups; and 5) a summary and the goal of my research.

## Symbolic Interactionism and Ethnography

As mentioned in Chapter 2, the analytical tools I used for research are borrowed from social constructivist and symbolic interactionist perspectives. Social constructivism allows me to build on knowledge about people's learning processes through cultural-historical context and social interaction with the external world. At the same time, symbolic interactionism provides me with a lens to view and study the world, specifically the practical knowledge that people gain in their everyday lives. These tools are well-suited for examining my inquiry for how lay people incorporate learning experiences into building and maintaining everyday practices. More specifically, the interactionist emphasis on micro-sociological (face-to-face) interaction, individual interpretation, and negotiation of meanings are useful in examining how the participants in both studies solve individualized problems through peer-to-peer interaction.

In the interactionist way, there are no set rules for conducting ethnographic research. Herbert Blumer (1997) perhaps gives the most forthright definition of the symbolic interactionist approach:

The symbolic interactionist approach rests upon the premise that human action takes place always in a situation that confronts the actor and that the actor acts on the basis of defining this situation that confronts him.

Blumer's account relies heavily on the situational meanings that actors decide themselves on a day-to-day basis. Thus research questions become interpretive and experiential. Baker (1973) once reflected on the experiential account of the real world:

The real world [is] the experience of actual men and women and not abbreviated and shorthand descriptions of it that we call knowledge (p. 255)

Rock (2001) emphasized the reflective nature of consciousness, where consciousness can bridge the divide between known and knowing as it unfolds thoughts into a single dialectic. This is similar to what Vygotsky explained with "internalization" where people constantly add meaning from external events to what they already know about the world. The reflection about what people already know plays a central part in the process of learning about the world.

The symbolic interactionist takes a situated, tentative, empirical, experiential, and reflective approach to people's practices and provides several key perspectives that maybe useful for observing research sites. This is specifically the case for inquiries that require an understanding of knowledge sharing practices in person-to-person interaction. The research should focus on the process where "acts, objects, and people have evolving and intertwined local identities that may not be revealed at the outset or to an outsider" (Rock, 2001) grounded in field observations (Baszanger & Dodier, 1997) rather than statistics. The perspective of grounding findings on data and not on researcher presuppositions has been extensively explored in grounded theory (e.g., Strauss & Corbin, 1990). Observed activities create interpretive strands and layers to reconstruct the actor's world-

view, "not in a lordly way but faithful to the everyday life of the subject" (Rock, 2001).

An interactionist perspective also allows openness toward serendipity, creativity, and old-fashioned luck (Fetterman, 1989). This is again in contrast to an empiricist approach that is orderly, standardized, and comparable. The interactionists look to uncertainty and confusion when the observer initially goes into the field. These uncertainties will require continual unpacking as researchers actively become "interactive and creative, selective and interpretive, and illuminate patches of the world around in giving meaning and suggesting further paths of enquiry" (Rock, 2001, p. 30). It is also encouraged to reformulate questions as the interlaced processes of research, data collection, and interpretation advance (Okeley, 1994).

The interactionist view advises researchers to be doubtful about standardization and the comparison of social phenomenon. Rock (Rock, 2001) argued that:

Knowledge is necessarily provisional, bound temporally and contextually, shaped both by the particular purposes and experiences of the observer, and by the encounters which he or she had with particular others in the field. (p.31)

Thus the information gathered about a research site needs to encompass the context of where it came from and retain its original meaning as when it first emerged. The information should also be grounded in field notes or participants' direct accounts and quotes.

Procedure-wise, there are several key activities and roles that are helpful for researchers to use in their fieldwork. First, conducting participant observation gives researchers the ability to enter the symbolic lifeworld of others and to hear and see a little of the subjects' social life (Geer, 1964; Liebow, 1993). The role of the observer is to come as an outsider who does not know the rules or who does not understand what is going on in the field. The role of the observer is to ask questions that the subjects would not normally offer or think about because they take certain things for granted. At the same time, the researcher should attempt to remain alienated, seemingly as a stranger who does not fit in and does not understand the situation.

In the case of studying MythTV users and diabetes patients, my ability to observe the participants acting as a stranger was limited in many ways. For the MythTV user community, I did not have the technical expertise of the users nor did I have the same motivation to do what they did. As a result, the language they used, and the motivations and triggers they relied upon for performing their daily work, did not come across as what I could personally "hear and see." However, I was able to ask, as an outsider, questions about what they took for granted to inform my observations and analysis during the interviews. Thus, I was able to generate meaningful interpretations that the subjects had not thought of themselves. For the diabetes patient support groups, the situation was similar. The support groups and online communities I attended consisted of people in their 40's or older. As I am an Asian woman in my early 30's, I found that assimilating myself

into the world in which they live as a participant was challenging. However, I could ask questions that the patients had not thought about or were outside the main purpose of their meetings, such as the patients' characterization of other patients in the support groups.

Other practical guidelines Rock (2001) suggests for conducting ethnographic research include: reading before going out into the field, making sure to take adequate time to do the field work, taking field notes because we do not know what we think until we say it (Weick, 1979), and looking out for informants.

Rock described informants as "someone will emerge, dues ex machina, like a fairy godmother, to help the forlorn ethnographer" (p.34). I wholeheartedly agree that this is true, as I had informants emerge for both studies. I had a MythTV user who connected me to key developers, described insider views of the various types of members, and offered to participate in future collaboration in case I get to develop a plug-in application for the MythTV system. In the diabetes patient support groups, I had an elderly gentleman, who provided me with a number of accounts of how he saw the support group run throughout the years, and offered to take my mother on a boat ride with him and his wife. For the online diabetes patient community, an informant helped me get connected with his "friends" in the online community to recruit interviewees and introduced me to other diabetes websites. These informants gave me insider accounts of what was happening in their world, which allowed me to triangulate my observations of them and their communities.

I reported the results to the participants. For the MythTV users, I sent publications to those who requested it during the interviews. While the interviewees made no reflections specifically about the findings, they showed excitement about the fact that their activities were observed. Also, the interviews worked as informal sharing of the findings and opportunities for triangulation. For the diabetes study, I presented the study findings in front of one of the support group leaders, who has been a diabetes patient (Type 1) for over 40 years. She agreed with my findings as well as the challenges I saw in reaching out to patients not participating in support groups.

In summary, the symbolic interactionist view of ethnography embraces the process-centered and grounded approach, the uncertainty and serendipity that allow for continuous evolution of interpretations, and the situatedness of knowledge. These characteristics need to be considered as researchers perform the procedural steps of sampling, collecting, and analyzing data. Whether I conducted online ethnography through archived emails, interviews, or face-to-face observations, the same lessons apply.

The prime ethnographic maxim for interactionists is one cannot know what one is exploring until it has been explored (Strauss & Corbin, 1990). Researchers wanting to conduct research with a symbolic interactionist ethnographic approach need to accept that the phase of confusion and muddle is a "phase that will come and will go, that it is an inevitable precursor of understanding, and that one should bear it with fortitude" (Rock, 2001). This approach rules out the need to generate

hypotheses and the need for research results to confirm or disconfirm the presuppositions of the researcher. Rather, the process needs to be inductive, iterative, creative, emergent, and evolutionary, and in the end the researcher comes to theoretically generalizable findings (Strauss & Corbin, 1990).

Keeping in mind the interactionists' approach toward ethnographic research that helped me formulate questions, sample, collect and analyze data, and come to the findings, next, I review how I decided on my current research design. I then provide a description of the two study sites and the methods used to study them.

## Research Design Rationale: The Exploratory Process

This section explains my reason for choosing to study MythTV user community and diabetes patient support groups. My selection of sites to examine collaborative help for individualized problems was born from a years-long exploration of finding what was important and interesting to me. The process of "following the trails" until I reached "saturation" was discussed by Strauss and Corbin (1990) in theoretical sampling.

My search for research sites and discovering what is important for my research began with a question of how systems could support people to help one another in complex everyday environments, whether it is about technical devices or personal health. I wanted to find suitable sites that have complex environments that require people to continuously update, fix, and maintain, so that I could learn how people cope with the problem respective to the environment. I studied how

people use multiple personal information management systems in online environments (Huh & Ackerman, 2011) how people maintain multiple components of discontinued machines (Huh & Ackerman, 2009; Huh, Nam, et al., 2010), and how adults with Attention Deficit / Hyperactivity Disorder use personal strategies to manage personal information (Huh & Ackerman, 2010).

Through my studies, I realized that the challenges in maintaining complex environments stem from dealing with uncommon, rare, and individualized problems for which it is difficult to get answers. People in my studies wanted to find ways to tailor existing solutions and fit them to their own individual settings. This finding led me to examine further communities with complex environments that often cause individualized problems. I also sought communities that would have a critical mass of helpers who are willingly assisting one another in finding tailored solutions.

I explored technical communities with devices that require maintenance of multiple components and therefore have complex configuration problems. After examining several technical communities, I selected the community of MythTV users, users of an open source system for home entertainment. I found that the MythTV system is complex enough to create individualized problems, but at the same time, it is tractable and flexible enough for the users to give help. The community members have been helping one another through the mailing list since 2003, and the number of posts has not decreased significantly since the peak in 2006. This potentially shows that the users have been fairly successful in helping

one another to solve problems over time. The MythTV user community is an excellent site to examine how users are dealing with individualized problems, and how, through the community interaction, the users are giving individualized help to one another. MythTV users may model a future computing environment where we need to constantly work to configure multiple devices that are tailored to individualized use.

In addition to studying a technical domain dealing with individualized problems, I wanted to understand how help interactions differ in other problem spaces. My study with adults with AD/HD gave me good sense of how adults with AD/HD dealt with personalized problems, especially since one solution does not fit all. Each patient had his or her own way of remembering information, managing personal information, and learning materials. Some patients liked visual aids while others liked text-based to-do lists. Many chronic illnesses and many are in fact increasingly personalized (Meyer & Ginsburg, 2002; Swan, 2009). I wanted to see how individualized problems in personal health are solved through social interaction. I chose diabetes patient support groups among many chronic diseases for several reasons. I had easy access to social websites and local support groups. Diabetes is a prevalent disease recognized for its importance by the medical community. More importantly, the diabetes patients display issues that are analogous to the MythTV users' concerns—maintaining complex issues altogether in their daily activities—and the communities of diabetes patients are actively sharing knowledge and information to help one another with managing diabetes.

Therefore, I wanted to examine the MythTV user community and diabetes patient support groups to see how individualized problems in two different cases are solved through different collaborative help interactions in their own communities. I wanted to find differences as well as similarities between the two sites to discover how we can better support individualized solutions problems through collaborative help systems.

While I have discussed the rationale and exploratory process that led to my selection of research sites, I now discuss the details of the sites themselves and the methods used in researching those sites.

## Study 1: MythTV User Community

As mentioned, I chose the MythTV user community as a study site for two reasons. First, each user's configuration of MythTV is often distinct from others and, second, the MythTV configurations are reasonably complex yet tractable.

Accordingly, studying the MythTV user community helps to gain broader insights into designing collaborative help solutions to individualized configuration problems in computing environments. I describe first the technical details of what the MythTV system is and then describe the typical challenges MythTV users face when creating and maintaining their systems.

#### **MYTHTV SYSTEM**

MythTV (mythtv.org) is an open-source software system that allows users to perform a variety of tasks, such as record TV shows to their computers, play games, check weather, browse the Internet, watch streaming online videos, rip DVDs, and listen to music (See Appendix E for MythTV system interface). The system can be installed on Linux, Mac, and Windows platforms. Alternatively, MythTV software can come in packaged versions where the operating system and the MythTV system are bundled so that users do not need to separately install MythTV (See Appendix E for examples of various MythTV installations). MythTV consists of a frontend, which is in charge of the user interface, and a backend, which deals with the database that contains recorded content. A given MythTV system can consist of multiple frontends and backends that do not have to be on the same machine. Each user needs to configure their own Mythbox, the machine that runs the MythTV system, by choosing a platform, graphics card, amount of RAM, CPU, tuner card, remote control, and monitor. Environmental factors affect the configuration of one's MythTV system, such as which country the user lives in, whether the user has cable service or over-the-air service, and whether they are subscribed to a standard or high definition TV service. Considering all the possible combinations of the above system components, each user's MythTV system configuration is often unique or at least very uncommon.

#### **MYTHTY COMMUNITY**

Members of the MythTV community receive information and communicate through several channels; most notably the official website, mailing lists, IRC, the wiki, and forums (See Appendix E for further details). These communication channels mainly exist for knowledge sharing as well as maintaining and developing MythTV as an open-source project. The wiki is used for growing solutions about individualized problems and providing how-to instructions for various configurations of MythTV. The MythTV documentation is primarily developed by the developers and used to document official installation procedures.

Because I wanted to learn about the MythTV community's current help practices as well as challenges that arise, I focused on examining the archive of the MythTV-users mailing list (mythtv-users@mythtv.org), where most of the help interactions among users are happening. There are other small unofficial forums and websites, but the activity levels in those places are substantially smaller than those of the "mythtv-users" list. To give a brief sense of the activity level of the list, the list started in February 2003 with 785 posts in the first month and reached a maximum of 8,082 posts per month in March 2004. Since then (as of January 2010) it has steadily been declining with an average number posting of 3,813 per month. There are 559 people who posted in December 2009 with a total of 3,293 posts.

For July 2006 (which will be analyzed at length in the following chapter), a prevalence of self-disclosure in mailing list posts made it possible to infer that the

members who spoke out on the users' mailing list are largely in their late 20s to 30s and are males working in technology industries or in staff jobs at broadcasting companies. Some of them come to the community to learn about Linux, some want to save money, and some come in for a hobby. Most are US residents, but there are a considerable number of Australians and British as well. I also observed a few users from India, South Africa, Germany, and Japan.

### **MEMBERSHIP**

The formal member roles in the MythTV community consist of developers and users. Developers have their own mailing list (mythtv-dev@mythtv.org), but they often listen in on conversations on the users' mailing list either to update users' progress of system development (e.g., letting users know whether certain features will be in the next release) or to participate in discussions of whether certain features are worth putting into the development pipeline. Rarely do they offer technical help, which is done largely by experienced users. One of the interviewees told me that the community implicitly agrees that developers should spend their time on developing MythTV and users should contribute back by providing help for newer members and documenting solutions. The community welcomes newcomers and kindly points to the archived solutions when newbie questions are asked.

#### DATA AND METHOD

The total number of email messages in the data set is 288,983. I analyzed approximately 4,000 messages, of which 3,273 are from July 2006. The sampling rationale is based on the symbolic interactionist's philosophy of trailing to where researcher's interest lies. This rationale is also formally discussed in Herring et al.'s (Herring, Barab, Kling, & Gray, 2004) guideline for computer-mediated discourse analysis (CMDA), which encourages the use of motivated sampling driven by research questions over random sampling that sacrifices context. Because the research questions involve how the community helps individualized use of MythTV, I largely examined periods where MythTV was stable enough for users to further tailor the system to their own use. To identify such periods, I informally reviewed message threads at the beginning and end of the archive as well as subject lines throughout the archive (See Appendix G for list of codes). This helped to get a sense of how the community's conversation changed over time. Based on this review, I decided to focus on July 2006, which offers a suitably stable but active period.

Using Atlas.ti as a qualitative analysis tool, I began the analysis by going through each message line by line to generate descriptive codes about the activities happening in the mailing list, following grounded theory (Strauss & Corbin, 1990). As my analysis developed, I looked for emerging themes, which were iteratively tested with more data as I advanced the analysis, again following the symbolic

interactionist approach. As the codes accumulated, I began seeing patterns in codes that were interesting enough. As more data were coded, sub-codes began to emerge, and I continued to break down the codes into more detailed ones, revising, rewording, and deepening existing codes throughout the analysis. Once the initial analysis was over, I went over the coding together with my collaborators, probing for any remaining questions. We then went back to the data and continued to question the themes that emerged, looking for any exceptions or hidden meanings that may have been overlooked. In the end, the codes were analyzed using affinity diagram (See Appendix G for pictures of affinity diagrams and code lists). Major themes emerged, particularly around how individualized problems are solved through collaborative help. These themes became my major findings to be described in Chapter 4.

As findings emerged out of the mailing list data, I contacted recent posters as well as those who were registered on the MythTV wiki to validate the findings. I conducted a total of 12 interviews, three 30 to 60 minute phone-based semi-structured interviews, and nine by email where the interviewee and I sent emails back and forth for further questions and clarifications (See Appendix D for interview protocols). The interviewees were asked to describe their history of using MythTV, the kinds of help that they received from the community, any breakdowns in getting help, their use of the wiki, any challenges in maintaining their MythTV over time, and what they thought about what I had observed to that point in the community.

## Study 2: Diabetes Patient Support Groups

The role of my second study was to continue the analysis of help practices for individualized problems in areas different than the technical use case of the MythTV users. Diabetes patient support groups are appropriate alternate research sites that can give information on how collaborative help works (or does not work) for individualized problems. Diabetes patients, like most chronic illness patients, increasingly deal with individualized problems, since everyone's body is different. Accordingly, each individual needs to construct personalized strategies to successfully manage their disease. Also, diabetes is a prevalent disease that is widely recognized with abundant resources to help with research: Good access to local support groups and online communities is possible. Seeing how two very distinct communities—the MythTV user community and the diabetes patient support groups—deal with individualized problems shed light on design implications for how collaborative help systems can better support individualized problems in different domains.

I examined both face-to-face support groups and an online community (dLife). In this way, I was able to observe how help interactions differ in two different social spaces. I conducted field observations, a total of eighteen sessions of face-to-face support groups over eleven months (four groups were regularly attended while the other two groups were attended only once or twice), and did content analysis of 1,400 messages randomly collected from dLife.com. I also

conducted twenty semi-structured interviews from both face-to-face support groups and dLife. In the following sections, I describe face-to-face support groups and dLife in detail and how I conducted research and analyzed data.

#### FACE-TO-FACE SUPPORT GROUPS

I first contacted a local hospital to search for diabetes support groups to interview their leaders. The UM geriatric center had a support group once a month for type 2 diabetes patients. I interviewed a nurse practitioner, who was in charge of running the group, to get a sense of the general activities of the support groups, the role of support groups, patient challenges, and the topics discussed. I also received a list of nearby support groups in the Detroit and Chelsea areas. I was not able to reach a Type 1 diabetes support group until the end of data collection even though it would have been helpful to be able to compare how the help interaction differed in Type 1 and Type 2 support groups. I mainly studied Type 2 diabetes patients because they showed more uncertainties and complex factors than type 1 patients.

I attended a four-week diabetes class as part of learning about the field and being a participant observer (Strauss & Corbin, 1990). For my main data collection, I visited six support groups; however, two groups were lecture-oriented support groups with little patient-to-patient interaction. I attended four support groups per month beginning February 2010 and continuing until December 2010 for a total of fifteen sessions (I did not attend all the support group meetings due to travel and

other time constraints). Two support groups (FF1 and FF2) were attended twice, one (FF4) was attended five times, and the last support group (FF3) was attended six times. I also attended two other support groups, attending three sessions in total. The analysis was done concurrently with data collection, and the decision to stop observations came with a combination of reaching data saturation (Strauss & Corbin, 1990) and time constraints (Rock, 2001).

The four support groups were all for Type 2 diabetes geriatric patients. FF1, FF2, and FF3 were near the Ann Arbor area, and the members were often welleducated including retired teachers and engineers. They were knowledgeable, active, and independent information seekers. On the other hand, FF4 was located near Detroit and had members from diverse age groups with the youngest in the mid-40s and the oldest in the late 70s. The members in FF4 were not necessarily as active and independent information seekers as they were in FF3. This observation came from the materials being discussed in the class. FF4 teaches the members very basic knowledge of diabetes management, such as how to identify the symptoms of high and low blood sugar level through games, which I did not observe in FF3. Discussions in FF3 were mostly patient driven where patients challenge existing information and compare various resources. At the same time, all support groups have discussion components for sharing personal experiences and strategies when possible. Even if the members did not share practical knowledge, they still asked questions that allowed me to learn the taken-forgranted assumptions for how to solve ongoing challenges. I did not observe any

members mention online communities. However, in the online communities members do discuss face-to-face support groups.

I took field notes with pen and paper or a laptop during the observations and attempted to catch the noticeable social interactions as well as what the members may consider routine or mundane interactions (Rock, 2001). Any verbal or gestural interactions were captured as much as possible for later analysis. I did not attempt to be selective in my recording because I wanted to follow the grounded and evolutionary approach in the symbolic interactionist perspective. What seemed to be unimportant at the time could illuminate the findings and other observations, thus I refrained from filtering out any data that I was able to observe. Because I did not audio or video record, there were limitations to the amount of data that I could capture.

Analysis was done in conjunction with the observations. The field notes were analyzed using the same coding method used for the MythTV study (Strauss & Corbin, 1994). I began with coding descriptive ones for each observation. As my data was accumulating from the interviews and the online community study, the focus of my analysis continued to evolve. Codes were revised, merged, and broken down as the analysis evolved and more data were collected. I also used findings from my analysis to revise where to focus my field observations.

For the first few sessions, I handed out recruiting materials (See Appendix A) for members to sign up for one-hour interviews. Fifteen dollars were given as compensation and I was able to recruit thirteen interviewees in total. Interviews

were done on the phone or face-to-face depending on the patients' schedule. The interviews were recorded and fully transcribed. The transcribed interviews were then analyzed using the same analysis method used for field notes. I asked the interviewees about the support groups, whether they were helpful or not, their personal strategies in maintaining diabetes, and their perceptions toward the support group members (See Appendix D for sample interview questions).

## ONLINE COMMUNITY: DLIFE.COM

As I became familiar with the terms used by patients and gained a general understanding about diabetes and face-to-face support groups, I began studying online support groups. dLife.com was chosen because it has the largest number of members (87,999 as of April 17, 2010) among the diabetes forums. Another competing diabetes community was diabeticconnect.com, but, as I examined diabeticconnect.com, I realized that the culture of interaction is more oriented toward emotional support than providing practical help. The members of diabeticconnect.com rely heavily on the use of words such as "I will pray for you." On the other hand, dLife.com members are more practical with the members attempting to give as much practical information as possible.

dLife.com is owned by the TV channel, dLife. The site includes sections where the patients can interact with one another, ask questions of experts, and share recipes. I chose to study only the community forum section because my research purpose was to study peer help interactions. Under the community forum,

the most relevant topic was the "Type 2 clubhouse" (See Appendix F for complete list of topics). From the "Type 2 clubhouse," I collected the seventh thread of each page for a total equal to the number of pages (there were 210 pages for total threads), resulting in 1,489 posts.

The full list of moderators is unavailable, and the fact that a member is a moderator is visible only when they post messages with a signature showing that they are moderators. Moderators intervene whenever conversations seem to get out of control or turn to flaming. I was only able to observe one moderator from the sampled data. There are several members that actively respond to unanswered questions. Some even lead a monthly thread on weight-loss buddies. These members are possibly regular avid members or the site hires them. One interviewee told me she started out on diabetic connect.com as a regular member and as her participation grew, one of the site owners contacted her and offered her a job of responding to other members. This may also happen in dLife. Rarely do members shun newcomers who ask newbie questions. The members are mostly friendly and supportive to one another with occasional conflicts about philosophical differences in managing diabetes.

I cannot give representative demographic information since it was not readily available for me to collect. I can give my impressions after reading 1,489 messages for my analysis. Ages seem to be younger on dLife than face-to-face support groups, which largely consist of geriatric patients. I frequently read stories from people who recently got married, got pregnant, changed jobs thus were

younger than retirement, and recently graduated college. The socio-economic status (SES) of users seems to vary more widely in dLife.com than in the support groups, particularly because one of the motivations for using dLife.com is limited access to local health care resources. I observed patients with disabilities, no insurance, or on Medicaid. At the same time, I also observed patients with professional careers, such as nurses, physicians, and engineers. The SES of dLife users does not seem to matter in their interactions with one another.

The collected messages were coded using Strauss and Corbin's grounded theory as I did in the MythTV user community. I began with descriptive coding, and then went back to the data and the codes to find relationships among the codes. As my analysis evolved, I continued to redirect my active interests and focuses. While initially the data seemed banal and confusing, over time, stories started to come together. I continually revised code names, merged codes, and broke down codes to incorporate what I found.

To recruit interviewees, I posted recruiting messages on diabetic connect.com and dLife.com (See Appendix A). I also sent private messages to the support group members who responded to ask for interviews. Seven people responded to my request through private messages. Unlike participants from the face-to-face support groups, the majority of the online community participants preferred to interview through email. No one in the face-to-face support groups wanted to communicate through email. The interviews were conducted over the phone, email, and face-to-face depending on the preference of the patients. The

interviews were transcribed and analyzed using grounded theory (See Appendix D for sample interviews).

## CONCLUDING DIABETES PATIENT SUPPORT GROUPS STUDIES

I did not formally link the codes with the findings from the three data sources: face-to-face support groups, dLife, and interviews. However, in the end, all the codes collected from observations of the face-to-face and online diabetes patient support groups as well as interviews were again reviewed using an affinity diagram (Beyer & Holtzblatt, 1999) (See Appendix G for the affinity diagram). The codes were categorized by emerging themes, particularly around meanings that people generate through their interaction with the peers. Through this process, I was able to further extend my initial understanding with face-to-face support group to other support group settings such as dLife.com. I also saw how individuals' understandings varied from the collective sense and how people attempted to present themselves to others. Breakdowns were marked where challenges occurred. Examples of breakdowns include members having hard time getting answers to their problems or having conflicting information about medical definitions.

## Summary and Goal of Research

I did not formally compare the MythTV user community with the diabetes patient support group studies. Rather, they were treated as two different studies.

Rather, the two studies were used to loosely inform each other and provide implications for designing collaborative help systems for individualized problems.

Above, I discussed how both the MythTV user community and the diabetes patient support group studies were analyzed using Strauss and Corbin's grounded theory (Strauss & Corbin, 1994). That is, I performed an analysis along with data collection, and the codes continuously evolved in iterative revisions by merging and breaking down codes into sub-labels. Through this process, I slowly gained a coherent picture of the overall story. Data for the MythTV user community consisted of interviews and content analysis of email messages. The analyses from the two data sources were compared to one another to find emerging themes and any discontinuities. This is also the case for the diabetes patient support groups study where I collected interview data, face-to-face support group field observations, and online community post messages that were each analyzed and later triangulated against one another.

As discussed, both studies initially began with an exploratory focus and became more coherent over time as patterns began to emerge in the data and as uncertainty and confusion diminished. I found patterns that I thought were interesting and I saw how the stories fit together from the various data sources. The next two chapters will report on my findings. In chapter 6, I return to a discussion of what all the findings mean for my overall question—what can be improved about current collaborative help systems for supporting individualized problems.

## Chapter 4

## **Collaborative Help in the MythTV User Community**

In this chapter I discuss how members of the MythTV online community collaboratively help one another to maintain their individualized MythTV systems. I arrived at three key findings that shed light on how people collaboratively help one another to support individualized use of technologies. First, sharing configuration artifacts help to facilitate the transfer of knowledge and context from one person to another. Second, because of the individualized nature of maintaining MythTV systems, using configuration artifacts as solutions often breaks down. The community then collaboratively generates tailored solutions for individualized settings. Finally, I found that configuration-based help needs to be carried out within the larger context of how users maintain MythTV over time, and stories of maintaining MythTV over time—individual use trajectories—are used as resources for generating solutions. As users share their use trajectories, the community comes to an agreement about how one should maintain MythTV over time, a consensus I refer to as a "community trajectory." This is critical for maintaining MythTV in individualized settings.

This chapter is divided into three parts. Part I describes the kinds of individualized problems and challenges that MythTV users encounter. Parts II and III present the central contribution of this study, namely the help interactions I call "configuration-based help" and "use trajectory alignment and negotiation work."

Part II includes a discussion of how the community utilizes configuration artifacts as proxies to exchange experiential knowledge. While exchanging configuration artifacts such as scripts and configuration files is sometimes seen to increase the efficiency of knowledge transfer, it also presents several challenges. Breakdowns in blackboxed configuration-based help and navigating what I will call "the customization and appropriation gulfs" are major challenges that MythTV users encounter. At the same time, how members of the community collaboratively help one another overcome these challenges illustrates the core concept of how the community provides individualized help for each member. In Part III, I discuss "use trajectory alignment and negotiation work," where use trajectories are defined at the level of individuals and the community. At the individual level, trajectory alignment work refers to how configuration-based help is done within the larger context of sharing use trajectories of the members. Sharing use trajectories not only contextualizes problems during the help process, but also provides practical help for troubleshooting individualized and uncommon problems. At the community level, trajectory negotiation work is done as the community builds a conceptual pool, which evolves over time, of what it considers to be appropriate solutions, a negotiated norm of what an ideal MythTV system looks like, and an agreed-upon

trajectory of the MythTV system from the perspective of users and developers. I conclude the chapter with a discussion about the relationship between configuration-based help and use trajectory alignment and negotiation work, and how the challenges presented in Part I are addressed through those two activities.

# Part I. Individualized Problems and Challenges in the MythTV User Community

In Part I, I survey individualized challenges in identifying appropriate solutions that members of the MythTV user community encountered as they installed and maintained MythTV over time.

#### PROBLEMS IN INDIVIDUALIZED USE

The fact that MythTV can support a wide range of individualized uses creates challenges in solving technical problems. Beyond general troubleshooting, several problems are aggravated by the individualized nature of the MythTV system. These include compatibility issues, idiosyncratic problems, and problems pertaining to the personal environment.

The most widespread problem observed in the individualized use of MythTV is that of compatibility issues among hardware and software components.

Compatibility issues are aggravated by the individualized nature of MythTV configurations and uncertainty about how different system components will work together. During the installation phase, finding the right set of hardware and

software components such as tuner cards, graphics cards, CPU, operating systems, drivers, and patches, all of which need to be compatible, is a challenge. As a result, successfully installing MythTV could take anywhere from a day to several months. Also, adding new features, upgrading components, or replacing parts of the system can break the system if there are incompatibilities with the existing system configuration. In replacing a graphics card, upgrading the operating system, or adding features over time, MythTV users need to anticipate what changes will occur, specifically pertaining to maintaining the ecology of the components of the system. Unless the user has dealt with a problem before or is highly experienced, the ability to anticipate outcomes is a challenging task. For example, MythTV user Matt upgraded his Ubuntu distribution as well as his IVTV (a driver that allows capture cards to run on Linux systems). This created a new problem, which turned out to be a compatibility issue between the upgraded versions and the graphics card:

I recently upgraded my ubuntu distro to 6.06 (2.6.15 kernel). Afterwards, I upgraded my IVTV to 0.4.6. After the install, I can get sound and picture to work just fine with my PVR-500, but I only get a picture (no audio) with my PVR 250s. I can't figure out what's wrong, and I've been struggling with this for several hours now. Any advice? [and shared dmesg output] (Matt, July, 2006)

Matt had a hard time figuring out where the problem originated and shared an output of dmesg<sup>4</sup> in the hope that other people might be able to give him hints. In response to Matt's post, another member diagnosed where the problem might be coming from. From the dmesg output, the helper, Mike, pointed out that missing "module msp3400" was the key problem:

```
> ... [4294680.170000] ivtv0: Failed to load module
msp3400

You won't get audio on a 250 without that. Might get it
on a 150/500, but it's a good place to start. (Mike,
July 2006)
```

Notice that Mike only suggested what the problem might be, but did not give step-by-step instructions for how to solve it. This illustrates how the individualized nature of each user's system setting makes it challenging for other users to provide concrete solutions. Matt later found that he needed to rebuild his kernel and he made sure the module was loaded. He was then able to get the audio to work. The aforementioned helper did not give a concrete solution to Matt—rather, the helper only gave him a suggestion about where the problem might be coming from, and Matt had to infer from the hint to solve his own problem.

There are also idiosyncratic problems that pertain specifically to individualized situations. The problems in this case are either unseen or rare. The members again suggested possibilities for what the solution might be instead of providing a definitive solution or diagnosing a specific cause for the problem. For

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<sup>&</sup>lt;sup>4</sup> According to Wikipedia, "dmesg" is a command on Unix-like operating systems that prints the message buffer of the kernel. Dmesg can be used to debug and monitor system activities.

example, John found that his MySQL server was acting oddly. Although it might not be a critical problem that would prevent the regular functioning of MythTV, he wanted to know why the server was behaving strangely:

My MySQL server seems to be having some odd things happening. They may be okay, but I would like to know either way.

- 1.At times there are several long running processes in
   the processlist. I've seen some running for 14000s
   (~4h) or more. There are entries in the
   slow\_queries.log, but I don't know what they are
   trying to do. I can tell you they are huge, having 9
   JOINs, 28 ANDs and 11 Ors.
- 2.mythconverg.recordedmarkup has over 1 500 000 rows.
   Most entries have a 'type' of 6, which I suppose is a
   keyframe. It looks like for a lt (all?) of the
   recordings, there is an entry for every second.
- 3.Mythconverg.oldrecorded becomes corrupt sometimes.
   Specifically,
   /var/lib/mysql/mythconverg/oldrecorded.MYI is the file
   MySQL complains about. When I run mysqlcheck on
   mythconverg, that table is flagged as crashed. A
   mysqlcheck -r has always repaired it.

Thanks in advance for any insight! (July, 2006. ML. John)

Notice his last line "mysqlcheck –r has always repaired it." He had his own workaround for the problem, but it did not resolve the issue completely. John's problems were not severe enough to cause the system to break, but they caused enough of a disruption to get his attention. Nobody replied to the thread, leaving John's abnormal problem unsolved.

Users also encounter individualized problems due to their particular physical environments. Such problems include power outages, errors in the listing

service that disrupt channel listings, and problems related to geographic relocation. Because most MythTV users are residents of the United States, users from other countries often need to develop resources independently. Also, users perform various maintenance activities over time, such as upgrading, downgrading, installing, rebuilding, and adding various drivers and patches, individualizing each user's system even further. The historical context of each person's system is often invisible, making it even more challenging to diagnose problems.

The majority of problems stemming from individualized use of MythTV described above are not solvable through "official" published solutions such as documentation and FAQs. The community thus developed several standard help interactions on the MythTV user mailing list similar to what Singh and Twidale observed in open source software communities (Singh & Twidale, 2008; Singh, Twidale, & Nichols, 2009). These include how-tos, detailed explanations, pointers to other resources, comments such as "I had the same problem" or "If X happened Y will happen," and many more. The MythTV community also maintains a wiki to capture solutions to common problems related to individualized use. However, there are still problems that community help interactions cannot fully address.

#### CHALLENGES IN SUPPORTING INDIVIDUALIZED USE

So far I have briefly examined individualized problems encountered by MythTV users. In this section, I discuss challenges that emerged during the help process as members attempted to solve individualized problems on the mailing list

and wiki. I observed three major challenges in supporting individualized use: identifying suitable solutions for individualized use, the contextualization process during help interactions, and the process by which solutions are maintained over the long-term.

### **Identifying Suitable Solutions for Individualized Use**

MythTV is a complex multi-component system where each user's system is unique, making it difficult to construct one-size-fits-all solutions when problems arise. Existing solutions from the product documentation, FAQs, the MythTV mailing list archive, the MythTV wiki, and various Internet sources often need to be modified to meet the needs of individualized MythTV systems. However, determining the appropriate solution to start with and adjusting that solution to fit a user's individualized settings often requires extensive expertise.

This can be a challenge for inexperienced users and represents an example of what Won et al (Won, Stiemerling, & Wulf, 2006) called the "customization gulf." Not only does solving MythTV problems require knowing how and where to modify the system, it also sometimes requires determining one's own configuration information. For example, MythTV user Graeme had difficulty using a set of instructions because the instructions did not work for his particular setup. He did not know how to obtain specific information about his system configuration to even know how to adapt the instructions for his situation. Graeme wanted to add an outdated tuner card, and he found instructions from the LinuxTV wiki

documentation on how to install the card in his MythTV system. When the instructions did not work, he assumed that it was because of the built-in modules in his kernel. However, he did not know how to check whether this assumption was correct:

It [the documentation] says for all devices I must modprobe [a program for loading modules to the kernel] i2c-core, crc32, firmware\_class, dvb-core and dvb-pll. This works for all but crc32 and firmware\_class. I understand that this could mean they are built into my kernel, but I don't know how to check that. I am running Fedora Core 4 with kernel 2.6.16-1.2115\_FC4 (ML: Jul 21, 2006, Graeme)

The instructions also confused Graeme regarding whether he needed to load all firmware, or only one specific piece of firmware particular to the frontend information of his tuner, which he did not know how to access:

This is confusing, because I'm not sure if I should load all of these [modules] or just the ones specific to my frontend/demodulator. I don't know which frontend/demodulator I have.

A helper taught Graeme how to get information on his built-in kernel modules as well as how to check the frontend/demodulator information—it could often be found on the card itself, or by running a command, dmesg. When Graeme checked, he did have the correct module built in to his kernel, but not the "firmware\_class" (a particular module), making it difficult to understand why loading the module did not work for him. Also, he ended up taking a look at the card itself, only to find out that the frontend/demodulator information was obscured:

I opened up the usb box, there is a conexant chip in there that starts with cx22. The rest of the numbers are obscured with heat sink compound.

Furthermore, the instructions directed him to use a firmware that would clearly have a compatibility problem:

The linuxtv site advises me to use the Philips firmware file, but as I don't have any Philips chips, this must be wrong, no?

Graeme's case exemplifies how challenging it can be to select and modify solutions that will work for a specific user's unique configuration. The inability to understand one's own configuration settings, identify unexpected constraints, and know the limitations of how far the instructions can be applied to work in different configuration settings are clearly problems for inexperienced users. In Parts II and III below, I describe how the community develops help mechanisms, using configuration artifacts and shared use trajectories, to generate individualized solutions. In order to provide individualized solutions, members of the MythTV user community first needs to understand the individualized context of problems.

### **Contextualizing Problems During Help Interactions**

Contextualization has long been discussed as a challenge in reusing information from knowledge repositories (Ackerman & Halverson, 1998). The mailing list archive and the wiki of the MythTV user community are not exceptions. Because MythTV configurations can be complex, those asking for help often have to choose what information to present about error messages, system configurations,

and the history of how their systems have changed over time. A MythTV wiki page about mailing list etiquette attempts to provide guidance for inquiries:

Which MythTV version are you using? Please state whether you are using version 0.18, version 0.18.1, 0.19, 0.20, etc.

However, much of the page's instructions are ambiguous and rely on the user's discretion:

If your hardware or config details are unusual or noteworthy and you suspect that information may be pertinent, include it.

Include any relevant log file information like the output from mythbackend, output from mythfrontend, output from /var/log/messages, error message[s] during compile. NOTE: Only include the relevant information. It's okay to trim mundane stuff out of logfiles.

These instructions suggest that questioners provide information that they "suspect" might be helpful or pertinent, a relative qualification that might result in different information being reported depending on who is reporting it.

In the example below, a user's contextualization is challenged because of mismatched assumptions between the asker and the helpers. Vamshi, who attempted to install MythTV in India, had difficulty playing live TV. He assumed that this was partially due to him using a TV listings grabber for UK residents because the grabber for Indian residents was not yet available. The only contextual information he provided for his configuration was that he was using the grabber for UK residents. He also attached the error messages that he received when trying to initialize the MythTV database. In response, different helpers solicited additional information depending on their assumptions about the cause of his problem:

Where did the messages you posted come from? Which log file? They don't look like errors from mythfilldatabase, they look like errors from mythbackend. (ML: Jul 3, 2006, Phil)

While this helper focused on the connection between the frontend and the backend, another helper asked for configuration information for the capturing component:

What capture card are you using? What channels are you expecting to receive, and do you have frequency information for them? MythTV does need good data in the channel database and watchTV can be unpredictable if some channels are configured incorrectly. Maybe you can configure your channels manually? (ML: Jul 3, 2006, Watkin)

This thread illustrates a typical challenge in queries: despite the asker attempting to conform to the rules of etiquette, contextualization requires substantial dialogue between helpers with misaligned assumptions to elicit the context that they need. This work of aligning assumptions, knowledge, and anticipation among members is a crucial challenge for sharing knowledge. I discuss this use trajectory alignment work further in Part III. Providing context efficiently is a challenge, and users employ configuration artifacts for better exchange of contextual information.

Even though the community shares working solutions, technologies continue to evolve and members need to remain aware of changes in the computing environment to prevent their systems from becoming outdated and breaking. Users seek opportunities to improve their systems, whether that entails performance tuning, upgrading, or enhancing functionality of MythTV systems.

During this evolutionary process, existing solutions become obsolete and irrelevant. Also, new problems emerge, requiring members to continuously come up with new solutions.

### Maintaining Community Knowledge Over the Long-Term

Unlike the formal documentation and FAQs, the MythTV wiki is open to revision and inclusion of instructions by the user community. However, when users attempt to use these community-maintained instructions, two main challenges emerge: the obsolescence of solutions and missing context about solutions.

Solutions become obsolete, irrelevant, or ineffective because of the changing nature of the computing environment. For example, in 2006 one user posted a question about how to record from S-video or composite inputs. The only solution he found dated back to 2003:

Is there any way to record from Svideo (or composite) inputs on a tuner card? If so, how do you set it up? The only other thread on this topic seems to point to a post from 2003 that involved hand editing the mysql database. There must be a nicer way then that. Seems like the functionality was taken out around .12 or so. (May, 2006. ML. Greg)

Although the solution posted in 2003 still worked, Greg wanted to see if there was a more recently updated solution for his problem. Even though the original solution was at one time very useful, it became outdated over the long run. Solutions would have to be continually updated to recognize new versions of MythTV and to take advantage of new technologies that evolve over time.

Wikis are not known as a medium that facilitates frequent updating (Roth, 2007). Accordingly, even though updated solutions are generated in the mailing list, such updates are not always immediately incorporated into the wiki.

Obsolescence of information has been shown to be a challenge to the viability of wikis (Roth, 2007), which proved to be the case in this study as well. Once a user posts a solution to the MythTV wiki, due to the collaborative nature of wikis, the community officially maintains the solution rather than the original poster. This creates problems in maintaining the solution. A solution might not be sufficiently managed over time due to its ambiguous ownership, giving the wiki a reputation for being outdated on less popular topics.

As a result, many users perceive the MythTV wiki to be outdated. Not knowing how current a MythTV wiki page is proved to be one of the reasons users turn to the mailing list:

I've just purchased a TV Tuner card (Yuan SmartVDO EzDVD MPG150/160/600). The board is labelled MPG600GR REV 1.1. I'm aware that on the ivtv wiki page it says that this board is not supported due to the Phillips SAA7174HL chip but I don't know how current that info is. Has any body had any experience with this board or chip? (ML: Nov, 16, 2004, PoorH)

On the MythTV wiki, a page can become obsolete not merely because no one cares about the page, but also because the page has to serve the community as a whole. An author on the wiki could not modify the page to note how well the solution worked on her current updated system because information on the wiki that is outdated for her might still be relevant to others:

It [the wiki] tends to get updated by those who tried to use it, found it was wrong, found out how to do what they wanted to do, and went back and fixed the wiki. Unfortunately those people (people like me) are unable to remove the cruft because they do not know if it is still valid for some people or not. (I: Peale)

Comments and warnings on the wiki seem to play an important role in validating information, but if these are too prevalent they can create trust issues for using the information.

In considering long-term issues of maintaining solutions over time, both obsolescence and decontextualization of the solutions are problematic. During the knowledge distillation process of moving information from the mailing list to the wiki, solutions lose their context. Information about how a solution emerges – what the original problem was that started the thread, how much interest the problem received, what detours were made in coming to the final solution, or at what point in the community's conversation the problem emerged – becomes lost. As a result, users often consider solutions on the wiki to be less useful than solutions discussed over the mailing list. During an interview, Kyle described how the community discussions related to a particular solution serve as important context that should not be abandoned when the thread gets distilled into the wiki:

A forum (the mailing list) is just different, people are going back and forth, presenting arguments, etc. With a wiki, you can't see which parts were debated over, which were just stuck there, and who stuck them. (I: Kyle)

Another piece of contextual information that is lost in translation between the mailing list and the wiki is who initiated the solution, which would influence the credibility of the information. Kyle again said:

```
On the forum, if the owner of the project says something, you think about it differently than if you read it on the wiki. (I: Kyle)
```

Maintaining the balance between revealing necessary information while avoiding information overload proved to be challenging. In Part III, I identify the process of a community reaching an agreement about appropriate solutions as one of the critical interactions for maintaining individualized MythTV systems over time. Accordingly, the decontextualization of solutions emerges as an important challenge to address.

#### **SUMMARY**

In Part I, I discussed individualized problems common among MythTV users and challenges to the community in collaboratively identifying solutions for those problems. I talked about how individualized problems are born out of the MythTV system's flexibility that allows for individualized use, and how challenges in providing solutions arise from unique user problems. Furthermore, maintaining and generating solutions over the long-term to keep pace with the rapidly evolving computing environment also poses a critical challenge that the MythTV user community seeks to deal with. Next, in Parts II and III, I discuss how the

community, by using configuration artifacts and sharing use trajectories, develops help mechanisms to address the challenges discussed in Part I.

# Part II. Configuration-Based Help

By configuration artifacts, I refer to encapsulated forms of computergenerated or machine-readable information about how a system is or should be configured. Examples include configuration files, such as those that end with ".conf," scripts that perform configuring activities, and error messages and outputs that provide snapshots of a system's current configuration.

Past work has briefly examined sharing of configuration artifacts in the context of component-based software development (Stevens & Draxler, 2010). The authors examined the use of the Eclipse software ecosystem and found that Elipse users collaboratively shared components or preference settings to facilitate appropriation practices. One of the challenges they found was that of coping with the antagonism of stabilization and innovation among users. Further work is needed to understand how to support users in setting their roles in establishing collaborative relationships in such open and loosely coupled software production.

The act of configuration itself has been examined to support recombinant computing, a framework to support arbitrary devices and services to serendipitously be interconnected and used together without prior knowledge of one another (Newman et al., 2002). Configuration artifacts, the products of how configuration as activity is encapsulated, play a novel role in facilitating

collaborative help for individualized use in the MythTV user community. Owing to the individualized nature of MythTV systems, help is often based in the specific knowledge artifacts that define one's configuration. Similar to Alavi and Leidner's (2001) discussion of knowledge artifacts, knowledge in the MythTV user community is frequently shared in the form of concrete configuration artifacts such as settings files, logs, scripts, error messages, and the outputs of certain diagnostic tools. Similar to how Nardi and Miller (1990b) saw spreadsheets as "cognitive" artifacts" which provide a point of cognitive contact that mediates cooperative work among spreadsheet users, configuration artifacts in the MythTV community can be seen as proxies for transferring an individual user's contextualized knowledge about a problem and the system setup in a simplified form. Unlike communicative artifacts discussed in the knowledge management literature (Alavi & Leidner, 2001), however, some of the configuration artifacts in the MythTV user community are executable, providing "pluggable" solutions for users' problems while also serving as boundary objects for communicative purposes. While this makes certain help interactions more efficient, it also presents a new set of challenges. Since each user's configuration is different, configuration-based solutions are often not easily transferred from one user to another or from one situation to another. Reusing the knowledge in a configuration artifact is often tricky, and a significant amount of translation work might be necessary to utilize others' configuration artifacts.

Next, I introduce configuration-based help that supports individualized help in the MythTV user community. I first discuss how configuration artifacts are used to contextualize problems for the helpers to give relevant help. I then discuss configuration artifacts as executable solutions. Often, due to individualized problems, configuration artifacts fail to execute as solutions immediately. MythTV users then attempt to work around the failures by collaboratively modifying configuration artifacts. I conclude Part II with a discussion of how the community explores the notion of transparency of configuration artifacts as a necessary part of the help process, helps members deal with customization and appropriation gulfs, and uses configuration artifacts as boundary objects for communication.

#### CONFIGURATION ARTIFACTS FOR CONTEXTUALIZATION

The challenges of contextualization have been discussed extensively in prior work on organizational memory (Ackerman & Halverson, 1999). When askers request help on the mailing list, the context around their individualized use—for example, hardware and software configurations, family members' use of MythTV, or geographical constraints – and the processes by which the problem occurs are often hidden. The asker and the helpers provide feedback iteratively, requesting any important information that may have been missing. Also, an implicit norm of the mailing list is that the asker would report back what worked and did not work, although this does not always occur. The iterative interaction between askers and helpers consists primarily of requesting and providing diagnostic evidence such as

error messages, configuration files, query results, symptom descriptions, and data on results from tests. Using such evidence helps the community infer a user's system configuration and clarify the problem at hand, allowing helpers to tailor suggestions to an asker's particular situation rather than giving general advice.

During this process, error messages and commandline outputs play an important role in providing objective and accurate contextual information about the behavior of the system. That is, members can easily share system output instead of trying to manually explain the situation. For instance, Mwright encountered an error message that he was not able to parse himself and sought help:

Another member who had the same experience told Mwright that it might be due to the MSN website being down at the moment, and he could solve the problem by reinstalling the 2.7 version of the imir script. In order to solve his problem, Mwright needed to provide context for what he tried before getting the error message and to specify the output that he was showing. Other members

recognized the error message as one that they had experienced before and suggested an appropriate solution. In other cases, helpers attempted to parse the configuration artifacts that the askers shared with them before suggesting solutions. In this way, configuration artifacts provide an efficient and easy way to convey problems, especially for novice users.

However, not all problems come with error messages, and in those cases, users need to know which command to enter in order to make their systems generate necessary outputs. Also, since outputs and error messages can be lengthy, another challenge is to know which part is critical to show others. Another possibility is that the error messages might be insufficient, requiring users to supply missing information. An asker might not know what and how much to contextualize, thus the contextualization process itself becomes a negotiated learning process between the helpers and the asker. The following example illustrates a case where the asker does not know which configuration artifacts or how much to post to contextualize his situation:

```
I figured I may as well post the full output in case something obvious is happening and I'm just not seeing it. [presenting a log] (July, 2006. ML. Spentboy)
```

Spentboy did not know which part of the log was important to show, so he just decided to post the full log hoping that other members would be able to diagnose the problem, which they did:

```
Both of the above errors point to the fact that mytharchivehelper is failing to run for some reason. An exit code of -11 means it segfaulted. [...] are you sure
```

```
you don't have two versions of mytharchivehelper installed? (July, 2006. ML. Paul)
```

Another user similarly did not know which part of the output to include, and posted all the outputs that seemed relevant to him:

```
I have to apologize if this is too much info, but I'm really not certain which will be relevant, so I'm trying to post all the seemingly-relevant details I can locate. (July, 2006. ML. Phil)
```

Some users even asked the helpers to tell them what information they needed to provide:

```
If you need more information or verbose output, let me know! (July, 2006. ML. Geemark)
```

Helpers provided specific instructions for the askers to produce the output needed to solve the problem:

```
What does
# lsmod |grep "lirc"
give? (July, 2006. ML. knowledgejunkie)
```

Using the instructions, the asker provided the necessary information for knowledgejunkie to be able to help.

Askers provide what they consider to be relevant information, and helpers respond by requesting further details if there is not enough information. During this process, configuration artifacts play an important role in facilitating the exchange of contextual information. However, the role of configuration artifacts is not confined to contextualization. Configuration artifacts could also be used as solutions. Next, I discuss how configuration artifacts are used as independent solutions.

#### CONFIGURATION ARTIFACTS AS INDEPENDENT SOLUTIONS

Configuration artifacts in the form of scripts, code, or files are used as independent solutions. These configuration artifacts can be plugged in and/or executed by others with minor modifications. This is especially useful in adding a feature, adding a patch for a bug, fixing configurations, and copying recording profiles and other configurations from users who succeed in accomplishing a particular setup. In this section, I describe three cases that illustrate how configuration artifacts are used to help share new ideas and solutions, test configuration settings, and find a missing file critical for maintaining the system without breaking it. These are essentially standardized, out-of-the-box solutions that users do not necessarily have to understand or modify. The solutions can be directly adopted and used as they are.

Phil, a member of the MythTV user community, volunteered to share a perl script file he developed that could be used with MythStream (an optional feature to watch streamed online media on MythTV) to get on demand video content from ABC Australia. He gave a brief introduction to what the script could do, as well as detailed instructions on what to install and where to put the script:

Aussies, I've written a couple of harvesters that can be used with MythStream to get on demand video content from ABC Australia. [...] They both use the perl module LWP::Simple so you'll need to make sure that's installed. Put them in your MythStream parser directory (in my case that's /home/MythTV/.MythTV/mythstream/parsers) and make them executable. Then add these lines to your streams.res file: [code lines omitted] Hope someone finds these

```
useful. I find it great for getting news on demand. (ML: Jul 1, 2006, Phil)
```

Supposedly, no modification was necessary for other users to make the script work as it did with Phil's Mythbox. This is just one of may examples of how MythTV users share the scripts that they create, including instructions for how to run and modify them when necessary.

Configuration files are not only shared as a complete solution to a problem, but sometimes as a way to test various configuration settings. In the following example, one Australian user trying to configure his TV listings grabber failed repeatedly. Another user suggested trying his own configuration file to see if it would solve the problem:

There has been some noise about the configure option not working. I have attached \*my\* config, in case it helps you build your own without using the configure option. (July, 2006. ML. David)

David's configuration file worked perfectly for Michael:

```
Works perfectly! Thanks... that's what I needed (I started to build one by hand today... but you saved me the work...) (Muly, 2006. ML. Michael)
```

If David had not shared his configuration file, Michael would have needed to build his own configuration file from scratch. The sharing of configuration artifacts is useful for exchanging ideas, new functions, and solutions. Likewise, sharing configuration artifacts is useful for efficiently testing various configuration settings. When users know exactly which files they need but do not have access to them, because the files are either outdated or uncommon, they turn to the community to

find the artifact they need. In the following example, Steve made a small change to his MythTV system that required a specific installation package in order for his system not to break. Unfortunately, that package was not available because it was too outdated:

I was just moving my ATI remote from my frontend to my backend (becoming both), and discovered I am running a sightly different kernel version.

I need the lirc-kmdl package for 2.6.16-1.2115 Anyone out there running 2.6.16-1.2115 ..... I would really appreciate your rpm from your yum cache ..... atrpms seems to move everyday, and I hate to upgrade my kernel for this ..... things might \*break\*!!!! (July, 2006. ML. Steve)

MythTV systems are quite fragile—if any part of the configuration changes, the whole system could easily break. Installing a new version of a driver might break other unanticipated parts of the system. Accordingly, if the intent is not to rebuild the whole system, it is important that members always maintain the current configuration of their systems. However, since technologies such as drivers, installation packages, and patches evolve and are updated at a rapid pace, users often have to find a specific older version. They sometimes also have to solicit help from their peer members who may still have the specific outdated version of the files they are looking for.

Thus far, I have discussed situations where configuration artifacts are successfully shared and adopted as solutions. However, since each user's MythTV is individualized, it is often difficult to use configuration artifacts as executable

solutions right away. In the next section, I talk about how the use of configuration artifacts breaks down due to the individualized nature of MythTV systems.

#### BREAKING OF CONFIGURATION ARTIFACTS AS HELP

Providing help through configurations as blackboxed solutions is an ideal solution in certain situations. However, because each user's system settings are unique, blackboxed solutions do not always work. For instance, Phil's script for streaming videos from a movie channel to MythStream was designed for Australian users who wanted to watch ABC Australia. If UK residents wanted to get content from BBC through MythStream, they would have to study, understand, and modify Phil's script to make it work for UK residents' particular configuration settings. Even among users who appear to have similar configuration settings, unanticipated problems occur that make it difficult to transfer one-size-fits-all knowledge because MythTV systems are increasingly sensitive to compatibility issues.

When MythTV user community members are given configuration artifacts that they could directly adopt and use, this process often breaks down because the solution does not immediately work. Members regularly have to modify solutions to make them work for their settings. However, modifying configuration artifacts requires expertise and not all members have the requisite knowledge. For instance, MythTV user Farmstrong was having audio problems with his Mythbox. He found a set of instructions online that provided a configuration file he was advised to

modify to use for his specific audio problem. However, Farmstrong did not know how to modify the file:

I found this online, and I know it says to tweak it, but i'm not sure how to do that. [providing content of the configuration file] (July, 2006. ML. Farmstrong)

Another member, Mtdean, volunteered to help modify the configuration file after Farmstrong fixed one thing:

Your ALSA install is severely broken. Fix it first, then I'll help with the ALSA configuration file (if it still doesn't work)... (July, 2006. ML. Mtdean)

Farmstrong ended up not being able to fix the ALSA install. Mtdean never replied back to help out with the problem. About a month later, Farmstrong posted a new thread about the same audio problem again, this time extensively describing his configuration setting information about audio input and output. Mtdean replied suggesting that Farmstrong modify a part of his configuration setting, and this advice solved the problem. Other cases similarly illustrate how direct adoption of configuration artifacts as help can break down for a user's individualized configuration settings. Accordingly, members often need to adapt other users' solutions and workarounds to make them fit their situations.

To provide another example, Hugh had problems making a shared configuration file do the work he wanted. Another member shared his strategies for modifying the configuration file, helping Hugh infer how he could modify his own configuration file to eventually solve the problem. Hugh wanted to set up a dual monitor setting for his MythTV system where one monitor would show regular

computing activities and the other would show MythTV. He searched for existing solutions and found that the official documentation had instructions for setting up a dual monitor setting that came with an attached configuration file. According to the documentation, he could just run the configuration file on his system and it would do the work. However, when he ran it, it did not do what he expected. His system now showed MythTV on both monitors. In order to solve this problem, he needed to understand the major configuration artifact used for solving this problem, the xorg.conf file. Part of what a xorg.conf file does is manage configurations of advanced input devices and output to multiple monitors. Even though xorg.conf is part of the XWindows system and not MythTV, the MythTV official documentation shared a modified xorg.conf file that would permit using MythTV with two TV monitors. Accordingly, Hugh needed to modify the xorg.conf file distributed in the official documentation, but he had a hard time making it work for his setup:

xorg.conf file [in the guide] is configured for TV out only and does not provide for a usable CRT/Monitor to do normal computing. I have tried modifying the xorg file using Jarrod's initial information and adding a second monitor, device and screen, without success. After several hours of experimentation I need some help/direction. (ML: Jul 7, 2006, Hugh)

For Hugh, understanding and modifying the shared information was challenging. Goh, who had a similar experience, was able to help Hugh by walking through Goh's modification to the xorg.conf to set up two screens for computing and watching MythTV, and referred to his resulting xorg.conf:

```
I've done something similar. Hopefully my experience will help you. [...] Here's the process I followed to get this configuration to work:
```

```
[...] - Tweaked Jarod's example xorg.conf for the PVR-350
to fit my configuration (it became xorg.conf.tvout);
- Copied xorg.conf.tvout to /etc/X11/xorg.conf [...]
- Merged xorg.conf.lcd and xorg.conf.tvout into
xorg.conf.twinhead;
- This step required changing all instances of Screen0
in xorg.conf.tvout to Screen1.
[...] (Another online reference mentioned the need to add
a "Load xtrap" line to xorg.conf to allow the mouse to
traverse both screens, but I didn't find that
necessary.)
```

My xorg.conf.twinhead file is included below. [the code of the script included in the message omitted] (ML: Jul 8, 2006, Goh)

Using Goh's example, Hugh inferred his own way of modifying xorg.conf.

Similarly, members share their unsolicited solutions from which askers could infer individualized solutions. Members also share solutions that could work through using common configuration files across different distributions, so askers could easily develop individualized solutions:

Most distros have tools to manage /etc/modprobe.conf, so check and see what your distro has available.

Using modprobe:
Modprobe ivtv tuner8
Or this should be added in /etc/modprobe.conf:
Options ivtv tuner8 (July, 2006. ML. Dab)

In other cases, members shared detailed instructions for modifying a configuration file to make it work for various system settings. In the following example, Australian users were suddenly unable to grab TV listings data because 9msn, the website from which they scraped TV listing information, added images and blank spaces to their site to prevent scraping. The Australian users came up

with the idea of grabbing TV listings data from OzTivo, but they had to reconfigure their grabber configuration file. While the members on the thread were concerned about the amount of work that might be necessary to reconfigure their systems, one user posted instructions for how to easily modify the grabber configuration file:

```
Should be easy. Get the script from [link]
I run it from a shell script like so:
/usr/local/bin/tv grab au reg --days 7 --config-file [...]
Here's my tv grab au reg.xml config file. Put your own
XMLTVIDs where it says local=
<?xml version="1.0"?>
<config>
<!--
Insert your username and password information here:
<login provider="tvguide" user="xxxxxxxx"</pre>
password="yyyyyyyy" />
<!--
Modify the following to list the channels you wish to
grab. The 'display' attribute is the human readable
display name (currently ignored by mythTV 0.18 when
using DVB). The 'tvguide' attribute is the channel name
on the tvguide.org.au web site. XMLTV ids can also be
re-written by adding a 'local' attribute:
Note: Here is an example of a re-written XMLTV channel
ID:
<channel display="ABC Digital" tuhs="ABC-NSW"</pre>
local="ABC-NSW.tvguide.org.au" />
--> [...]
</config>
Remember to set your download type in XML in the
tvguide.org.au web ui settings. (July, 2006. ML.
Philledwards)
```

Similar to the way various scripts and code files are shared through comments, Phil used the comments to describe where and how to modify the configuration file to grab information from OzTivo instead.

This type of assistance is helpful when members are dealing with modifying configuration artifacts. Too much information regarding modification overwhelms the users. For instance, Avenard had difficulties making his Mythbox recognize hardware devices in the same order each time he booted the system. A helper referred Avenard to documentation for udev rules (a Linux configuration artifact that determines the order of devices recognized by the system) and a previous mailing list thread that described how to set up the udev configuration to fix the problem. The udev configuration information offered in the thread could be used as it was. However, for Avenard, following the instructions did not help. In order to diagnose his problem, he wanted to know more about which driver was actually handling his remote control device, information beyond what was included in the archived thread. He did not need to understand all of the udev rules—he just needed to know how to change a certain line of the udev rules file:

After reading a lot about udev, and trying a few different configurations, I've been unable to get it to work as I wanted. I guess my problems come from that I do not know which driver is actually handling the IR interface... which makes it hard to guess the correct line in the udev rules. (July, 2006. ML. Avenard)

Notice the last comment about finding the correct line to fix in the udev rules. MythTV users often need to modify only a specific part of the configuration artifact. In seeking to look solely at the driver that handles the infrared interface in

his system, Avenard did not need to understand his whole system, only enough of it to fix his problem.

As exhibited by the examples above, blackboxed configuration-based solutions do not directly apply to all situations because of individualized problems. The community helps one another modify solutions by sharing tips, offering their own solutions, and providing specific instructions, so askers can generate individualized solutions. The configuration artifacts used in the examples in this section show how blackboxed configuration artifacts need to be made transparent for users to view what is inside and make necessary modifications. The challenge lies in where to make information transparent, and how to deal with the information that is revealed through the process of converting a black box into a white box, or "whiteboxing."

#### **DISCUSSION**

The sharing of configuration artifacts as a help activity raises many concepts worthy of discussion. The notion of color/transparency in configuration artifacts shows an interesting dynamic that users have to overcome as they encounter individualized problems. MythTV users face a common challenge as they share configuration artifacts as help. That is, the users have to deal with a gap between what they need to do and what their technical abilities permit them to do.

Configuration artifacts are not just tools to contextualize and be utilized as solutions. They also serve as boundary objects through which the community can

place references, analyze, and generate solutions, helping the community communicate more efficiently. Next, I discuss three related concepts—dealing with transparency, crossing customization and appropriation gulfs, and configuration artifacts as boundary objects.

# **Dealing With Transparency**

The notion of transparency as a system's ability or parts to reveal its content and be modified has been discussed extensively in the software engineering literature. "White box reuse" (Poulin, Caruso, & Hancock, 1993) refers to reusing software artifacts through modification for new project requirements. On the other hand, "black box reuse" (Brereton & Budgen, 2000; Mørch et al., 2004) allows software components to be reused "as is," without modification (or with only limited customization of parameters to allow for some flexibility).

With regards to MythTV, reusing blackboxed configurations is the easiest way to get help from others. However, as previously mentioned, these artifacts often require extensive effort to understand how to reuse them and to then modify artifacts to work for specific problems. This reuse process reveals how the transparency of a configuration artifact often switches between black box reuse and white box reuse for configuration-based help depending on whether or not the artifact could be used as it is. Further, the configuration artifact in question needs to be understood within the overall configuration settings, which is often blackboxed. While in some cases whiteboxing a configuration is not a difficult task, in other

cases whiteboxing is a skill that needs to be learned. This was the case for Farmstrong, who had difficulty modifying an audio-related configuration file. His difficulty lay in knowing which part of a configuration artifact should be opened and how to utilize that information. As seen in the case of Philledwards, who taught MythTV community members how to modify a grabber script by commenting in various places on the script, the transparency of a configuration artifact has to be compartmentalized—opened up just enough to solve the problem at hand. The case of Avenard also nicely illustrates how the transparency of the udev rule needs to be componentized so that a user would learn to modify only the parts that need to be modified to solve the problem at hand.

In summary, MythTV configuration artifacts generally do not have determined transparencies of their own (they are all available for inspection with a text editor). Rather, their effective transparencies are negotiated through use. Phil's Perl script for Australian users was technically whiteboxed, but was shared with others as black. Hugh's xorg.conf was treated as blackboxed by the official documentation, but had to become white in order to work for Hugh's needs. One of the biggest challenges in configuration-based help is the process of blackboxing artifacts, then re-opening (whiteboxing) and closing them again to be shared as blackboxed configurations for other potential users. The critical problem in configuration-based help, however, is not only about making configuration information black or white. Determining which parts of the configuration and what other parts of the system's configuration need to be transparent is critical.

MythTV users need some form of gray box reusability (Wulf et al., 2008). For MythTV, configuration information is shared with great transparency, no transparency, or partial transparency, depending on the context of the problem. Gray-boxing would be a more systematic way of allowing users to simultaneously ignore details when possible, open up a configuration artifact completely if necessary, and deal with parts as required. While providing such facilities would be challenging, supporting graybox reusability could facilitate sharing and learning about how to modify reusable objects solutions.

## Navigating the Customization and Appropriation Gulfs

For MythTV, customizing the parameters of a blackboxed component is not always sufficient for dealing with the many sets of configuration differences among user community members' systems. More than mere parameterization is required to reuse a solution or a configuration artifact and to collectively diagnose problems. At the same time, the complete transparency offered through white box reuse is unnecessary and burdensome. The following section describes the gap that exists between the skill for enabling customization and appropriation that requires handling whiteboxed configuration artifacts.

For many MythTV users trying to solve individualized problems, finding the right solution to adopt and understanding how to appropriate it are technically challenging tasks. As discussed earlier, Won et al. (2006) referred to MacLean et al.'s work (MacLean, Carter, Lövstrand, & Moran, 1990) in describing the

customization gulf—the considerable effort and skills necessary for moving beyond simple parameterization. Similarly, a significant amount of experience and skill is required in order for MythTV users to go beyond the simple tweaking of solutions in the official documentation and FAQs in order to reuse solutions available in the wiki and on the Web. For example, Hugh, who had to modify xorg.conf to make it work for his particular needs, needed someone to guide him through the "gulf" to modify his configuration file.

As Hugh's example demonstrates, MythTV users often have to understand the "appropriability of a solution" (Huh et al., 2011), that is, knowing which existing solutions can work without modification and knowing whether a solution might be appropriated for individualized use. The problem of how much a solution can be modified is referred to as "the appropriation gulf of solutions" (Huh et al., 2011).

The appropriation gulf is widened in the MythTV community due to the wiki lacking context about how up-to-date a solution might be, for whom a solution does not work, for whom a solution works best, and in what circumstances a solution was originally created (all of which are generally better described in the mailing list archive than in the wiki). It is difficult for users to see a decontextualized solution and then decide how they might adopt that solution for their own particular settings. This is when users turn to the mailing list for help, because it is difficult for them to determine the appropriability of potential

solutions. An asker with a seemingly unique problem may not initially realize how he could utilize an existing solution to address additional problems.

Mailing lists or forums are better for helping members overcome the appropriation gulf in that they allow people to creatively repurpose solutions for unanticipated problems. For example, one user posted on the mailing list the desire to create a quiet living room by moving his backend server to another room, meaning that he had to deal with the wireless (or wired) connections between the frontend and the backend. A second user replied that he used MythTV with his laptop through a wireless network. This helper was able to give advice about the resolution of movie files given the constraints of the wireless network. A third user posted a more advanced way of utilizing a wireless network for using MythTV in his truck. He was sending video files every night to the truck from his basement, a setup which could be utilized for other circumstances such as using laptops or creating quiet rooms. The asker did not initially ask about MythTV's use in laptops or trucks to solve his problem with noise in the living room. However, helpers who understood the key technical challenges in making a room quiet were able to bring in appropriable solutions for that particular problem.

The customization and appropriation gulfs create a barrier for users when they attempt to move beyond appropriating official or "safe" solutions to find potential solutions for their individualized use. Helping users understand which potential solutions might be modifiable and helping users know how to appropriate those solutions would be useful.

### **Configuration Artifacts as Boundary Objects**

Configuration artifacts contain knowledge about the configuration information of a system, or how a system can be configured. As examples of configuration artifacts, I discussed scripts, configuration files, and error messages. Configuration artifacts can be conceptual or material. Configuration artifacts work as conceptual entities that help MythTV community members construct shared context upon which they can collaboratively build individualized solutions. Example cases include the use of error messages and outputs to contextualize problems. At the same time, configuration artifacts as material entities provide executable solutions that users can plug into their systems. Examples include scripts and configuration files that members share through attachments.

When using configuration artifacts as help, MythTV users do not always understand what they mean or for what purposes they were originally created. As described in the cases related to using configuration artifacts for contextualization, users do not necessarily understand what the error messages mean, why they were created, or which part of the log to show to others when seeking help. Regardless, these configuration artifacts are shared among community members for the common purpose of solving a problem. As MythTV community members negotiate what and how much information to share, they gradually make sense of what the configuration artifacts mean and how they could help diagnose problems. Similarly, when configuration artifacts are shared as solutions, users do not

necessarily understand the original intent for how and why the configuration artifacts were created. Yet, with the common goal of solving problems, members collaboratively analyze the configuration artifacts and modify them to solve the problem at hand. The members together transform the material nature of configuration artifacts to arrive at fully operable solutions.

Configuration artifacts, with their undefined nature, coexistence of conceptuality and materiality, multiplicity, and the way they connect expertise to collaboratively construct individualized solutions connect well with the notion of boundary objects. Star and Griesemer (1989) defined boundary objects as follows:

Boundary objects are objects which are both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual-site use. They may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable means of translation. The creation and management of boundary objects is key in developing and maintaining coherence across intersecting social worlds.

Configuration artifacts are never fully understood or defined by users for what they can do or how they can be altered, yet they perform as common objects that MythTV users can utilize to help solve individualized problems. While retaining their conceptual and material nature, configuration artifacts work as common objects the MythTV community can efficiently communicate and use to share values, negotiate, produce knowledge, and transfer experiences. In the context of this work, configuration artifacts are never fully understood by all

members, but are strongly structured for local use. For instance, Hugh's case of xorg.conf for a dual monitor setting shared from the official documentation has a specific original purpose, but the file can be modified in various ways to fulfill various local needs. Xorg.conf shared from the documentation became a reference point with which members could communicate to illustrate complexity, uncertainty, failure as an individualized solution, and points of collaborative modification that members could help Hugh structure for his local needs.

I revisit the concept of configuration artifacts as boundary objects in Chapter 6, where I discuss how cases from the MythTV user community together with examples from the diabetes patient support groups expand the original exploration of boundary objects by adding temporality and transparency to the concept. In Part III below, I further examine how configuration-based help activities are placed within users' stories of maintaining their MythTV systems over time—which I refer to as use trajectories. These use trajectories again work as critical knowledge representations that members use to negotiate standards, generate norms for ideal use, and create a community pool of knowledge.

# Part III. Use Trajectory Alignment and Negotiation Work

In Part III, I describe how individual use trajectories, stories of how users maintain MythTV systems over time, and community use trajectory, the community's shared understanding toward an ideal way of maintaining MythTV systems over time, are used as critical resources for providing individualized help.

Users generate meaning out of the work of comparing and inferring from one another's use trajectories. The term "trajectory" is derived from Anselm Strauss (Strauss, 1993) who explained 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.

Strauss used the concept of trajectory as a way to describe how people make sense of everyday activities. He used trajectory to describe various social groups, such as doctors, nurses, or patients themselves, as having important roles in creating norms and generating meaning in a patient's experience of an illness over time. The notion of trajectory has also been applied to organizational memory to understand how the past informs current practice and how projected consequences and assumed trajectory affect practice development (Ackerman & Halverson, 1999; Hutchins & Lintern, 1996).

Strauss's use of trajectory in terms of its past application to organizational settings also pertains to the case of the MythTV user community, in that users maintain their MythTV systems over time, and encounter emerging events and new phases as they continue to maintain the systems. During this maintenance work, users encounter various stakeholders such as the developers, various vendors that sell MythTV components, and peer users. The coordination work among these stakeholders in "total" creates the experience of being a MythTV user. I discuss trajectory as a resource with which users provide help to one another.

There are two ways in which "trajectory" is used in this chapter. One is "individual use trajectory," which contains stories of how a MythTV user maintains his MythTV system over time. For example, any trajectory might start with how a user gathers various information for deciding to adopt and install MythTV, makes mistakes and encounters failures during installation, appropriates MythTV to meet emerging needs, maintains MythTV, and upgrades, downgrades, or tunes performance for improved use. More importantly, various stakeholders involved during the process—the MythTV community, other competing products, users themselves, geographic location, available computing resources, family members who disapprove of MythTV, and so forth—all require coordination in order to balance one's use of MythTV over time.

At any given point in time, when users share use trajectories, those trajectories are never complete in the story they reveal. Unlike the way the term trajectory is used by Strauss, Hutchins, or Ackerman and Halverson, where trajectory refers to complete understanding of how things happened over time, the users are sharing "partial" use trajectories that are immediately relevant for the problem at hand. Complete individual use trajectories theoretically exist, but when users share use trajectories, they reappropriate pieces from use trajectories for conveying the historical context of a given problem. When I say "users share use trajectories," I am referring to the necessarily partial pieces of use trajectories. Over time, users come closer to one another's complete use trajectories by continuing to learn about various partial use trajectories. This work of comparing, contrasting,

and inferring from parts of one another's use trajectories is what I call "individual trajectory alignment work."

Fragments of each user's use trajectory, as they surface both intentionally and indirectly throughout conversations among community members, gradually enter the "community use trajectory," which represents the second use of the term "trajectory" in this chapter, slightly differentiated from individual use trajectories. Individual use trajectories are practical and tangible stories used specifically for problem solving, whereas community trajectory refers to a conceptual shared agreement about ideal ways to maintain MythTV over time. By sharing solutions and seeing their applicability and adaptability in various individualized uses, the community generates what they consider to be appropriate solutions. Also, through the users' collective sharing of experiences, the community makes sense of what might be an ideal configuration setting for a MythTV system. As users share ongoing needs and ideas for new features, the developers and the user community continuously negotiate what is an appropriate developmental trajectory of the MythTV system as an open source project. In this sense, a community trajectory is a conceptual term that refers to the users' shared agreement about what is an appropriate solution, an ideal way to maintain MythTV, and a good way to develop MythTV as an open source software project over time. I refer to this work of coming to an agreed community trajectory as "community trajectory negotiation" work," borrowing the term from Strauss's (1993) "negotiated order," which describes how social order is continuously negotiated through time. Community

trajectory is a critical understanding that regular members hold in knowing how to maintain MythTV in individualized settings.

### INDIVIDUAL TRAJECTORY ALIGNMENT WORK

MythTV users often use the sequence of events and the historical background of their systems for various help purposes. As users share their use trajectories, a new kind of work—alignment—emerges. That is, users are sharing their use trajectories to compare and contrast one another's experiences for troubleshooting activities as well as to plan their future use trajectories. Through this process, users become aware of one another's use trajectories, which helps each member gain experiential knowledge, anticipate the future, understand pros and cons of various MythTV parts, and discover the most popular method of installing MythTV.

I call this "individual trajectory alignment work," because individuals share their use trajectories (partial ones) and align them (temporarily) together in various angles to collectively generate knowledge. This work happens primarily in three ways. First, because each user's MythTV system configuration settings are unique, it is difficult to predict what might happen when new graphic cards are added or when new updates are installed. Users then depend on other users' past experiences, however incomplete, to infer what might happen in the future. This is "aligning one's future use trajectory with others' past use trajectories." Second, for troubleshooting problems that do not have existing solutions, users compare their

use trajectories with others' use trajectories in order to diagnose problems and improve practices if necessary. That is, the users "align experiences," essentially utilizing empirical cases to infer solutions to a problem, rather than only relying on expert knowledge. Lastly, as a result of the ongoing experience of sharing work, users "become aware of the community's various individual use trajectories." This results in members understanding common problems and ideal solutions, discovering areas of concern, and generating new ideas for improving their MythTV experience.

# **Aligning Future and Past**

As users maintain their MythTV systems over the long term, they begin asking questions that relate to how their system should operate in the future. That is, depending on certain interventions—such as updating a driver or reinstalling the operating system—the system might undergo unanticipated consequences. Users are cautious about problems that they cannot anticipate. Accordingly, they ask for feedback about their plans, suggestions for creating new scripts, guidance for choosing appropriate solutions, predictions for what consequences might happen, and information on any future updates on system development. The common need in these inquiries is the reduction of uncertainty about the future and the minimization of any undesired consequences, accomplished through borrowing others' experiences and expertise. During this help process, members increasingly rely on sharing their past experiences. It is especially useful when a helper has

been in a similar situation to the asker's and can share what happened after they implemented a solution. Helpers also warn or critique other members when they see that a user seemingly taking action that could have unanticipated consequences. I describe several cases here that illustrate how users align future and past use trajectories.

The following case illustrates how the MythTV community provides a user with precautionary information that helps to reduce uncertainty about the future. Ivan was about to move to another state to begin school. He was concerned about any unanticipated "crisis" that his MythTV system might encounter after moving and asked for general advice:

Hello. This September, I'm going away to school. I'm moving from Minnesota to New Jersey, and I'm planning to take my Myth system with me. I have no idea what kind of cable I'm going to run into (that is to say, quality of service, channels available, etc.), \*and\* I'm crossing time-zones. What is this going to mean when I move my Myth system, and what can I do to try and avert any crisis? (July, 2006. ML. Ivan)

To this, a member replied telling Ivan to only worry about keeping the IP address the same, and that he would not have to worry about other items:

Keep the IP addressing the same, it will make \*alot\* of things easier. Other than that, there's not much that needs to happen. Run mythtv-setup, clear your program data, set up your new lineup at zap2it, configure it as a video source, map it to an input on your tuner and run mythfilldatabase and all should be good. (July, 2006. ML. Kuphal)

With Kuphal's help, Ivan learned what he needed to be concerned with, reducing uncertainty about the future.

Similarly, Maillist was about to rebuild his system and wanted to make sure that the rebuild would not cause any serious problems. Unlike Ivan's case, the problem was not so simple—it was increasingly individualized, resulting in varied responses. Maillist was able to collect various future trajectories that he might be able to anticipate, again reducing future uncertainty. Maillist asked:

Is core 5 safe for a build. I have to rebuild my system got some new toys for it, just wanted to check before I did anything. [explains his configuration setting and what "new toys" entails] (July, 2006. ML. Maillist)

Responses varied, ranging from users who had experienced no problems with the product in question, to those who ran into manageable problems, to those who spent a week of frustration:

Its working great for me! Just follow Jarod's guide, and substitute FC5 where necessary. (Bigwavedave)

I have all stuff working like on the FC4 exept lirc.[...] I would say FC5 is safe for a build anyway, its just annoying not to have the remote working like it did in FC4. (Andreas)

I had a big headache with MySQL 5 included FC5. [...] Out of frustration, I downgraded MySQL back to 4.1, the problems went away. Eventually, I ended up going back to MySQL 5 for other reasons, and that problem didn't return. Everything is working smoothly now; but it was a week of frustration with MySQL 5 for me. So, count at least one person who had issues with the MySQL 5 part of Fedora Core 5. (Kane)

In this example, Maillist presented a time-point in his use trajectory along with his desire to rebuild his MythTV system with a new operating system, Fedora Core 5 (FC5). He wanted to be able to anticipate what would happen as a result of upgrading his system. He asked the community to share their expertise around this

particular experience. The members who had experience rebuilding their systems with FC5 explained what happened for them. Andreas mentioned FC4's trouble with the remote, as if the problem was well-known in the community. Such shared prior experiences influence members' expectations for the future. Andreas asserted that Maillist would not have to worry about the remote problem based on his own past experience with FC5. Kane also shared his problems with MySQL5, which no other member had mentioned, indicating that afterwards, the trouble with MySQL disappeared. This served to reassure Maillist that unsolvable problems would not emerge as a result of the operating system upgrade. Through the shared experiences of others, Mallist was able to gather various potential future trajectories that he might experience, reducing uncertainty about the future.

The cases of Ivan and Maillist illustrate how users align common points in their use trajectories to help members see one another's trajectory before and after the point. This is individual trajectory alignment work, specifically the act of aligning future and past trajectories.

Ivan and Maillist's cases illustrate how aligning future and past trajectories reduce members' uncertainty about the future and help generate necessary preventive measures. Alternatively, the following case portrays how more experienced users warn about potential negative consequences so other users can avoid them. A user posted asking for advice about how to partition his video storage. In response, multiple members shared various partitioning schema, discussing the pros and cons of different choices. One member, G8ecj, then

warned, using illustrations from his past experiences, that in addition to the partitions themselves, how to connect and control them was important. He then contrasted his prior approach with his current one, shown through iterative tests of various connections. Through his post, other members learned new things about partitioning—the power of controllers and cables—that influenced the efficiency of the system. G8ecj presented concrete solutions that could help improve current practices of the members. G8ecj started his post with the following:

A word of warning about controllers, cables etc. This is what I've just discovered on my own system and may be relevant to others.

### He continued to explain his particular partition to contextualize his setting:

I have 2x PATA 250G drives partitioned as 50G raid1, so I have a full mirror (raid1) for the OS and stuff I REALLY don't want to lose such as email and 200G raid5, and 2x SATA 200G raid5 to give a total of 4x 200G partions in the raid5 array. This array gives me 600G of raw space that has LVM2 on it to split it into resizable partitions with various filesystems appropriate to the data being stored (eg. JFS for Mythtv recordings, ext3 for pictures)

#### Then he explained the past connection scheme of the drives:

The way I USED to connect them:

- the pair of 250G PATA drives on one port of the  $\ensuremath{\text{m/b}}$  controller
- DVD writer + exchangable drive on the other PATA  $\mathrm{m/b}$  port
- the pair of 200G SATA drives on the m/b SATA ports

### He then critiqued his own prior connection and presented the test results:

Note that the raid1 disks were on the same cable - BAD NEWS. A few tests after having problems burning DVDs showed I was getting transfer rates down at about 4M/s -

probably because both raid1 and raid5 want to write to 2 disks at once which can't be done if they are on the same controller port!!

Next, he presented the solution to the problem, which resulted in a success case that other members could adopt:

The way I NOW connect them after dusting off an old PCI IDE controller:

- the pair of 250G PATA drives on seperate ports of the  $\ensuremath{\text{m/b}}$  controller
- DVD writer + exchangable drive on a Promise Ultra100 TX2 PCI card
- the pair of 200G SATA drives on the m/b SATA ports

Finally, G8ecj presented the positive outcomes that the changed connection could bring:

Without having to change any conf files, the raid arrays configure themselves in the new arrangement and my transfer speeds are up to 18M/s (May, 2006. ML. G8ecj)

G8ecj's case illustrates how the members actively align parts of their use trajectories to help others who might benefit from the work. G8ecj briefly discussed some of his past trajectory, specifically around a common point—optimizing partition schema—that members on the thread shared from parts of their use trajectories. As a result, members were able to learn new things about partitioning from G8ecj's use trajectory. This work of "warning" is similar to "critiquing," which has been identified as essential for giving tailored help (Fischer, Lemke, Mastaglio, & Morch, 1991). The core emphasis of the alignment work is that members are

utilizing tangible illustrations of their use trajectories rather than their assumptions or filtered knowledge.

As I described in Part II about configuration-based help, one of the core values in the MythTV user community is communicating through evidence such as configuration artifacts or anecdotes. Additionally, "firsthand knowledge" is welcomed, as one MythTV community member said, "[...] if anyone has first hand knowledge, it would be much appreciated" (Aaron, Dec 2009). However, when community members encounter conflicting answers or varying experiences, it is important that they can provide "real-world figures" that will help distinguish individual differences more efficiently:

Do you have any real-world performance figures for your installation? If you don't have performance numbers, how many videos have you been able to move at a time, have you tried HD, what distance apart are your units? Could you describe your setup? Do you live in 110 or 220 volt territory? (I wonder if the two systems have performance differences) (July, 2006. ML. Beww)

This particular post came from a thread that included conflicting performance outcomes for wireless frontend (storage/recording device and MythTV system being connected through wireless). In order to address individual differences and understand outcomes, comparing tangible descriptions, such as one another's use trajectories, becomes important.

### **Aligning Experiences**

By "aligning experiences," I mean the work of comparing and contrasting use trajectories that may seem similar but have important differences. Comparing one's use trajectory to those of others with similar experiences could serve to diagnose the problem (e.g., we have similar configuration settings but I am the only one who has trouble with audio) or improve the system (e.g., we have similar configuration settings but my system is much slower). By detecting differences, users could infer what might be causing their problems and areas where their systems might be improved. Overall, side-by-side comparison of use trajectories help to troubleshoot, contextualize individual differences, performance test, share solutions, and build an information base for solving problems. Also, members want to know if any unusual experiences they encounter are "normal" by comparing their experiences with others and identifying similarities and differences. In the following example, I describe how members shared use trajectories to troubleshoot, test performance, and to attempt to find out if what they were experiencing was normal.

Comparing use trajectories is often helpful for performance tuning. One user, Migmog, posted a question about how he should revise the current configuration setting of his MythTV system to reduce power consumption. Another member was impressed by how little power Migmog's system consumed and wanted to know how the system was set up. He offered his current setup so that a

comparison could be made, as well as his desire for how his system would operate in the future:

Wow, that is some great power consumption. My combination backend/frontend uses 100w idle and 15-20w more when active. :( It's a Duron 800, 2 PVR250s (10w each idle!), GeForce FX 5200 and a single 250gb 7200 drive. I estimate that replacing the Duron with a Sempron 3000 will reduce idle power by 10-15w, but I'd really like to get power utilization under 50w when idle. 14w would be awesome, can you elaborate on the setup of each of your boxes? (July, 2006. ML. Drees)

Drees presented his current power consumption and the hardware configuration of his MythTV system. He also presented his potential plan to replace his CPU, speculating about his possible future trajectory. Migmog responded to give more details on his system as well as various options that he had explored for setting up his current system:

Backend is small form factor Compaq ENS, PIII 550MHz, 256MB Frontend is a VIA M10k. It does not break a sweat using the hw mpeg decoder, though I should have gone for a fanless model as then there would be no moving parts other than a DVD drive, and would use less power still.

NAS is a Maxtor shared storage. Runs linux and has been neatly hacked (Openmss.org) so you can run your own programs on it. Has USB ports so I have connected my printer, and a VCD screen (plumbed through to the frontend so the frontend does not need to be on to display a clock). (July, 2006. ML. Migmog)

Migmog not only explained his current settings, but also explained how his frontend had never caused any problems with a movie file converter. He presented a possible alternative option that he could have pursued in setting up his frontend, and also mentioned the past history of his shared storage—that it had been neatly hacked. Migmog and Drees were not only sharing information about their current

systems side-by-side, but also alluded to their use trajectories. This work of aligning use trajectories helped Drees understand how he could improve his system to reduce power consumption. The thread continued with other members adding their ideas for how Migmog could improve his system's power consumption.

Members' comparing use trajectories also helps to determine if a problem is idiosyncratic or relatively common. In the following example, Robert had difficulty fetching TV listings information. He was unsure whether it was particular to his setting or if it was the fault of the grabber script—tv\_grab\_au:

Hello all fellow tv\_grab\_au users,

I have a strange issue with v2.11 of the immir tv\_grab\_au script. I just completed a fresh install of the mythtv system and hence grabbed the latest tv\_grab\_au script v2.11. (I am using knoppmyth install R5C7) After sorting out the perl dependences and getting the right java script going I ran the script and notice that it was unable to pull all the show details down. It has all the show times and titles but no details. [explains he has checked the forums but nobody has mentioned the same problem]

So my question is - Is everyone's v2.11 script working fine? And if not is it another 'tweak' by ninemsn that has upset it? Or have I done a silly thing in the install? (I will assume that if it works for everyone else then I have done something silly...opps) Any help is much appreciated. Thanks. (July, 2006. ML. Robertmc)

Notice how Robert asked "fellow tv\_grab\_au users." When side-by-side comparison occurs, users generally have some shared context that is worth comparing. Robert then proceeded to describe the history of how he reinstalled his MythTV system and the script, up to the point when the problem occurred. By seeing if others had similar problems, he could determine whether the problem

derived from his installation process. Another member posted a letter from a developer stating that there was a problem with the script, informing Robert that it was not his system setting that was problematic. Another user replied to say that he had been having some issues with the script as well and presented his experiences through "testing results":

[...] Just to add some testing results from Melbourne. Last night, I changed my Melbourne config to the Sydney one. That worked perfectly. So it would seem that Sydney-based settings work fine... (I think I read that somewhere else in the forum)

I just noted that there are some code mod's have been posted today for tv\_grab\_au... I'll test those as soon as I blow a problem away here at work..

But for now, if you are in anywhere other than Melbourne... And you can't use Sydney settings for the time being.. You might have big problems.

Hope that sheds some light on it. (July, 2006. ML. Michael)

Michael shared his testing results that showed there were no problems with the script for Sydney users. He also promised he would share additional testing results using the modified script that was scheduled to be posted that day. Michael's response included his past problem with the script in supporting Melbourne users, his testing process and results, and what he planned to try out in the future. Michael and Robert shared use trajectories around the problem of grabbing TV listings information to determine whether it was Robert's system or the script itself that was at fault. The thread ended without any real conclusions, but it still serves

to illustrate the work that members perform to determine whether a problem should be of concern.

To summarize, the MythTV user community share their use trajectories and align them side-by-side to examine differences and similarities. This work supports troubleshooting activities, improving practices, and determining the severity of problems. Through the ongoing work of aligning future and past use trajectories as well as side-by-side comparisons, the members build an awareness of one another's use trajectories. This allows members to benefit from the experiential knowledge of many others in the group.

# **Being Aware of One Another**

Members collectively sharing use trajectories helps the MythTV user community as a whole to learn from one another's mistakes, failures, and successes as they monitor and participate in conversations on the mailing list. Because they understand that seeing others' progression over time is valuable information, members provide follow-up on whether solutions worked and whether they encountered any unexpected problems. Members also share their decisions and future plans, their ongoing struggles, and how their use trajectories evolve over time. It is important to note that such reporting and sharing behaviors are only observed from those who do report, thus the findings presented here do not represent every member's activity. Rather, the findings reported here describe the visible work that is being done in the community.

In the next section, I focus on how members update their use trajectories to the community. I describe how members provide (or fail to provide) follow-up information, and how they report their future plans and decisions to inform the community of the stories that could have become invisible to the community otherwise.

The following case describes how a MythTV community member, Jake, updated his progress regarding various solutions that were suggested by the members as well as some that he found himself. At the same time, other members who had similar problems, but with different hardware configuration settings, updated their progress. Even though their systems were individualized and their end solutions did not work for everyone, by sharing their progress over time, the community members collaboratively learned individual differences for problem-solving.

Jake initiated a thread about his system's stuttering audio problem. Other members suggested that Jake try various diagnostic tools—disabling audio connections and checking whether he had the right kernel version. Jake then responded with information about how his system reacted to the suggestions. The suggested solutions did not work, but then Jake located a thread that might be relevant to his problem. He promised the community that he would report back what happened:

I found this thread: http://www.mythtv.org/pipermail/mythtv-users/2005-

```
December/114730.html. To try to fix the PCI issue, I'll let you know what happens. (July, 2006. ML. Jake)
```

The solution in the thread worked. Cbrabandt, another member, had the same audio stutter problem and suggested Jake try various diagnostic methods. However, Jake and Cbrabandt had different hardware configurations. Cbrabandt volunteered to let the thread know whether the suggested solution that did not work for Jake would work for him:

```
> do you want to try out alsa-driver 1.0.12rc1 on it,
> maybe it fixes it. There are 1.0.12rc1 kmdls for
> FC5 at ATrpms (in the testing repo). If they
> don't serve the pupose you can easily remove
> them again.

Thanks, Axel (and thanks for all the rpms)!

Jake and I are on different Via chipsets (I have P4M800Pro / 8237) so I'll try this over the weekend too. I've never had a problem with Xine, however--only MythTV. (July, 2006. ML. Cbrabandt)
```

Even though Jake and Cbrabandt had different configurations that could possibly require different solutions, they both followed up on the thread about their diagnostic methods and solutions. Jake shared what the results were regarding the solution thread he found:

```
I HAVE IT WORKING!!!!! This solved both my stutter and my xine problem.

edit /etc/grub.conf

and modify your kernel line adding to the end:

noapic nolapic pci=noacpi acpi=off

I believe what really solved it was the pci=noacpi and acpi=off but I do not need apic either so it won't hurt.

Anyway this solved all the porblems I have been seeing.
```

Glad to finally track this down. Try it out and let me know if it works for you. (July, 2006. ML. Jake)

The solution eradicated the audio stutter problem. Jake summarized what needed to be done in order to solve the problem. Notice that Jake asked Cbrabandt if the solution was still relevant for his situation. Unfortunately, Jake's solution did not work for Cbrabandt. Cbrabandt further explained how he attempted to solve the problem:

I tip my fedora to ya'! That's great news. Unfortunately, it didn't help my stutter. I've played around with the .asoundrc file and I can can change the nature of the stutter slightly, but it still stutters. I've changed the period\_size and buffer\_size parameters and also tried dxs\_support=4 and dxs\_support=0. [...] (July, 2006. ML. Cbrabandt)

Cbrabandt continued to ask for assistance, presenting his configuration file. Jake, who had the exact same settings as Cbrabandt, suggested the solution that had worked for him. That solution also failed to work for Cbrabandt. Cbrabandt again replied to Jake to the thread, updating possible causes for his problem:

Jake,

I think I'm understanding my stutter problem better and I also think it's not the result of the same problem you had. I'm running the Unichrome Pro chipset on an ECS P4M800Pro-M mobo and the Pro is supposed to work with HD mpeg2. [...] The audio stuttering is due to Myth trying to keep the audio in sync by inserting dead spots in the audio to keep the audio from getting ahead of the slightly slow video. I have the same problem when playing "live TV" or recordings--there's no difference.

I'm going to have one more go with Knoppmyth and see if it knows how to setup this board. If not, the board is going back to Fry's! [lists a number of things he will try] (July, 2006. ML. Cbrabandt)

Even though Jake had already solved his own problem, Cbrabandt continued to update the solutions he tried, what did or did not work, and what he planned to do in the future. Another member, Newbury, entered the thread to say that the solution that had worked for Jake created a new problem for him, asking for help to fix the problem:

I added them [the solution that worked for Jake] to the kernel line for my Via SP130000 and...

myth stops playing about every 8 minutes, the screen freezes, the sound starts a short loop, like an jumping needle on a vinyl record, and weirdest of all, the power LED on my case starts flashing on and off. (July, 2006. ML. Newbury)

Another member offered Newbury a solution to solve the problem and the thread ended. This thread illustrates how members continually update their progress with regards to the various solutions that are suggested and what they plan to do in the future. They make explicit promises on the mailing list to update their progress. Even though Jake's problem was solved, Jake asked others to tell him whether the solution worked in other settings as well. Through sharing how a solution worked or did not work in different settings, the community gains a better understanding of individual differences around a common problem. It should be noted that members often fail to report their progress, despite their promises to do so.

Members' reporting progress in various individualized situations helps members understand problems in greater depth. At a broader level, community members slowly build their understandings about common issues related to the MythTV system. Some of this community-based knowledge is transferred into the

wiki's FAQ section, and some continues to surface through hearsay that the members share within their conversations:

I've heard from numerous people that XFS has worked wonderfully for them. They said it does much better on the bigger files. (July, 2006. ML. Timothy)

Further, there was a thread about 3 weeks and several persons, me included, complained that when the fs gets about 90% recordings get corrupted. (July, 2006. Mario)

If using MythTV 0.19, do /not/ use MySQL 5 because you'll lose connections in the scheduler. If using MythTV 0.19-fixes, either should work (although I'm still using MySQL 4 and have heard of people losing connections with MySQL 5 even on SVN head). (July, 2006. ML. Mtdean)

The most common card people used for HDTV in the dawn was the Geforce 5200 (July, 2006. ML. Brad)

I use the pchdtv card, and play the raw mpegs back directly. A lot of people transcode though. (July, 2006. ML. Mark)

We've seen discussion of people keen to build RAID arrays for their myth boxes and other forms of backup. (July, 2006. ML. Brad)

The unspecified "people" in the quotes refer to the members who participate in the threads. The examples illustrate how members learn from the threads, whether or not they participate, and continue to use what they learned from the conversations not only for their own use but also in conversations with others.

Members of the community continually work to remain aware of one another's use trajectories, about specific problems and troubleshooting processes or more general experiences.

So far I have discussed individual use trajectory alignment, where members share their individual use trajectories to reduce uncertainty about the future, learn how to avoid negative outcomes, troubleshoot, upgrade system performance, and come to a fuller understanding of individual differences in the behavior of their systems. Individual use trajectory alignment then refers to practical and procedural help activities that the members perform using vignettes from parts of their use trajectories to get individualized help.

In the next section I further discuss the ongoing alignment work of feeding members' use trajectories into the community's trajectory as a whole. Community trajectory negotiation work refers to more conceptual work than individual use trajectory alignment work, which tends to be centered around practical activities. The term "community trajectory" refers to shared understandings about how things were before (such as FC4 used to have issues with remote controls), how things are now (such as what is the best way to set up a wireless frontend using the technology available now), and how things should be in the future (such as MythTV should have a feature for sharing recording profiles). The community's trajectory is negotiated through the alignment of various arguments, perspectives, problems, and solutions that are produced out of individual trajectory alignment work. This process of negotiation is what I refer to as community trajectory negotiation work.

#### COMMUNITY TRAJECTORY NEGOTIATION WORK

The arguments, perspectives, problems, and solutions generated through individual trajectory alignment work are constantly challenged, confirmed, and negotiated. The resulting outcomes deepen the community's understanding of specific problems and solutions and of ideal ways to build and maintain MythTV systems, and result in an agreed-upon trajectory of how the MythTV system should be developed over time as an open source project. As users post problems and solutions, community members challenge, revise, and confirm one another's solutions, leading to a richer understanding of common problems, individual differences, and exceptions. Furthermore, as users share one another's experiences with their own settings, the community as a whole is able to understand different perspectives on various system settings that would affect their MythTV systems. As community members collectively piece together a holistic picture of the ideal ways to maintain MythTV systems, generate solutions, and fulfill user needs, they construct a collective understanding of how the MythTV system as an open source software project should be developed over time, and how one should manage MythTV. These agreements constantly evolve, and it is important that the MythTV user community members keep updated with one another's trajectories in order to avoid potential individual problems and solve the problems they do encounter. In the next section, I discuss negotiated solutions, negotiated norms of an ideal MythTV system, and aligning trajectories of MythTV development.

### **Negotiated Solutions**

As shown by the cases related to individualized maintenance practices of MythTV systems I have discussed so far, it is difficult for the community to find answers that would work for all settings. Accordingly, mailing list contributors challenge one another's opinions, point out exceptions, and provide alternative solutions. Through negotiation, the community re-evaluates solutions and build upon one another's experiences to gain a more complete understanding about problems, especially around individual differences and the applicability of solutions. Next, I describe a case that illustrates how users encounter conflicting solutions, share diverse alternative solutions, challenge ideas with counterevidence, or confirm solutions with similar experiences, deepening the knowledge about a specific problem and negotiating appropriate solutions for various individualized settings.

The following case involves a thread of 24 messages by 15 different members. This thread shows how there can be many strategies for solving the problem of setting up a wireless frontend, and how the community collaboratively negotiates appropriate solutions. One member stated that a solution worked for him, then another member challenged the solution by questioning its adaptability, cost, and sustainability. Other members also posed counter-evidence. Through this exchange, instead of coming to a unified solution, the community established a dynamic boundary defining what is feasible, realistic, and ideal. The community

learned the factors that might change the feasibility of the ideal solutions, what the exceptions are, what should not be done, and various appropriations of the solution, all from collecting what members experienced about the specific problem.

The thread was initiated by a member who wanted to set up a wireless frontend for his living room while having the backend upstairs, but was unsure whether this was possible. Respoding to this post, Phill informed the asker that it worked for him but with a certain caveat:

...For a quick answer, yes, it can work depending on your recording settings. My settings end in a 2.2Gig/hr file and it plays well, but has a few hicups now and again. (Phill)

Beww challenged Phill's positive response to suggest why Phill might have had a glitch. Note that his practical scenario was backed up by theoretical reasons rather than personal episodes:

While it is theoretically possible to use an 802.11g link for a single SD video, in practice it requires an absolutely ideal situation for it to work glitch-free.

You need to have just about perfect signal reception, no interfering signals (microwave ovens, 2.4Ghz. cordless phones, other 802.11 devices etc.) and no 802.11b devices talking on the network.

Bear in mind that your neighbor's appliances can cause trouble as well as your own. So if you have absolutely no alternative you might give it a try, but don't be surprised if the results are less than satisfactory. (Beww)

Beww also added hearsay about wireless frontends in the houses with AC wiring, eventually suggesting wired frontends:

BTW - folks who have tried the devices that work on the AC wiring of their homes have reported very poor results, this is apparently not a good alternative. If it's at all possible, run a wire. (Beww)

At the same time, Myth challenged Beww's cynical view toward wireless frontend by claiming that wireless frontend ran on 802.11g with some workarounds for him:

I post-processed all my back end recordings to a watchable, but rather low mpeg4 bit-rate and got my wireless front/backend combo streaming to 2 wireless front ends without a problem on 802.11g. The 3rd box caused stutter, but still relatively usable. (Myth)

Myth further provided a trick for preventing signal interference among home electronics:

The trick to getting good g signal is to turn off B on your router so any devices on the B frequency (other networks, cordless phones, microwaves, etc) don't interfere. (Myth)

Tang added to the conversation that in his experience, adding a reflector helped provide information about his configuration with which he was largely successful. Tang's reflector idea diversified the solution space, while possibly addressing Beww's concerns about interference:

I'd like to add a data point to this discussion. I'm using a backend over wireless. I transcode my SD video down to MPEG4 and end up at roughly 750MB/hr, which is a little artifact-y but seldom is it distractingly so. I've run as many as 3 frontends simulatenously (1 wired to the "receiving" wireless router, 2 wireless) and have very nearly NO hiccups at all. This is all on 802.11g and using the simple-to-make parabolic antenna reflectors found at http://www.freeantennas.com/projects/template2/index.htm 1 (the Ez-12 antenna, which honestly took me about 15 minutes to print, glue, cut out, and fold). (Tang)

Tang then continued to discuss how installing a reflector changed the outcome:

Before I used these reflectors, I would have problems getting even one frontend to play flawlessly, and I would have frequent disconnections (especially if someone started up the microwave). Once I put these reflectors onto my wireless antennas, I honestly can't even remember having any hiccups at all during playback. If you're thinking about using wireless, I highly recommend these reflectors to boost your signal - especially for my situation, where my backend is down in the basement and there's only one direction I need to radiate my wireless signal. (Tang)

Notice that Tang suggested adding a data point. This collective gathering of data points about a specific problem is a typical way for the community to learn the boundaries around which certain things could or could not be done, what is normal, what exceptions might exist, what are ideal situations, and what are varying factors that affect the situation.

Tang's unique solution was again challenged on the basis of cost and sustainability. Beww requested further details on Tang's configuration. During Tang's description of his own configuration, he provided the community with boundaries at which one might experience what he deemed "acceptable" quality, and what interventions could possibly expand that boundary:

Just for the record, I use 2 WRT54G routers with the Sveasoft firmware (Alchemy) in a WDS setup (which isn't the fastest way). I'm using the standard antennae, and the signal passes through 3 walls at a fairly bad angle.;)

I have my recording preferences at 704x480 and the end result is 2.2G/hr. Playback is smooth with occasional jitters. Fast-forward buffering isn't instant, but it's acceptable. (This would improve with a lower bitrate mpeg.) These results are with a standard PVR-250 mpeg on a 54G wireless network running WDS. Results of when

using a wireless card in the frontend should be somewhat better, I believe. (Tang)

In the midst of these success stories, another member provided his failed experience with his wireless frontend. This hinted at other workarounds that could be used to overcome the speed problem in wireless frontend settings, but it had some major drawbacks, allowing the community to see diverse workarounds and potential consequences. Other members provided links to alternative solutions for the wireless frontend, confirmed some of the suggested solutions with their own successful experiences, and provided examples of situations where the solutions did not work for particular settings.

Throughout the lengthy thread, members propose, challenge, prove, disprove, and analyze one another's real life experiences. The units of analysis are strictly real life performance measures, configuration information, and symptom descriptions that together create a rich shared understanding about a specific problem. By sharing one another's experiences and opinions, MythTV community members negotiate what would be most ideal, problematic, or appropriate for individualized situations. The community develops a shared understanding about what an ideal MythTV system would look like—which configuration settings would be safest and error-free and what would be considered top performance.

# Negotiated Norms of an Ideal MythTV System

As the community shares problems at various levels—from having trouble with the installation to missing audio to appropriating the system (e.g., installing

MythTV in a truck)—the community as a whole continuously makes sense of problem frequency, performance standards, and realistic expectations for the MythTV system. This process is actualized through individual trajectory alignment work, such as warnings from more experienced users, emerging problems shared by users with individualized settings, and comparing and contrasting one another's experiences. The community collectively establishes what is considered to be an ideal MythTV system. A newcomer might have little access to the norm, thus having little idea of how to begin—which graphics card to use, which platform to use, and which version of the MythTV system would be most stable. The following example shows that coming to know ideal ways to install and maintain MythTV system is a process learned through negotiated interaction between members. The example will also show that even regular members need to be constantly updated as to what are considered ideal ways of maintaining MythTV. A newcomer utilized the mailing list to ask whether PVR-350 (a video capture card) was a good one to choose for his new MythTV system:

I'm really new at this, so please bear with me. I have just been given a relatively new desktop, and I would like to turn it into a mythTV box. I have gotten to a point where i need to pick out hardware, and I've been reading up on capture/output cards. I hear that the PVR-350 is a good card for this project. (July, 2006. ML. Thestudx)

Thestudx had studied which capture cards would be best to install. However, he also read that playing back external video is not captured and that the encoding quality was "pretty bad." To this, mailing list member Ivan responded that it "was"

a good card for MythTV, but not any more, now that the MythTV version had changed from 0.18 to 0.19:

Well, it \*was\* a good card for the project, back with MythTV 0.18. However, 0.19 has dropped official support for the PVR-350's on-board video decoder. You'll need to go through a few extra steps to get the XVideo output on the PVR-350's TV-Out port. Information can be found on the Wiki. (Ivan)

Notice that Ivan said it "was" a good card for "the project." The fact that what Thestudx found was already outdated shows how the notion of what is considered ideal constantly changes, and those who do not keep up with the conversation inside the community—those who are not part of the alignment work—cannot easily access such changes. Also, the fact that Ivan specified whether PVR-350 was good or bad for "the project," not necessarily for individuals, also shows how understanding about the efficacy of various aspects of MythTV, such as a graphics card, is ultimately understood from the perspective of the project as a community.

Ivan further described what "pretty bad" meant in this case:

```
> but i hear that playing back external video not
captured and
> encoded by the card is "pretty bad."
```

Well, define "pretty bad." As far as visual quality goes, I've heard it's actually pretty good, and eliminates any possible problems with deinterlacing. However, I've heard mixed results as far as system efficiency goes with using XVideo on the PVR-350's TV-Out. Back with 0.18, though, when using the on-board MPEG-2 decoder, I've heard tell that non-MPEG-2 video played through the 350 wasn't that wonderful at all.

Ivan did not present any authoritative guidelines from MythTV developers saying that the quality of PVR-350 was good or bad. Instead, he was getting his knowledge

from members of the MythTV user community as he monitored conversations where members shared their experiences and negotiated expectations for performance. Ivan then transferred negotiated information from the community to Thestudx, a newcomer who had not been part of the negotiation process. The following quote from Thestudx illustrates how community norms were constantly negotiated rather than fixed:

And since I'm not all that good of a judge of what's good and bad, if someone could give me an example of what bad looks like, it would be appreciated. If it helps any, I'll be playing it back on a 32" tube TV via s-video. Thanks! (July, 2006. ML. thestudx)

Ivan suggested an ideal solution for choosing the right graphics card for a new MythTV system, based on what he had heard and learned from the community about what constitutes a good MythTV system:

It might be more worth your time and money to get an nVidia GeForce FX 5200 for your machine, and use its S-Video Out instead, and use a PVR-150 for video capture. The 5200 is a reliable card, and will help future-proof your Myth system. Depending on your CPU, the 5200 should be able to give you enough oomph to process HDTV over the DVI-Out port, and allow you to use the OpenGL animated menus that should be making their way into 0.20. If you shop smartly, a combination of a 150 and a 5200 might, possibly, cost less than a 350 (but I haven't looked into this recently, so I could be wrong). (Ivan)

Finally, Ivan stated that "I haven't looked into this recently, so I could be wrong," which pointed to the fact that the information was not fixed—it needed to be updated through social interaction in the community.

Thestudx and Ivan's case illustrates how knowledge about what an ideal MythTV system is proved to be a negotiated process between the members based on their use trajectories. A newcomer or someone who rarely participate in the community interactions and fail to become aware of other's use trajectories, as described in the individual trajectory alignment work, will find it difficult to know what the ideal is for installing and maintaining MythTV. Furthermore, even with experienced members, continuous participation is necessary to keep knowledge current. This is because norms about what constitutes an ideal MythTV system constantly changes as the technology advances over time.

Next, I describe in further detail the negotiated process that generates performance norms. The thread in the following example started with a user who wanted to know the optimal capture resolution for DVD burning that would balance resolution and file size at the same time:

I am currently capturing the video signal from my TV at a  $720 \times 480$  resolution. [...] The only problem is that the resulting data occupies a lot of disk space: A three hour show takes up some 7 GB.

What I want to do is to capture material and then burn it to a DVD. I understand that capturing at 720x480 is overkill, for broadcasts in the US do not have that resolution. My question would therefore be, What capture resolution should I use, if I want to burn the resulting material to DVD to be watched on a 32" or larger TV, while keeping the best quality without wasting space? (July, 2006. ML. 1.41421)

Another member posted to indicate what was considered as "reasonable quality," and standard rules for screen resolution based on the signal and the output format, while sharing an application with personal experiences:

You can change the width of the capture and still have DVD compliant MPEG, eg  $352 \times 480$  is reasonable quality and low datarate. Note that the acceptable output formats for DVD are (from DVD FAQ)

MPEG-2, 525/60 (NTSC): 720x480, 704x480, 352x480
MPEG-2, 625/50 (PAL): 720x576, 704x576, 352x576
MPEG-1, 525/60 (NTSC): 352x240
MPEG-1, 625/50 (PAL): 352x288

Most DVD players will play other widths also. I
discovered my exceptionally fussy Pioneer player will
play 544 wide video. (Nick)

Soon, however, Nick's rule was challenged by another rule, suggesting that instead of resolution, bit rate was what determined the file size.

File size is determined /exclusively/ by bitrate. It has nothing to do with resolution. (http://www.gossamer-threads.com/lists/mythtv/dev/74963#74963) [...] (Mtdean)

In a previous thread, whether resolution or bitrate affected file size had already been discussed and the conclusion indicated the answer to be bitrate. Mtdean alluded to this prior thread. Furthermore, Mtdean gave, along with his own experience, examples of what "other people do" that he had accumulated over the years through individual trajectory alignment work, to give 1.41421 a sense of the norm for user strategy:

Some who take archiving seriously record at high resolution/bitrate and transcode to a lower resolution/bitrate for DVD's. Others just record 720x480 and slap the show on the DVD.

Mtdean even referred to a specific user as an example of using "transcode" to make up for high quality creating a large file size:

For example, Cory Papenfuss (who seems to be pretty serious about quality) records at 640x480 with a high bitrate (~5Mbps--like yours) and transcodes to 352x480

(Half D1 resolution) with some filtering [link to the specific thread on Cory's case].

# Mtdean also described the range of effort that 1.41421 could expect:

Note, though, that on a 2.4GHz machine, transcoding takes about 3-4 hours per one hour show /after/ removing commercials (3-4hrs per ~40min of content).

#### Limitations and boundaries were discussed:

The only resolutions you can burn to DVD are 720x480, 704x480 (which isn't appropriate unless you clean the edges of the video), 352x480, and 352x240. So, if you record at any other resolution, you have to transcode to a DVD-compliant resolution. Therefore, even though the PVR-x50's electronics seem to max out at about 480x480 (and well before 640x480), the length of time required to transcode to a DVD-compliant resolution is great enough that most just record at 720x480.

### Mtdean ended his post with his own experience:

Personally, I watch and delete shows, and I just record everything at an extremely low bitrate (giving about VCR quality). After all, I watch TV for the articles and stories, not for the pictures. (Of course, that's not preventing me from setting up an HDTV system to go with my 67" 1080p TV--which is still displaying SDTV at VCR quality...)

Mtdean, through his posts, presented another rule—bit rate—and explained various applications of the rule, citing actual experiences of the members.

However, any rule needs to be constantly modified and revised as the users present exceptions and personal experiences that do not align with the proposed rule.

Another member extended Mtdean's argument about bit rate and argued that the resolution under NTSC was useless if it went higher than 270 because NTSC only had a horizontal resolution of 270 lines:

According to this (the font of all (mis)information)

http://en.wikipedia.org/wiki/Display\_resolution. NTSC only has a horizontal resolution of about 270 lines.

Ultimately you'll have to suck it and see - it will depend on the quality of the MPEG encoder, your TV reception etc! (Nick)

Also, Nick warned 1.41421 that the quality was affected by much more than just bit rate—the quality could be influenced by the MPEG encoder and TV reception.

Another member, Papenfuss, challenged Nick's understanding about resolution and added that the line numbers and resolution were separate things:

This particular subject is mis-understood more often than not. [...] The number of "lines of resolution" for analog video is related the \*horizontal\* bandwidth. Think of it as the number of alternating black and white vertical lines on the screen. Keep putting them closer and closer together until you cannot distinguish one from the other. [...] (Papenfuss)

Papenfuss then summarized what the resolution would be in relation to line numbers:

To summarize: Best possible SDTV resolution taking into account aspect ratio of 4:3 and the conservative Kell factor of 0.7 results in: Device "lines" Necessary capture resolution

```
VCR 240 240 * (4/3) / 0.7 => 457x480
OTA-SDTV 270 270 * (4/3) / 0.7 => 514x480
HQ-SDTV 330 330 * (4/3) / 0.7 => 628x480
```

This thread began with a simple understanding about the relationship between resolution and output, another factor—bit rate—was introduced, and the relationship between bit rate and resolution was discussed. Along the way, personal anecdotes related to these rules were presented in order to show "what people do" and to demonstrate what people consider to be acceptable.

The two cases described in this section illustrate how the community as a whole continuously adapts their understandings about expectations for the MythTV system, how good the system could be, and what people could do to improve their systems. Such understandings are not easily accessible. Rather, they are embedded within the alignment work of individual use trajectories. The understandings are never stable; they are challenged, modified, and improved as community members continue to encounter problems and generate solutions. Community members constantly maintain norms for what are considered to be safe ways to maintain MythTV systems over time. Members work to upgrade or downgrade to the norm by switching to commonly used devices, so that they may avoid encountering idiosyncratically difficult problems.

So far I have defined the concept of community trajectory in terms of shared understandings of solutions and norms for maintaining the system. The notion of community trajectory is intimately related to how MythTV developers advance the product over time. What are considered to be user needs and problems are constantly negotiated, resulting in conversations about whether those needs should be addressed in the future development of MythTV. In the next section, I discuss how developers and the user community together develop shared understandings about how MythTV should be developed over time as an open source software project.

# Aligning the Trajectory of MythTV System Development

Because MythTV is part of an open source project, users actively engage with the development process. MythTV software developers and users often interact through official means (e.g., bug reports) as well as informal means such as the users' mailing list. Developers have their own mailing list, but they still monitor the users' mailing list to clarify questions about MythTV features, point to existing solutions, and provide updates about new versions of MythTV software. Developers also consult with users about which features to add to MythTV, which includes discussions about the legality, technical feasibility, and philosophy of open source software. Examples include switching from the current database (MySQL) to other ways of maintaining data, developing shared recording profiles, determining whether to include a shared rating system for movies, and setting up options such as when to automatically delete files.

Interaction between the developers and users are occasionally combative.

Users and developers often disagree about which features to develop or whether they are worth developing in a series of "design wars":

The reason this list devolves into design wars ("there's a problem with Myth's impl[e]mentation!" vs "if you want it improved then code it yourself!") is because some of us start from the position of "what should myth do, given limitations caused by past assumptions?" while others ask "what would Aunt Tillie expect?" (July, 2006. ML. Chris)

Chris's point illustrates the typical arguments exchanged by MythTV developers and users. That is, users present their own experiences, needs, and expectations,

which differ from those of the developers. Developers respond by suggesting workarounds for unique problems, intending to minimize the amount of coding work that needs to be done for "fringe uses":

```
writing a lot of code for this fringe case is not worthwhile. Thus, I won't write any code for it. :) If someone else wants to write the code, please feel free to do so. (July, 2006. ML. Mtdean)
```

Mtdean was generally supportive in providing solutions and workarounds for users who ran into problems. At the same time, his response above suggests a common attitude that many developers had toward users' suggestions for changing design. Developers do not just automatically incorporate all re-design requests. Design requests that end up being implemented are those that have achieved a critical mass of support from the user community, and developers have to agree that it is a necessary and appropriate modification to the MythTV system.

The tension between developers and users is noteworthy because this is the departure point for the question of "what is important to develop." The following case shows the complete thread of Mtdean's fringe case scandal above. The thread included 61 messages with more than 15 members participating. The case illustrates the conflict between the users' individualized expectations and daily practices and the developers' assumptions about how to appropriately use the MythTV system. Through negotiation and debate, the thread concluded with a developer committing to add an option that would address the expressed needs of the users.

The thread commenced with a message from a user whose recorded files were automatically deleted because his Live TV (regular TV—MythTV automatically records all the Live TV shows one is watching) was on long enough to auto-expire (automatically delete—in this case when the disk was full) specified files. This evoked conversations about how to change options for Live TV recording and auto-expiration. Mtdean suggested alternative solutions for how to eradicate the problem:

```
The right solution, though, is to stop LiveTV when you're not watching it... Another solution is to get more hard drives.;)
```

[...] if the problem is that you're falling asleep during the commercials in LiveTV;), check out the "Sleep" menu--hit MENU ('M') in LiveTV and scroll to "Sleep". There you can specify that Myth should turn off playback in 30, 60, 90, or 120 minutes.

Mtdean essentially faulted Yves's (the original poster's) use practice—his way of using MythTV. Mtdean explained to Yves the right way to watch LiveTV: to turn it off when not watching, and how to maintain MythTV: to get more hard drives that would not easily fill up and auto-expire files. Mtdean then suggested that alternatively, Yves could put the TV in sleep mode. Another user responded to specify why the alternative solutions would not work due to the WAF factor:

```
I'll gently suggest that such a solution is low in WAF (Wife Acceptance Factor) and KCF (Kid Competency Factor). I remember to stop LiveTV. Others don't, and won't. (Lists)
```

Something like the WAF factor is what users encounter in their daily lives—e.g., kids accidentally leaving the TV on at night—which might not necessarily have

been a consideration when developers designed features. Mtdean then suggested another solution, which was to manually start recording only when needed. He also suggested telling the family to make sure the TV was off when they were not watching. Such suggestions still did not fully address the concerns of the thread participants, thus conversation continued back and forth between the users and Mtdean. Eventually, a developer volunteered to create a fix that would address the problem:

Don't worry. (Due to popular whining, ;) Isaac committed a fix that prevents any LiveTV recording from being more than 8 hours in length (and adjustable through an undocumented setting) (Mtdean)

The users themselves have different individualized needs, opinions, preferences, and concerns that all need to be aligned when discussing a possible new feature. The following thread describes how the community discussed a P2P approach for sharing TV listings and other kinds of information, such as cutlists (when to cut recording), and even possibly sharing video files. This suggestion opened up a debate that began with issues of trust and reliability:

I believe this whole idea of sharing videos or movies would be rejected by the core developers for obvious reasons.

The idea of sharing other information has been discussed in the past on this list also, and I think one of the major problems would be ensuring people don't screw up the data (possibly deliberately). For example, someone could flag part of a programme as a commercial, which would effect everyone who relies on that data. (David)

David was speaking to the users, not necessarily to the developers. The thread then evolved into a discussion about new features, potential consequences, and how to

develop an idea so that the downside could be addressed while still supporting the good part:

So then we need some kind of a majority logic, e.g. getting information from a number of peers and then only accepting information that a majority of peers agree on. For cut lists, this would be a kind of "union" agreement. (Aharwood)

Another user specified rules for how the design could work, asking for critique:

For cutlist info you are probably right, but what i came up with recently is trusted networks for recommendations on recordings. Think of it as gnus (the emacs newsreader) for videos.

This could work as follows:

Configure MythRecommendation to use a reserved part of your storage (basically a quota).

Until this quota is reached mythtv would start recording any recommendations it gets.

Next a ruleset will give weight to the recommendating person, the channel, keywords in the title etc.. based by your behaviour or explicit settings.

When you delete a recording without watching it 5 points are taken from the person, 2 from the channel, 1 from the keywords, whatever.

When you do a cutlist on the recording points are added to person , channel ...

When you archive the movie even more points are given.

After a while you should find interesting recordings, that you would have missed otherwise.

what do you think ? (Rawdlite)

The thread then explored the idea of creating "interest groups." Challenges due to individualized practices were also posed:

Even cut list cannot be shared because of the following reason:

Programs are sometimes delayed here in Ireland because of some reason or the other. To get around this problem, I always start recordings 5 minutes early and end 10 minutes late.

Now how can the cut-list be shared in such a case? I don't think so until some AI is built into mythtv. (Vijay)

Vijay's argument was challenged, and legal issues were raised. The thread then discussed whether a recommendation system (e.g., MythRating), movie sharing, or cutlist sharing would be desirable. Action items were also discussed, such as what would be the location of the central infrastructure to handle this transaction, how the transaction would take place (through which route), and which toolkit would be appropriate to develop the application. In the end, it was left to the developers to decide what goes into the Myth core:

Anyway, if you want to try a P2P system, check with Isaac. He may not be willing to do it. He said a central recommendation system would be run by him only, and he gets to decide what goes in myth core. (Brad)

The thread about P2P systems above illustrates how users voluntarily share their ideas, concerns, needs, and counter-arguments as part of the negotiation around which new features to develop. Users do not throw out abstract ideas, but attempt to think about how their ideas could actually be implemented, what legal consequences they could bring, and how the design would generalize to various individualized settings.

This process of coming to an agreement about which features to develop, which parts of the MythTV system need improvement, and what the improvements would entail represents the alignment work between developers and users, and among the users themselves. This alignment work results in the community's understanding what would be an appropriate development trajectory for the MythTV system. That is, the current performance of MythTV features, potential improvements, and what those improvements would look like. Developers ultimately determine what will be implemented, so aligning the interests of users and developers is critical. Community trajectory negotiation work, especially in aligning with the MythTV system development trajectory, reify the importance of coordination and translation work among the trajectories of multiple users and developers.

#### Conclusion

In this section, I attempt to connect my findings back to the challenges I witnessed in the community in terms of the kinds of individualized problems they encountered, and how they generated solutions for those individualized problems.

Also, I discuss the relationship between configuration-based help and use trajectory alignment and negotiation work.

The main challenges that MythTV users face in maintaining their systems over time—compatibility issues, idiosyncratic and rare issues, and not being able to find ways to modify existing solutions—all stem from the fact that each user's

settings are unique. Accordingly, a given solution might not be implemented immediately. Solutions have to be adapted to each user's unique settings, and the process of adaptation is collaborative and depends upon inference from the documented prior experiences of other users, which often fails to fully address problems. Also, some problems are so uncommon that finding solutions requires a great deal of inference, many assumptions, creative minds, and modification of existing solutions.

The MythTV user community then shares blackboxed solutions—configuration artifacts that could be directly plugged in and executed immediately. This way users do not have to deal with understanding problems or solutions. However, because of the individualized nature of some problems, these solutions often do not work. This is when members need to go through the process of "grayboxing," which is not just a physical opening of the content of the solution, but also involves helping users understand what the content means and where and how to modify the artifact to render an appropriate solution. During configuration-based help, members also use configuration artifacts for contextualization. In order to understand unique idiosyncratic problems, the problems first have to be understood. The community uses configuration artifacts, an easily mobilized form of knowledge, as boundary objects with which to generate understanding around the context of the problem and enhance the communication process.

Understanding individual differences is critical for the contextualization process. Here, a mere snapshot of current settings is not enough. It helps when

members share the past history of their systems as well as what they plan to do next. Configuration-based help is done within the context of the users' use trajectories. Sharing use trajectories becomes not only a way to contextualize but also a help resource. Partial representations of use trajectories become objectified knowledge that community members can compare, contrast, and connect to derive meanings and generate new kinds of solutions.

Individual use trajectories are used to negotiate, at the community level, a common understanding of what constitutes an ideal solution, an ideal way to maintain MythTV, and how MythTV should be developed over time as an open source software project. I refer to this as the "community trajectory." The individual differences of the use trajectories allow the community to have resources for negotiation, divergence, and agreement in arriving at an agreed-upon community trajectory. Consider the following quote from Bowker and Star's (1999) account on multiple interpretations:

[...] information is only information when there are multiple interpretations. One person's noise may be another's signal or two people may agree to attend to something, but it is the tension between contexts that actually creates representation. p.291)

The very challenge that creates the major problem—individualized use—is the solution to the problem. That is, as Bowker and Star said, without multiplicity, the information would not have stood out. Multiplicity is what transforms invisible knowledge into visible representation. In the MythTV user community, the individual differences that members noticed between one another's use trajectories

became the solution, or at least the key knowledge for building solutions. The individual differences are where diagnosis, modification, inference, and creativity emerge. When Fostandy asked members to compare his setting for autotranscoding with others, or when Robertmc asked other Australian users if they also had problems with grabbing TV listings information, they were looking for similarities and differences, which in turn resulted in finding the causes of the problems or hints for solutions. During the process of identifying differences, solutions and meanings emerge.

Configuration-based help and use trajectory alignment and negotiation work are analytically separated, but they are an intermeshed process. Configuration-based help has to be done as members align their use trajectories. Community trajectory negotiation work, the work involved in coming to an agreed community trajectory, does not occur after individual trajectory alignment work is done. As members work on one issue, other issues are agreed upon and negotiated into the community's use trajectory. The community's use trajectory is constantly revisited and revised through comparison of individual use trajectories, as seen in the case of 1.41421 who tried to find the right recording setting for burning a DVD. Appropriate solutions of the past are revisited, and updated with new information and new perspectives brought in through members with additional individualized settings.

Together with the community use trajectory, the MythTV user community creates a small social world with its own norms, not only in terms of how to

behave as a member of the community, but more importantly in considering how to maintain MythTV as part of their everyday lives. The norms govern the way the members install, maintain, and plan the future of their MythTV systems.

Experiences around the use of MythTV systems become information, which has both symbolic and material aspects, as seen in the categorical work—the work that creates boundary infrastructures that represent how people define things and convey meanings in communication—described by Bowker and Star (1999). The information is transformed into configuration artifacts and stories that represent use trajectories, which then become solutions. Maintaining MythTV is a central activity in the social world users participated in, although probably to a lesser degree than it would be in the members' work or family environment. MythTV system maintenance is not a mere technical task, but a social activity that involves negotiated order, categorical work, and norm production—it is its own social world.

It is interesting that the social world becomes a solution space that allows various help activities of troubleshooting, diagnosing, and generating tailored solutions. Individualized solutions are generated through the very social activity Strauss attempts to understand by exploring how we live our everyday lives and make sense of the world in which we live. For MythTV users, it is this world of maintaining MythTV systems that allows them to generate solutions for their individualized problems.

## **Chapter 5**

### **Collaborative Help in the Diabetes Patient Support Groups**

In this chapter, I describe how diabetes patient support group members in the online community and face-to-face support group settings (which I hereinafter refer to collectively as "the support groups") transfer experiences to one another and help one another cope with individualized problems in managing diabetes. The key findings are: (1) Operationalized experiences help patients easily transfer knowledge and context, (2) the operationalization process often breaks down due to individual differences, but the breakdowns become opportunities for enriching members' understandings toward individualized diabetes management, and lastly (3) operationalization has to be done within the larger context of sharing illness trajectories, and aligning with one another's illness trajectories helps members better shape diabetes management practices. Operationalization and illness trajectories are only separated for analytical purposes. In reality, the two activities are intertwined practices that allow community members to develop commonenough understanding about how to ideally manage diabetes.

This chapter is divided into three parts. In Part I, I describe the processes of operationalization and breakdown of operationalization. Part II discusses illness trajectory alignment work, an effort among members to use one another's patient illness trajectories as resources for learning. I begin Part III by discussing how members build common-enough understanding by developing awareness about one another and coming to agreement about diabetes management strategies. I then examine how operationalization of patient experiences and illness trajectory alignment work are intertwined processes. I follow up the discussion by identifying some of the discontinuities witnessed in help interactions between the two social spaces—online communities and face-to-face support groups—specifically with regards to the participation of medical experts, differing social dynamics, and demographical differences of the two spaces. I end the chapter with remaining questions of the study and future work.

# Part I: Operationalization of Patient Experiences

Allowing patients to share experiential knowledge is a unique opportunity that support groups provide for patients, as noted in the literature (Borkman, 1976, 1999; Civan, 2009). However, strategies and experiences are often situated in individualized settings. Transferring such situated experiences from one person to another is often challenging. To address these challenges, members operationalize their everyday experiences in managing diabetes into forms that would help them easily transfer knowledge to one another.

By operationalization, I mean activities that allow abstract concepts to become measurable or comparable. A representative example would be lab results that allow patients to be diagnosed and informed about the severity of their disease. An everyday life example would be listing foods one ate for lunch, includindg ingredients and their nutritional breakdowns, along with pre-and post-consumption blood sugar levels. Such information gives numbers and categories of things that one can compare and record consistently over time in order to detect changes. Operationalized information gives easy but incomplete access to context. Inevitably, some context will be lost, but at the same time, it is an efficient and usable way for people to share and compare their situations.

In support groups, patients operationalize their context into patient profiles and personal experiment findings in order to share individual experiences with other patients. Not only contextual information but also strategies are operationalized, for instance, into step-by-step instructions or recipes—information that others could easily adopt and adapt for themselves. Operationalized solutions also work as references from which the members can discuss particular points about managing diabetes. Operationalized information helps the members understand individual differences in their problems, collaboratively construct individualized diabetes management strategies, and inform one another about diabetes. More interestingly, such collaborative operationalization processes often encounter limitations, and the members have to reveal their illness trajectories and further reflect and collectively act upon the breakages as part of continuing to

improve managing their diabetes. Collective discussions around limitations become critical in understanding individual differences and finding information that would be suitable for individualized situations.

In the following section, I first discuss various operationalization processes observed from the data, and how the operationalization process helps members deal with individualized diabetes management problems. I then discuss how the operationalization process breaks down due to individual differences and how the members attempt to resolve the breakages through negotiation. The data<sup>5</sup> to be presented in the following analysis were collected from the online community forum dLife.com, interviews, and face-to-face support groups (see Chapter 3 for further detail on the methods employed for collecting and analyzing data).

#### OPERATIONALIZING EVERYDAY DIABETES MANAGEMENT

Operationalization of patient experiences takes place for two purposes: contextualization and sharing of strategies. First, members contextualize their diabetes conditions, experiences, and personal preferences with easily exchangeable forms of information such as numbers and short descriptions. Examples include short patient profile descriptions, digital signatures, or experiments. Especially when shared with its content values changing over time,

<sup>&</sup>lt;sup>5</sup> Quotations in this section will assume the following format: (Date. Source, anonymized patient ID), where OC stands for the Online Community forum, FF# stands for one of the face-to-face support groups, (IOC, P#)—date omitted—stands for interviews with patients from the online community and (I, FF#\_P#) stands for interviews with patients from one of the face-to-face support groups.

this information helps to contextualize patients' individualized challenges to provide them with potentially useful information and to help them find the right people to talk with. Experiments allow other members to learn about individualized experiences of various interventions including diet and exercise regimes, food products, or medications. Secondly, the members share know-how, advice, and procedures with operationalized procedural steps that others could easily adopt and modify for their own individualized uses. The important part of the operationalization process here, in addition to directly giving operationalized solutions, is helping other members learn how to individualize a given strategy.

#### **Operationalizing Diabetes Conditions for Contextualization**

In this section, I describe how operationalization is used for patients to contextualize their diabetic conditions and to convey various experiences to others. I talk about patient profiles and digital signatures as examples of tools that patients use to connect with others, identify good examples, and contextualize individualized situations. I also discuss informal experiments in which the patients share their results with others in order to collaboratively come to an understanding about the individual effects of various interventions.

The members share information about patient profiles to connect with other members, provide individualized advice, and present good examples that other members can use to motivate themselves. The most frequently used indicators for

patient profiles include A1C<sup>6</sup>, fasting blood sugar (FB)<sup>7</sup>, after-meal blood sugar readings, weight, and the dates and times these indicators are measured. In addition, which medications or insulin a patient is taking, when they were diagnosed, what type of diabetes they have, how old they are, which diet and exercise regimes have been used, and whether any complications exist are also important pieces of information for contextualizing one's diabetes. These indicators represent information that patients can use in order to easily explain their individualized situations to others.

The patient profiles assume many forms across dLife.com and the face-to-face support groups I observed. In all of the face-to-face support group meetings I attended, at the beginning of the sessions patients introduce themselves. During this introduction, patients share numbers and short descriptions that indicate the severity of their conditions, the treatment strategies that they employ, complications, updates since the last meeting, and any ongoing problems that they are struggling with at the time. This process helps familiarize group members with one another so that they can later ask for help. For instance, during the first session of a four-week diabetes class, two patients who introduced themselves as having become diabetic due to organ transplant surgery immediately came together to utilize as much time as possible during the break and asked one another further

<sup>&</sup>lt;sup>6</sup> A measurement showing the average plasma glucose concentration over prolonged periods of time.

<sup>&</sup>lt;sup>7</sup> Blood sugar taken at bed time, before meal, or after 12 hours of fasting.

questions after the meeting. During interviews with members of face-to-face support groups, the interviewees were aware of whom to talk to when they had questions in using insulin or moving onto an insulin pump, for example. A typical introduction phase proceeds as follows:

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

Patient #2: I 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: Hi, I'm Sally. I was diagnosed in 2005. I am on insulin, but other than that I am fine.

Patient #5: I was diabetic since 95. I have been here [the meeting] twice.

Patient #6: I've been prediabetic since May of 2010. I can't get into regular classes but come to diabetes group because you learn a lot. I'm Sammy, by the way.

Patient #7: I am a daughter of Sammy, and I am here to get information to back her up.

Patient #8: I've been diabetic since 1995. I have some trouble doing exercise. I've discovered swimming. I don't feel like skipping any more and it's powerful to me. I want to live.

Patient #9: I am diagnosed as type 2. I wish I had known when I was prediabetic. I was pre for a while for a year and crossed over in March 2010. I take Metformin twice a day. (July, 2010. FF5)

As you can see, a typical face-to-face support group consists of patients at diverse stages. They each have different issues, regimes for controlling their diabetes,

gender, and age. Because the group is so diverse, patients are able to share experiences about the domains that each member is more familiar with than others. More importantly, explicitly sharing patient profiles helps members know who to talk to about their issues. John, patient #1, who mentioned that he 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 for addressing low blood sugar. After hearing that John used glucose tablets, she asked more specifically which glucose tablet he was using and asked him to explain to the group about his experiences in using glucose tablets rather than soda or orange juice. Similar learning experiences were observed in patients with insulin pumps, who shared how they dealt with the insurance company in getting the pump, and about appropriating pumps for individualized use.

In the online forums, describing one's patient profile is implicitly required when requesting help, so that helpers can suggest relevant solutions. The patient profile becomes a point of reference for the helpers to provide assistance and share experiences. By seeing that the askers pick out certain profile information while omitting other items, helpers are able to gauge the askers' assumptions about what the important indicators are to identify a specific problem. The helpers then help the askers think about the problem in a different way when necessary. For example, asker Juan\_perez asked how long it would take to reverse his neuropathy once his diabetes was controlled. When asking this question, Juan\_perez provided patient

profile information that he felt was relevant to the problem to help others give him appropriate help:

Hi there.

I have been diagnosed as type 2 on Sep/09. My A1C was 11.5. Only some days after my diagnoses, 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 inyections (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. (September, 2010. OC. juan perez)

In his post, juan\_perez provided information about his A1C changes over time and his experiences in trying out various vitamins as attempts to help out with his neuropathy condition. The shared A1C numbers could then be used as a comparative point with which the helpers and the asker can discuss individual differences in their experiences with neuropathy. For instance, helper Vpenning shared her own A1C numbers with temporal information on reversing her neuropathy:

When I was diagnosed, I had an alc of 8.9, and I had some neuropathy. It took me about 6 months to get my numbers under control. (under 6 alc). It took me one year to have the neuropathy reversed, and by that time, my alc had dropped below 5.5. (I hover close to 5 now[...])

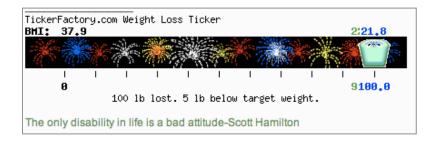
I do not know what others had for reversal...but, for me, it took about 6 months AFTER I had my numbers in good range before I saw results. (September, 2010. OC. vpenning)

Accordingly, Vpenning suggested that for her case with much lower A1C levels from the beginning she still had to wait at least a year in order for her neuropathy to be reversed. Juan\_perez had a much higher A1C at the time of the diagnosis, and his A1C level after a year was still higher than Vpenning's at the time her neuropathy went reversed. While such a comparison should not be regarded as any sort of absolute answer about how neuropathy works, at least the comparison provides examples of how other people experience neuropathy reversal over time. Vpenning also introduced a medical article that explained how vitamin B could be detrimental to neuropathy if used in excess, providing a possible explanation for Juan\_perez's negative experience with vitamins. In the attempt to fix Juan\_perez's assumptions about what important indicators to attend to for neuropathy, another member, Alan\_s, pointed out that A1C might not be the only indicator that Juan\_perez should be looking for. He suggested that Juan\_perez check his aftermeal blood sugar readings as well so that he could maintain the right amount of carbohydrate intake to prevent high blood sugar levels after meals.

Providing personal patient profile information in the question post establishes a reference point from which helpers can provide assistance and identify individual differences. It also supplies useful information for understanding the askers' assumptions about what information is important, enabling responders to suggest improvements.

While the examples so far illustrate patient profiles used within a conversational context, patient profiles are also presented in simplified forms such 182

as signatures appended below online posts so that other members can easily read patient profile information. The signatures, often showing successful cases, encourage and motivate members to improve their diabetes. As a form of showing patient profile changes over time, some members use tickers (figure 1, upper example). Tickerfactory.com provides small web-postable visualizations that present various numbers over time, such as weight changes, due date count downs, or fundraising levels. Other patients utilize emoticons and simple numbers in text (figure 1, lower example) to show how their diabetes profiles have changed over time. The signatures that are included in the collected data all illustrate some level of success in controlling diabetes, suggesting that they are good examples to other patients. These signatures help encourage and motivate other members to improve their health, and specifically make the patients want to know more about the treatment strategy behind those successful numbers. For instance, in dLife.com, a member Carbjunky told another member Melissa, whose ticker in her signature showed that she lost 91 pounds, that he wanted to know more about how she was able to achieve such improvement:



```
AnnaM T2 $\overline{9}$
06/12/09 A1c 7.2 F 154 $\overline{9}$
12/11/09 A1c 5.5 F 80 $\overline{9}$
06/04/10 A1c 5.4 F 82 $\overline{9}$
12/01/10 A1c 5.2 F 71 $\overline{9}$
Diet & Exercise ONLY! No Meds! $\overline{9}$
Total WtLoss Since 06/09: 103.5 lbs $\overline{9}$
[img]http://tickers.TickerFactory.com/ezt/t/w2MuUYf/weight.png[/img]
```

Figure 1: Examples of signatures appended below posts on dLife.com

Your signature shows tremendous improvement in a short time. Would you tell me more about your story? (September, 2009. OC. Carbjunky)

Signatures with examples of success motivate members to engage in behavioral changes. As another example of this, Mandaminor replied to a post that introduced a weight loss buddy group within the dLife community. Mandaminor said that she was encouraged by the poster's signature and wanted to participate in the group:

I read your signature and told my husband about it. Very encouraging!! I will check out that group! (July, 2010. OC. Mandaminor)

Sotxkinselmon was also impressed by a member's signature that showed significant improvement in weight loss, and this helped her to better listen to the member's story on exercise regimes. As a result, Sotxkinselmon was motivated to change her attitude toward exercise:

Valerie, I am impressed with your story. Besides the significant weight loss, which I know of from your signature line, your dedication to exercise is matched by few people I know of, with Jane being the exception. I am so sporadic with my exercise, depending on what is

hurting on any particular day. I have a treadmill and walking is usually the best exercise for me but doing it REGULARLY is a challenge for me. Kudos to you! Tho I have to say you gave me an idea. Right now my treadmill faces a blank wall. I usually listen to music when I walk but this blank wall sure is boring! I need to at least put something attractive up there to look at! (May, 2009. OC. Sotxkinselmon)

The signatures that show how a patient goes from a life-threatening diabetic condition to controlled diabetes gives hope to those who are in similarly life-threatening situations. Making successful examples from peers available to patients has been known to have a positive impact in helping the recipients adjust to chronic illness conditions (Dibb & Yardley, 2006) and in self-help groups in general (Medvene, 1992). Patient profiles and digital signatures are easy ways of making successful patient cases visible to support group members.

Patients also attempt to systematically share their situated experiences through various casual experiment results, such as testing before and after blood sugar changes of various diet and exercise regimes. Members conduct experiments collectively, where they coordinate protocols for the experiments and share the findings together. Through this collective activity, members are able to collect real life experiences and understand individual differences regarding various interventions for controlling diabetes.

For example, a nurse practitioner, who is the leader of a face-to-face support group (FF4), shared with the group samples of a new gluten-free pasta product that her friend had developed. The members of the support group then took it back home with a plan to try the pasta out with different recipes and made sure to check

after meal blood sugar to see how much their blood sugar rose compared with readings after eating other carb products. In the following, FF4\_P9 shared her positive experience with the pasta during the interview and stated the value of sharing the results with other members:

"Oh, this would be the good time to do that cup [of a new pasta product]." And I did it. And by golly, absolutely that lady was correct. There was very little, there was a very small increase within two hours. Much less, let's say, than I would start in from a potato or even in a regular spaghetti. So I reported that to the group and I said, "Well, if anybody had the chance to test it on their own. I would like to have a little more feedback as to how it turned out for you." [...] it's sharing, sharing, sharing, it doesn't matter what it is but you need to share, you need to... (I, FF4 P9)

Unfortunately, other members had not tried out the pasta so she could not hear how the product worked differently for them.



Figure 2: A face-to-face support group performing experiments together. The members collectively checked blood sugar level changes of before and after the short arm exercises.

Collective sharing of experiments works well when the support group is trying out the experiment together as part of the support group activities. At one face-to-face support group meeting (FF1), a nurse from a senior center was invited to give lectures on finding appropriate exercises. After the lecture, the group performed a quick five-minute arm exercise together (figure 2). The nurse asked the members to check their blood sugar before and after the exercise. A number of patients had brought their blood sugar monitoring devices since they were told to bring one at the last meeting. The changes were significant, particularly considering how minimal the exercise was. A gentleman sitting by me had dropped 5 points after the exercise. There were, however, varying levels of changes among the participants.

The lesson that the members received from this short experiment is not only to understand how such small exercises can 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 of the interventions. The same exercise, for instance, may be more effective for a 90-year-old man than for a 50-year-old woman.

In the following example, a thread in an online forum (diabeticconnect.com) helped the interviewee understand how a pizza influences blood sugar readings. Knowing consequences of the everyday decisions like choosing which pizza to eat is one of the central challenges in patients' daily diabetes management practices. The thread involved discussions around how variations of a pizza slice—such as whether it is whole wheat or has tomato sauce—can affect blood sugar differently, helping the interviewee get a sense of how to choose which pizza to eat:

And I read kind of like twenty posts and it seems like a lot of people were saying that when they have pizza, they have horrible blood sugar readings even if they had just like one piece. And then people were talking about what happens if you have whole wheat pizza, what happens if you've got them to hold the sauce. So what I got from that is pizza is potentially dangerous and I should be thoughtful before I eat it. Yeah, I kind of thought it was off-limits but it might be a real blood-sugar spiker. So it might be. It seems like it affects people in different ways, but I've got some ideas on how to eat pizza occasionally. And I know that sounds probably kind of trivial, but that's the sort of things you think about when [chuckle] you don't know. (I, FF2\_P12)

Collectively sharing small findings from personal experiments with food helps other members make informed decisions, at least in an informal fashion.

So far I have examined how the patients operationalize contextualizing their diabetic condition, and the influences of various interventions including sharing patient profiles, digital signatures, and folk experiment results. Operationalization happens not only to contextualize one's own diabetic experiences, but also to easily transfer knowledge and tips for various diabetes management strategies.

#### **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 into a form that is easy to adopt, try out, and tweak. The form of operationalization includes step-by-step instructions, bullet points of lessons, rules of thumb, blogs, and lists of links, books, and recipes. Such information is especially helpful for newcomers who need concrete guidelines. At the same time, because not all solutions will work for everyone, the members also help others learn how to operationalize, deal with exceptions, and find the right individualized solutions. In the following section, I describe several cases illustrating how members operationalize strategies and share how to generate individualized solutions. Also, I discuss how the members collectively attempt to come to an agreement about which operationalized strategies are the appropriate ones to use.

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.com, the members share what I call a 'startup solution kit' for newcomers who ask where to start. The startup solution kit includes basic information that all newly diagnosed diabetes patients should know, such as how to read food labels, how to calculate carbs, how to detect symptoms of low or high blood sugar, how to adjust diet in accordance with blood sugar readings, and how to detect various complications. 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, or book recommendations. The solution kit is free of heavy context or verbatim stories, and thus is easy to replicate or post in a variety of situations. Some members post the same message (containing the startup solution kit) whenever newcomers join the community. These concrete solutions, well-polished through repetitive use, help newcomers who are dealing with extreme ambiguity and don't know where to start. The following example represents a blog article that Alan\_s shared in dlife:

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You said you were eating lower-carb; but that is not the same as eating to your meter. Consider applying this (click on it): <a href="Mainto:Test">Test</a>, <a href="Review">Review</a>, <a href="Adjust">Adjust</a> (April, 2008. OC. <a href="Alan_s">Alan_s</a>)
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The following is the blog article, "Test, Review, Adjust":

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Start with whatever you eat now.
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Eat, then test after eating at your spike time and if BG's are too high then review what you ate and change the menu next time. Then do that again, and again, and

again until what you eat doesn't spike you. [explanations for exceptions and how to individualize depending on life styles]

As you gradually improve your blood glucose levels, review the resulting way of eating to ensure adequate nutrition, fibre etc are included and adjust accordingly.

Then test again.

Test, review, adjust, always towards better and better blood glucose levels.

And no - you won't have to test so intensively for the rest of your life. [...] (http://loraldiabetes.blogspot.com/2006/10/test-review-adjust.html, Alan\_s)

Alan\_s has posted this article 511 times on dLife out of the 2549 total messages he posted from April 2009 through April 2011. Other members showed appreciation for Alan\_s's startup solution kit:

It [your blog] has helped me a lot. I did not realize that cereal and 2% milk was not helpful. I will be changing my breakfast, thanks to you. (June, 2009. Blog comment. JolindaTX)

As patients progress with their diabetes treatment, they encounter new problems that were not addressed initially or explicitly by various diabetes education materials. One of the core purposes of the support groups is to help patients get solutions for newly encountered problems. For instance, a recently diagnosed patient (who had been diagnosed 6 months earlier) 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, and she was not sure whether squeezing was the best thing to do. Instead of answering her question right away, the nurse

leading the group at the time asked the group to share how they checked their blood sugar. A number of patients described what they do. One male patient said he has been diabetic for so long he developed a callus, so he had to use a longer needle to get it working. He then physically demonstrated how he could get the blood monitoring device to work better:

You can also turn that knob [showing the gesture] and make it harder. (July, 2010. ff5-1. A male patient)

Some patients told her to try poking the needle in different areas (other than her fingers), to try different fingers, or to run her finger under hot water first. Another patient shared what her doctor told her to do—take a baby aspirin before testing her blood sugar. Then the group started talking about a gadget that allowed blood sugar to be checked from the arms. Later on the nurse clarified that the arm and the fingers have a 20% difference in blood sugar (the arm is less accurate). Also, the nurse clarified that squeezing fingers could possibly push out the tissue, diluting the blood and thus resulting in less accurate blood sugar readings than those taken from blood that came out without squeezing.

In this fashion, patients shared various strategies of their own—try checking blood sugar from different places on the body or different fingers, using medications, running the finger under hot water, or trying out longer needles—which then led to a collection of operationalized strategies that the patient herself could try out to see what worked better for her. During this process, the nurse's

intervention in the conversation with tips and comments also helped the members to find better strategies.

Problems become more complicated when patients go past the initial learning curve and encounter unexpected problems specific to their own situation. In this case, unlike with the startup solution kit or collectively gathered diverse strategies, the helpers have to consider the asker's individualized situation to provide appropriate solutions.

The following example shows how a member in dLife.com encountered unexpected lab results that conflicted with his own readings taken at home. A helper suggested trying an alternative strategy for reading blood sugar more accurately than the asker's current method, and helped the asker find the right foods to eat to avoid spikes in blood sugar readings. The helper operationalized the strategy so that the asker could easily adopt the strategy. The asker, Gimarshall, posted:

I don't understand all of my readings at home have been between 62-160 with an occasional 200 (my carefree day about 1-2 times a month). No different readings than the last A1C. So how can I have an avg of 398. Yes I did have an absess tooth a couple of weeks ago but none of my BS readings were high. [...] how can I have a 398 avg. Don't understand. I've been in the 85-120 range more. Yesterday I was 110 at wakeup, 103 before lunch/dinner at work, 160 before my bike ride and 106 30 min - 1hr after my bike ride, and 95 when I got home and before bed. [...] Actos with Metformin which is what I orignally on before he changed me to Actos 30. (August, 2010. OC. Gimarshall)

Gimarshall was confused about why his lab results showed such a high blood sugar reading compared to the readings he was taking at home. Vpenning assumed there

might have been problems resulting from when and how Gimarshall was taking his blood sugar readings at home. Vpenning suggested a specific blood sugar reading strategy called 'bookend testing' which would help Gimarshall 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 Gimarshall commonly eats:

When you take your blood glucose, it is a snapshot of what your blood is. You do not know if it is on its way Up or on its way DOWN. The thing is, you are going UP somewhere. My guess is after meals.

You need to do bookend testing. And, you need to probably go through a few strips for a few days to see how you are doing.

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, like you said, then you should be around 143 post. If NOT, then that means you went way higher and are still coming down from a high. For instance, you said you were 160. If that was at the one hour point, (You should be around 50 point difference at one hour point if you are checking it) then that would have been OK, but if you were that high 2 hours or more after a meal...then, you went up pretty high. (August, 2010. OC. Vpenning)

Here, Vpenning not only gave step-by-step instructions for how to do bookend testing, but also provided numbers that would help Gimarshall identify whether the results were normal. 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. The helper identifies the potential source of the problem and provides a strategy that would help the asker to construct individualized solutions.

As operationalized strategies are shared, it also becomes important that the members understand which strategies are appropriate for their own needs. The process of negotiating differences in personal beliefs and interpretations allows the community to challenge one another while coming to a consensus about appropriate diabetes management strategies. For instance, community members initiated a thread in dLife.com about whether the glycemic index (GI) was a useful tool for constructing diet regimes. Initially the members participating in the thread discussed GI as something that is unnecessary because a meter would tell how each individual reacted to a food. Some experiences indicated that a food with a low GI did not result in low blood sugar readings, leading members to assert that a person might as well just check the meter instead of considering GIs. The counterargument to this line of reasoning was that GI helps patients proactively determine which food to eat, instead of relying on test results after the fact. Neither of the viewpoints was wrong, but the usefulness and reliability of Gl—whether it was a necessary and appropriate operationalizing tool for figuring out which food to eat—was called into question. A moderator who is a registered nurse intervened to clarify that GI is a useful tool for situations where one wants to get a sense of how a food would might affect blood sugar before eating it. The members of the thread continued to discuss in which cases GI is useful. By the conclusion of the discussion, commenters agreed that GI figures are useful for newcomers who have no prior experiences with test results for various food choices.

So far I have presented cases in which the operationalization process works well. However, there are times when such an operationalization process does not sustain very well due to the uncertain and dynamic nature of diabetes, decontextualizing characteristics of the operationalization process (incompleteness), individual differences among patients, and varying standards and definitions about relative terms such as what are good or bad strategies or high or low blood sugar levels. However, such breakdowns in the operationalization process are in fact opportunities for community members to further understand individual differences and exceptions that are taking place in diabetes management. Next, I describe how members reflect upon breakdowns in the operationalization process.

#### WHEN THE OPERATIONALIZATION PROCESS BREAKS DOWN

While the operationalization process makes knowledge exchange efficient, it also de-contextualizes the solution, making it difficult for patients to modify the solution for individualized settings and derive meaning out of the shared information. Patients hold differing belief about what constitutes appropriate diabetes management strategies and have varying standards for relative terms such as good, bad, high, or low. Even for health professionals, standards vary greatly across disciplines and institutions. The American Diabetes Association and the American Association of Clinical Endocrinologists, for example, disagree on recommended A1C levels. Standards for safe A1C levels for prescribing an insulin pump differ even among hospitals within Ann Arbor. Accordingly, it is often

difficult for patients to operationalize optimal solutions. At the same time, such breakdowns in the operationalization process work as opportunities for community members to reach an agreement about what they consider to be appropriate suggestions. The community members share illness trajectories and negotiate through discussions to understand "ideal" solutions and any exceptions that they need to be aware of.

The greatest difficulty in operationalizing solutions stems from the uncertain and complex nature of diabetes, and how problems related to the disease are extremely individualized. One member, who is considered a guru of the community because of his long experience of being able to control his diabetes well, described the difficulty in operationalizing solutions for diabetes through a metaphor of maintaining a constant temperature in a closed room:

[...] having Type 2 diabetes is like being told the following: "We're moving you into a new house, and you're going to be living in it from now on. Your assignment is to maintain a constant temperature of 71 degrees in the house. Now, be aware that the furnace is a bit defective, but we're not going to tell you how defective it is. And anyway, it's more defective on some days than others. Also, there's a hole in an exterior wall, up in the attic, and it's leaking outside air into the house -- but we're not going to tell you how big the hole is. You just have to adjust the thermostat to get a temperature of 71. But setting it to 71 won't work -you might as well realize that right now! You'll have to do something else. But we're not telling what that something else is. So, good luck!" (June 2010. OC. Tomross)

This uncertain and dynamic nature of diabetes, together with the de-contextualized nature of operationalized information and conflicting standards and definitions,

make it difficult for members to be provided with neat and easy operationalized solutions to follow. Accordingly, the operationalization process often breaks down and the members have to continue to discuss and reflect around the problem.

Next, I describe three ways in which operationalization breakdowns occur due to the incomplete nature of operationalized contextual information and individual differences in diabetic experiences: how operationalized practices of health care providers create problems related to sacrificing context for easier transfer of knowledge; how peer-to-peer knowledge transfer is challenged by members and has to be negotiated due to individual differences; and how varying standards and definitions hinder the operationalization process. I then describe how members attempt to overcome the breakdowns but fail to do so. Most importantly, I end the section with discussing how members attempt to amend the breakdowns and as a result the community comes to collectively understand exceptions and individual differences in diabetes management.

# De-contextualization of Operationalization in Health Care: "Bang, bang, bang, numbers, just numbers, okay."

One of the critical elements of operationalization in collaborative help is the ability to share executable strategies. Strategies are laid out in a format that others can easily adopt and execute. Operationalization, however, eliminates the context from which the strategy evolves and so obscures how the strategy could be amended as needed. Lack of context makes it difficult for patients to digest

information and to generate personal meanings for themselves. Representative examples include doctors' interpretation of lab results, step-by-step instructions for how to check blood sugar, which foods to eat, and instructions for taking medications. The common characteristic of these examples is that the information is simple and easy to follow but lacks context. It is difficult for patients to understand the meaning behind lab results and why they are given certain instructions, so that they could freely modify the instructions when needed. In this section, I describe several cases illustrating how operationalized information given by health care providers frustrates patients because they are unable to derive meaning out of the information.

One of the ways in which a patient's health status is measured and reported is through lab results. Lab results are one of the most objective and efficient ways to describe information about a patient's health status. From the patient's perspective, however, lab results are often full of numbers that are difficult for them to understand. Typically, patients are only able to learn whether their numbers are within the normal range. Such information does not help patients understand what the results mean to them in their daily living:

"You have metabolic syndrome, you've got a high testosterone level. Your creatinine appears high. You've got this and that. You got polycystic ovary syndrome." I'm like, 'What's all this mean? Am I going to die?' [chuckle] She says, "No, you're not in any imminent danger or anything." And she said, "The only thing is you're going to become diabetic. You notice stuff about it." (I, FF5 13)

As shown in the quotation above, FF5\_13 wanted to understand what all the high levels of various things and new syndromes meant in practical terms for her day-to-day living. The answer that she received back from her doctor was that she was "not in any imminent danger." Similarly, another member said during the face-to-face group meeting said that lab results failed to include information about how to interpret them. She wanted to know where she stood in comparison to other similar patients in terms of her vitamin D levels. The only information she received from her doctor was whether she was in good or bad shape, but she wanted to understand how much more she needed to improve or how much she could stop worrying.

Medications and regimes delivered to patients are canned solutions that patients can directly adopt to solve their problems without necessarily understanding the underlying processes. Such operationalized solutions are easy for patients to perform. As one patient noted in his interview about improving his dawn phenomenon<sup>8</sup>:

For my dawn phenomenon they have helped me understand why it is, that it is common and that many diabetics deal with it. I have learned to combat it to a degree with some snack suggestions from other members and to do my exercises at night instead of in the morning. Those things help, but I am still searching for the magic solution. I rather expect I will be looking forever. (IOC, DC1)

<sup>8</sup> Dawn phenomenon is defined as an unusually increased blood sugar level in the mornings.

Similarly, Dinycat from dLife expressed frustration at dealing with conflicting advice and individualized problems and just wanted "incontrovertible proof":

I just wish there was incontrovertible proof, one way or the other, so I could eat accordingly, and be done with diabetes ruling my life. (June 2010, OC, Dinycat)

Patients require a better understanding of operationalized solutions in order to independently execute the solutions and modify them when necessary. In the following example, a face-to-face support group member described her nutritionist's cooperative process of developing appropriate diet regimes. She talked about how the current diet plan from her nutritionist centered around numbers:

"How much do you weigh?" "Two hundred pounds." "How much do you want to lose?" "Fifty pounds." "Well, here is your plan. How much do you exercise?" "This is what I do." Bang, bang, bang. Numbers, just numbers, okay. And I believe a nutritionist should have a capability of figuring out what it would take for that person to lose that weight safely and have more or less the three meals pre-planned by saying, "Here is what you get for breakfast, here is what you get for lunch, and here is what you get for dinner. Can you do that?" (I, FF4 P9)

FF4\_P9 then went on to describe her desire for individualization to play a larger role in constructing appropriate diet regimes with her nutritionist. FF4\_P9 lamented that her nutritionist left out information that was crucial in helping FF4\_P9 to implement the solution independently, grounded in her daily practices:

And then if the patient is not happy with that meal, this is when the discussion should come in between the two of them as to modify the type of food, not necessarily the amount, the quantity, but the type of food which the nutritionist knows but you as a patient not necessarily. Okay? [...] Where's the protein coming from, and how much? And that didn't happen. (I, FF4 P9)

FF4\_P9 was instructed as to the amount of protein and carbs she needed to eat for each meal, but she wanted to further understand protein and carbs so she could make her own decisions about which foods she could eat to satisfy the requirements of the dietary regimen. FF4\_P9 needed help to be able to extend the solution and to create diverse meal plans beyond what she was initially given. The lack of background information on the solutions made it difficult for FF4\_P9 to freely adjust and modify the diet plans that were provided to her.

Insufficient information from doctors about prescribed solutions also frustrates members when the solution appears to be causing side effects that the doctors attribute to other causes. As a result, members turn to fellow patients in the support groups and other acquaintances to get more information about operationalized solutions. For example, FF3\_P4 was taking a medication called Cozaar to help out with his kidneys after he had undergone heart bypass surgery. When his doctor changed his prescription from Cozaar to a generic version of the drug, he started developing a sore throat and an earache that he had never experienced before. His doctor and the pharmacists told him that Cozaar and the generic version were identical to one another, so the generic could not be causing the symptoms. When he went back to Cozaar, the symptoms went away within a week. He found this to be the case for many patients he talked to, thereby supporting his assumptions:

And you've got to learn this from people because doctors aren't going to tell you. They'll [the doctors will] tell you there's nothing wrong with you. Well you know

if you got a sore throat for 10 days you go to the doctor. I wouldn't go to the doctor unless I had a reason. So, you then get a new doctor but once I got off of that generic, I don't know whether the pill, the makeup from the pharmaceutical company has put something in there that creates you to have an irritated throat, I don't know. But you'll learn these things from other people. There's another guy at rehab that he's been taking Lisinopril. He has been taking it for seven years, all of a sudden he gets a cough. Took him off the Lisinopril and his cough went away. How does he learn that except by talking to people. (I, FF3 P4)

The lesson here is not that what the patients do by gathering information from a small number of people outside of the medical profession is a scientifically valid thing to do. Rather, the stories that the patients share, represented by this anecdote, illustrate how strongly the patients perceive a lack of information related to the performance of operationalized solutions. To compensate, the patients turn to other people who are more willing to give information in personalized ways that make them feel supported.

# Breaking of Operationalization in the Support Groups: Individualized Problems and Conflicting Philosophies

To make the problem even more difficult, each patient has differing personal belief and expectations about what constitutes a good strategy. Members often go through a negotiation process to arrive at an agreement about what are appropriate solutions for various individualized settings. Through this process, members further deepen their awareness about various philosophies and practices present in other

patients. Also during the negotiation process, patients reveal their illness trajectories for further contextualization.

For instance, one patient on dLife.com requested help with balancing insulin and his meal plan. Members used the thread to negotiate what was considered to be an appropriate strategy for checking blood sugar and adjusting meals accordingly. The example described below shows how sharing personal strategies through operationalized solutions breaks down because of patients' failure to adequately share their personal histories, individual differences in how patients react, and conflicts in what patients believe are appropriate diabetes management strategies. The members are attempting to come to an agreement about what is an appropriate strategy for checking blood sugar. This alignment process involves not only resolving conflicts in personal belief, but also collaboratively making sense of operationalized information adopted from the ADA and doctors.

In the example presented below, the asker had been diabetic for 16 years, but still had not found a strategy that would help him choose the right meal plan. Fellow member, Diabetes86, replied with simplified information about a step-by-step procedure that the asker could follow in order to find the right foods to eat for himself:

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Take a pre meal BG write it down write down how many carbs you eat, (for now dont worry about the type of carb)
Eat take your BG 1 hour after eating
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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. adj one or the other until you get numbers similar to your before food BG. (October, 2010. OC. diabetes86)
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While Diabetes86's suggestion was simple and easy to follow, another member questioned its appropriateness. This was when the operationalization process broke down. Adas56 replied to Diabetes86 to ask about the necessity of checking blood sugar every hour. For Adas56, checking blood sugar two hours after the meal was sufficient to determine meal adjustments, and checking blood sugar every hour would hurt his finger tips and waste test strips. This belief indicated his personal preferences toward resources. Some patients would rather use up their test strips than risk having hyper- or hypoglycemia go unnoticed. Checking blood sugar two hours after the meal is a standard procedure that most diabetes educators suggest, because that is when blood sugar peaks. To this, Diabetes86 commented that every time his blood sugar spiked, his body organs 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. Adas 56 then replied that Diabetes86's assumptions about having acutely high blood sugar readings would not critically damage one's body so easily, since Adas56's wife, who is not diabetic, had blood sugar readings of 180 to 200 when she ate highcarbohydrate foods. To this, another member, Alan\_s, shared a protocol he found

from the ADA on diagnosing diabetes that supported Diabetes86's argument about the importance of checking high blood sugar at any given time:

Criteria for the diagnosis of diabetes mellitus

- 1. Symptoms of diabetes plus casual plasma glucose concentration  $\geq 200~\text{mg/dl}$  (11.1 mmol/1). Casual is defined as any time of day without regard to time since last meal. The classic symptoms of diabetes include polyuria, polydipsia, and unexplained weight loss. OR
- 2. FPG  $\geq\!126$  mg/dl (7.0 mmol/l). Fasting is defined as no caloric intake for at least 8 h.

OR

- 3. 2-h postload glucose  $\geq$ 200 mg/dl (11.1 mmol/l) during an OGTT. The test should be performed as described by WHO, using a glucose load containing the equivalent of 75 g anhydrous glucose dissolved in water.
- In the absence of unequivocal hyperglycemia, these criteria should be confirmed by repeat testing on a different day. The third measure (OGTT) is not recommended for routine clinical use. (October, 2010. OC. Alan\_s)

Bringing in official information from the ADA put an end to the negotiation about whether taking blood sugar readings at random times is considered important. Adas56 then questioned what was considered as severe, citing what his endocrinologist had told him:

I have been read[ing] a lot lately too, and I try [to] keep my A1C level between 4.2(72) and 5.6(121) and if this is a normal or not I don't really care it is normal for me. My endo. told me I have to keep below 240(A1C 9%) fasting and I will be fine, and I should listen him he is my doctor and he is educated in this field. (October, 2010. OC. Adas56)

Adas56 claimed that his endocrinologist told him to just stay below 240 (A1C 9%) for fasting and he should be fine. Notice that Adas56 stated how he did not care whether the community considered the suggested A1C level by his doctor to be 206

normal, because it was normal to him. This illustrates the difference that often exists between an individual's diabetes management strategy and that recommended by the group.

As Adas56 expected, another member questioned the number that Adas56 considered to be safe:

I must ask if you have posted the numbers correctly? I have to doubt the 240 (A1c 9%) from an Endo as their professional organization advises an A1c of 6.5% or lower. (October, 2010. OC. Robertia)

The conversation so far showed how even a doctor's individualized suggestion to a patient is negotiated into what is considered as appropriate to the support group. Adas56 continued to argue that since this information was obtained from his doctor, it should be considered credible. Alan\_s, who had supplied the information on criteria for diagnosing diabetes, again provided an operationalized strategy for checking blood sugar that he claimed was agreed upon by others members in dLife:

- I will be less charitable here. No-one told you to do to that combination. I could believe the following separate suggestions may have been made, by myself or others:
- 1. Find your peak post-prandial timing by testing several times, possibly every 15 minutes for a few times after meals. But you would also have been advised to test just at that time, not every 15 minutes, once you discovered the peak.
- 2. If you do not know your peak, I and others sometimes suggest you use your one-hour post-meal time.
- 3. No-one, as far as I know, has suggested that you must "keep steady is possible between 80 and 100 non-stop." If someone did suggest that there would have been many others disagreeing.

You are either badly misunderstanding the suggestions made here or you are deliberately exaggerating.

I will say no more on this regardless of any response, because it appears that no matter what is written there will be misunderstanding in this case.

However, I again urge you to take the advice I offered concerning your wife. (October, 2010. OC. Alan\_s)

Alan\_s attempted to summarize the conversation by describing an operationalized strategy that he considered to be agreed upon by others in the community. He argued that Adas56's information about his doctor's suggestion was flawed. Adas56 then revealed important information about his past—that he was first diagnosed with a blood sugar level of 500:

please do not tell me if I misunderstood my doctor I don't that is exactly what he said keep below 240 fasting. [...] When he told me that I was above 500 so I understand why he did tell me keep below 240 instead between 74 and 120. You know how it works if you're constantly 500 plus and change to 90 you'll drop death it is to big different from 500 plus to 90. You have to adjust gradually, not once over night. [...] I don't wish to be judge by anyone I don't judge anyone here just try speak from my experience, like most people here. I do not say I know everything, but you do. (October, 2010. OC. Adas56)

After learning that Adas56 was initially diagnosed with a blood sugar level of over 500, Adas56's doctor's suggestion appeared to be more appropriate for his particular situation. After Adas56 revealing his illness trajectory, a new member subsequently commented that Adas56's information about his doctor's suggestion could be appropriate for Adas56, considering his individualized situation.

This thread about finding the right foods to eat while taking insulin illustrates how operationalization of a strategy can break down due to personal conflicts in

belief, individual medical problems, and personal preferences. Revealing their illness trajectories helps members to facilitate coming to an agreement. Another example from the interview (I, P5) centers around the question of how often one should test blood sugar. Members repeatedly attempt to come to an agreement about what is an appropriate strategy. They also attempt to validate information by bringing in official guidelines from credible health organizations such as the ADA, as well as their own doctors' suggestions. Other examples of issues where the negotiation processes are evident include finding the balance between healthy and delicious foods to eat (I, FF\_P11;FFgch\_P2), understanding the effectiveness of cinnamon in diabetes (I, P8), determining when it is appropriate to have dinner and how much should be consumed (I, FFply\_P6), finding the right practices in calculating carbohydrates and insulin (I, P4), and determining whether eating sugar is appropriate in moderation (I, P4). Answers to any of these examples depend on the patient, and the patients appear to understand the situated characteristic of daily solutions in diabetes management. At the same time, the patients want to arrive at consensual answers for individualized situations through discussion amongst people with diverse perspectives and experiences.

The key to working around the operationalization breakdowns is the process of coming to an agreement. This process requires bringing in standards and definitions about what is considered good, bad, or severe that the patients personally believe because of what their doctors tell them and because of what they find from their research. These standards and definitions, however, vary

between the patients, creating further conflict, opening up further opportunities for negotiation.

# Varying Standards and Definitions, Coming to an Agreement

To generate operationalized guidelines and advice that patients will follow, having consistent standards and definitions is important. Inconsistency in standards and definitions, however, is observed in the information patients gathered from different doctors as well as in varying beliefs amongst the patients. Next, I describe three examples that demonstrate how patients are challenged by inconsistencies in information given to them. The first is a case where a patient could not get consistent advice from his doctors as to what his A1C level should be, and the second is a situation where standards given by lab reports conflicted over time. In both cases, members accepted standards that made the most sense to them. The third example describes an interaction where the definition of "cure" was repeatedly challenged and negotiated by the members of dLife, making it difficult to agree on the end goal in controlling diabetes.

P4 is a geriatrics patient who needs to be more cautious with hypoglycemia, especially because he uses an insulin pump. He needed to know whether to maintain his current management practice, 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 that came from his doctor, a nurse at one

diabetes meeting, and another nurse at another diabetes meeting all suggested different target levels of A1C:

Everybody wants to have a low A1C but when you get low then they say you're too low, so where is the happy medium that your A1C... What is your target A1C that you want to get? 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  $7 \sim 7.2$ . Well if she's going to be  $7 \sim 7.2$  and 180 when your blood sugars there, you're expelling sugars through your kidneys. (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 were standards—such as what is considered low, high, good, or bad—difficult to define, but the definitions themselves were often challenged and negotiated.

Varying and conflicting standards are often observed in the support group discussions, and the members handle such conflicts by adopting standards that "make sense" to them. In the following example, a member in dLife received a newly changed standard of A1C in his recent lab results. 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

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would let you know that my lab had changed. Other labs
may be different.)
It say that under 5.7 is normal
5.7-6.0 Increased risk for diabetes
6.1-.6.4 Higher risk for diabetes
= or greater than 6.5 Consistent with diabetes (August, 2010. OC. furball64801)
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When Furball64801 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 such as LabCorp and ReliOn and explained how their standards changed over time. Members then discussed their interpretations of what they considered to be '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. vpenning)

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. nomorecarbs)

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. In dLife, Cmkeyse started a thread with the title "Can Diabetes Be Cured." He recalled how on "The Biggest Loser," a reality TV show about helping overweight participants lose weight, the show's consultant Dr. Huizenga told one of the contestants that his diabetes had been cured. Cymkeyse

then analyzed what a cure for diabetes might mean, since the inability to produce insulin is known to be an incurable disease:

While in many cases a cure is NOT possible, I think Dr. Huizenga gave the best prognosis. Damage to the pancreas's ability to produce insulin can't be cured yet, but the other cause insulin resistance can be "cured". Since the person was newly diabetic, young, obese, and out of shape, one would expect his pancreas should produce enough insulin for normal metabolism if his insulin resistance could be lowered. (Oct 2010, OC, Cmkeyse)

Cymkeyse explained what "cure" for diabetes meant in this scenario—decreased insulin resistance, which could be accomplished through exercise and diet management. He went on to suggest that this is an example diabetics could learn from:

"The Biggest Loser" is about motivation and what can be more motivating after learning you are diabetic than to understand that you can cure the conditions and prevent the onset of diabetic complications. (Oct 2010, OC, Cmkeyse)

The statement that Cymkeyse made—that diabetes can be cured—spurred conversations about whether diabetes is in fact curable. The patients attempted to arrive at an agreement about what the definition of "cure" was, which would influence the way the members set up their goals in managing diabetes. For instance, Alan\_s replied to Cymkeyse, saying that a cure could not be made just by reducing insulin resistance, and that Cymkeyse's definition of cure was closer to "improved" or "managed":

I think the biggest loser doc, and many others, is confusing "improved" or "managed" with "cured". Apart from that, type 2 diabetes is not just a matter of beta

cell loss and/or insulin resistance. It is also about flaws in the signalling processes that tell the pancreas, liver and other organs to provide insulin, glucose or other needs when required. That is not "cured" by weight loss. [...] "Cure", used when discussing type 2 diabetes, is a four-letter word in my lexicon. A word used by charlatans and snake oil salesmen. (Oct 2010, OC, Alan s)

Another member joined the conversation, raising the issue of how one's interpretation of a definition matters. Depending on how a person defines "cure," he or she could be cured or not cured of diabetes:

I guess it depends on what 'cure' means to you. If my being cured, you mean that you have have normal blood sugars, and are not at risk for developing diabetic complications, then, yes I definitely believe you can be cured of diabetes.

If you mean that 'cured' means you can eat whatever you want and never have to worry about high blood sugars, then, no, you cannot be cured, and that includes most of the present non-diabetics. Keep eating refined carbohydrates, and you are going to see your blood sugar levels rise, if you live long enough. (Oct 2010, OC, Nomorecarbs)

The thread continued to discuss how "cure" can be defined in diabetes, and these definitions shaped their commitments for how they planned to manage diabetes:

My definition of cure is to get rid of what caused it, and to not come back. Since the actual cause of diabetes is unknown, then I don't believe you can cure it....You can control it, and keep it in check...but, without being able to attack the root problem...you will be in danger of it returning. (Oct 2010, OC, Vpenning)

If the community were to establish an equation for curing diabetes, the community first had to agree on the definition of cure. Depending on the definition, the community then could lay out their personal experiences and insights, what they know about the feasibility of finding a cure, and what to do to

get closer to being cured. Diabetes was an incurable disease for Vpenning because she believed diabetes would come back in any case. Thus for her, controlling diabetes is constantly making a commitment toward recognizing and maintaining her controlled status. Another member posted her definition of cure, which was derived from a report by a group of people from the ADA. That definition for cure was remaining normoglycemic<sup>9</sup> for 5 years without complications.

In other cases, the definition of what was considered "normal" was constantly challenged. Medically credible resources such as what members refer to as "Dr. Bernstein's book" (Bernstein & Aubert, 2003), information from doctors, and research findings also conflict in the numbers they present. The members continuously introduce information from various credible resources and discuss personal interpretation of the aggregated information to make sense of how they need to approach controlling diabetes. Understanding varying interpretations and individual differences broadens members' understanding of diabetes management thus helps them construct individualized strategies.

# When the Negotiation Fails

While the community is actively attempting to negotiate and come to an agreement about the conflicting information they encounter, their negotiations, at times, fail. This is observed primarily in dLife rather than the face-to-face support

<sup>&</sup>lt;sup>9</sup> Having a normal level of blood sugar

groups, presumably due to a well-known characteristic of online social interaction called "flaming" (Kiesler, Siegel, & McGuire, 1984). In the face-to-face support groups, rarely did I observe patients argue about whose strategy was better. The negotiation failure in dLife often happens when members encounter conflicting personal beliefs about appropriate ways to manage diabetes. For instance, two members argued over which diabetes management practice was more appropriate, which did not result in agreement. Rather, the resolution was that one of the two stopped posting in dLife. This case illustrates how operationalization breakdowns are sometimes unable to be resolved. Nomorecarbs believed in moderate control of diabetes numbers allowing pizza once a week but making sure he had enough exercise, while Shekarg believed in strict diet and control over his A1C. This difference in personal belief between Nomorecarbs and Shekarg is in fact a common difference observed from the support groups in general. The members generally respect one anothers' decisions, but sometimes they try to get others to adopt their personal beliefs rather than letting the disagreement persist. Janisroszler, a Certified Diabetes Educator and a moderator for the site, introduced her neutral perspective into the conversation between Nomorecarbs and Shekarg, moderating the flaming by providing an objective perspective:

Many people prefer a more restrictive approach, while others find ways to maintain great diabetes control and eat their pizza too. There are many ways to approach diabetes. If you can agree to disagree, please stay and continue to learn with all of us here on the board. (June 2010, OC. Janisroszler the moderator)

Furthermore, other members jumped in to discuss their experiences with the two extreme positions of Nomorecarbs and Shekarg, attempting to come to a resolution about how each of the two approaches could be appropriate in different situations:

I try both diet nomorecarbs and shekrag['s plan] for about 2 months each of try. Both work parallel but I prefer shekrag['s plan] because giving me more energy to do my kind of work and I am much more active if I could eat once a while more carbs then normal. I try to keep in mind but even so I do not eat more than 130g carbs a day and 55g fat a day, also my protein intake has [been] limit[ed] to 72g a day. I find out I have all results I want to keep [at] that kind [of a] pattern. I don't know how do you want to call this kind [of] diet and I don't care also. I agree with janisroszler this time only it is many ways to control diabetes and all of them has [their] own pluses.

I also [found] out[,] to control pizza[,] it is a lot easier th[a]n control[ling] white boil[ed] potatoes. I have no idea why, but I guess I am very sensitive to potatoes. (June 2010. OC. Adas56)

Adas56's opinion reiterated his understanding that different approaches need to be taken based on individual differences in how one's body reacts to food and exercise.

The sharing of such differences in personal beliefs, regimes used, and information gathered from doctors is one of the greatest advantages that the support groups are able to provide. However, occasionally the process of negotiation and agreement creates conflict between the members. The following section on illness trajectory alignment work further examines how sharing different experiences and beliefs serves as a learning experience, particularly for finding individualized solutions.

#### CONCLUSION

In part I, I described how patients use operationalization to contextualize and share strategies. More specifically, I examined how patients share information about the changes in their diabetic conditions over time, how various interventions affect patients differently, and how strategies and knowledge are shared through operationalized instructions. I further discussed the limitations of operationalization as a help process, specifically its inability to convey complete contextual information. Patients, however, actively reflect upon breakages in operationalization through agreement and negotiation, which in turn results in deeper understanding of the individualized nature of diabetic experiences.

As seen from cases where patients have to share illness trajectories when operationalization breaks down, operationalization is not singularly sufficient for collaborative help. The process has to be embedded within the context of patients sharing historical stories of how they manage diabetes over time. At the same time, sharing illness trajectories creates new kinds of help. In the following section, I discuss how patients share their illness trajectories to help one another, specifically in identifying individualized solutions. I further detail how the sharing of illness trajectories builds the community's common-enough understanding over time, and how this helps patients' gain enriched understandings of individualized diabetes management strategies.

# Part II. Illness Trajectory Alignment Work

One of the biggest challenges facing patients with chronic illness is uncertainty about the future (Piette, Richardson, & Valenstein, 2004). Newly diagnosed patients start out having little idea about how to manage their diseases, and constantly encounter new challenges as they strive for a deeper understanding of disease management strategies (Middleton, 1997). Being provided with information about other patients' paths for managing disease over time helps patients anticipate what might happen in the future and what solutions might work best for different challenges.

Part II describes how patients in the support groups utilize stories of peer patients' diabetes management practices over time as a way of helping themselves find individualized solutions. I refer to the practice of patients sharing stories about their illness trajectories and using them to help produce individualized solutions, as "illness trajectory alignment work." I 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 with others' experiences, patients can derive personal meaningfrom others' illness trajectories. The temporal component in the shared stories allows patients to deal with the uncertainties 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.

I describe illness trajectory alignment work in two ways. The first is "apprenticeship," which describes the core help procedure that occurs when patients are sharing illness trajectories. Apprenticeship occurs between patients with different experience levels (e.g., newly diagnosed patients and those who have been controlling diabetes for over 15 years). More experienced patients can share how they have dealt with a situation that a newly diagnosed patient is currently struggling with, give warnings, and offer reassurances about the likelihood of positive consequences. Moreover, patients can be encouraged by seeing successful cases, as described by the concept of 'upward comparison' in social comparison theory (Festinger, 1954). By seeing others' illness trajectories and how other patients have faced similar challenges, one can reduce uncertainty about the future.

Second, "collaging illness trajectories" describes the collective work of the community 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 collaged together to construct something the community can use to understand how one might experience a medication over time, for instance, and what individual differences could exist.

While the above two help processes may appear to be planned assistance—where the help is given through triggers such as a post about asking to collect experiences on a medication or a member warning another patient, I emphasize

that the category of apprenticeship and collaging illness trajectories emerged for analytical purposes. In reality, the illness trajectory alignment work, along with operationalization, is seamless and embedded in the patients' daily sharing of their experiences. Even though a patient might be asking a specific question about how to check blood sugar, by sharing various exceptions and personalized strategies, the result of the information transaction may not be limited to directions for how to check blood sugar. Rather, the value of the interaction stems from learning of various experiences that other patients have encountered when checking blood sugar in connection with other activities such as eating, exercising, and taking various medications.

The concept of patients learning from one another's holistic experiences is further discussed in the section, "The Community's Building of Common-Enough Understandings," I attempt to describe how patients, as they come to know how other patients manage their diabetes, gradually learn who to talk to about specific questions, better understand the individual differences in how diabetes is experienced, and expand their range of available solutions that would help patients gain new ideas for improving their diabetes management practices.

Next, I introduce the Chronic Illness Trajectory Framework (CITF), upon which my analysis of illness trajectory alignment work builds. I also describe how previous research utilized the CITF for discussing challenges and implications for patient care. Then I discuss illness trajectory alignment work along two lines: apprenticeship and collaging illness trajectories.

#### CHRONIC ILLNESS TRAJECTORY FRAMEWORK

Luse Strauss and Fagerhaugh's (1997) Chronic Illness Trajectory Framework (CITF) to borrow terms and analytical tools for understanding how patients shared their stories about managing diabetes over time. I chose CITF over other similar concepts such as ongoing sensemaking (Dervin, 1992) for describing patients' historical accounts of illness because of its emphasis on various stakeholders being involved in individuals' evolutionary stories of illness trajectory over time. In "Social Organization of Medical Work," Strauss and Fagerhaugh (1997) describe the phases which patients go through, starting with pre-diagnosis, diagnosis, denial, acceptance, maintenance, and death, and more importantly emphasize the work that is being done by various stakeholders such as doctors, nurses, family members, friends, insurance companies, and patients themselves. The important part of the work is the coordination amongst the various stakeholders—that is, how conflicting solutions get negotiated, how the needs of each stakeholder are met, and how communication is facilitated between various groups. 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. (Strauss & Fagerhaugh, 1997)

The application of this framework has been useful in understanding how to better care for patients with chronic illness. Examples of applications include helping patients to manage uncertainties (Brashers et al., 1998), modeling and characterizing chronic illness (Dorsett, 1991), and understanding temporality of

medical work (Reddy, Dourish, & Pratt, 2006). More recent efforts specifically related to patient empowerment (Anderson et al., 1995) have included further understanding patient work in the active role of coordinating with the rest of the stakeholders in improving their conditions.

The concept of trajectory also takes its own course in the field of social science. In sociology and related fields, personal life trajectories are used as resources for research. Bertaux and Kohli (1984) looked at how life trajectories could be shared as stories, and how these stories could be utilized for empirical research. The authors reviewed how the fields of sociology, linguistics, history, and anthropology have used life stories as a ground for formulating theories. Life stories can be in forms of letters, diaries, personal records, open interviews, autobiographies, and tape-recorded life stories. The innate characteristics of temporal components and personal memories that are embedded in life stories can shed light on experiential paths. For instance, in one study by Kohli (2005), interviews were used to study aging in the industrial workplace. Questions asked in the study included "how do aging workers cope with the problems, risks, and possibilities resulting from this organization?" The trajectory examined was not "downward trajectories" (Fischer, 1982) but rather "normality"—more or less eventful careers of people who are neither underprivileged or highly successful.

Trajectory has also been discussed as a path of events, people's assumptions, and context in developing systems. Ackerman and Halverson (1999) examined trajectory as a path that helpers developed by making assumptions and

projecting future consequences. The authors examined how, during hotline workers' collaborative work practice, workers made incorrect future projections and how this resulted in workflow breakdown. Greenberg (2001) reviewed trajectories as a dynamic construct. He suggested practical implications for context-aware applications, mostly in emphasizing challenges in a given event's temporal context.

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

Furthermore, I extend the discussion by Ackerman and Halverson (1999) on trajectory as a resource for future anticipation and how this becomes an integral resource in coordination work. I discuss members' anticipation about their future through illness trajectories and how trajectories are used as resources for sharing experiences, enriching the context for collaborative help. CITF provides building blocks for constructing my understanding of how patients share their experiences to give one another help in living with diabetes over time.

The patients' efforts, described in CITF, can be enriched by the increased access to health information and peer patients' experiences now available online.

The analysis I present below focuses on patients' use of the illness trajectory as an

object of knowledge that they can share in order to generate various interpretations, agreements, and solutions. Owing to increased access to health information online and an improved ability to communicate, the amount of information that patients encounter is far greater than it was when the CITF was originally discussed in 1991. The role of patients today is not limited to attempting to better detect symptoms or to more effectively communicate what they experience with their doctors. Patients' work has become diversified and empowered through the experiential knowledge they gather from peers, creating a new facet in illness trajectory framework.

In the next section, I discuss how patients share their illness trajectories as a way to convey their experiences. More specifically, the temporal aspect of the illness trajectory becomes useful as patients attempt to compare experiences to reduce uncertainty and help anticipate possible consequences.

#### **APPRENTICESHIP**

Apprenticeship refers to how patients' illness trajectories are shared and compared to one another to help them project into the future and reflect on the past. This process helps patients construct personalized meanings about their disease and reduces their uncertainty about the future. One of the biggest challenges that patients with chronic illness face is dealing with uncertainty. 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

(Piette et al., 2004). Hearing from experienced patients about how they overcame similar challenges helps to reduce uncertainty about the future. Additionally, getting practical advice and tips helps inexperienced patients better handle their current struggles in managing diabetes. I discuss three types of interactions for reducing uncertainty and providing practical tips in the support groups: "upward comparison"—how patients are encouraged by witnessing the success of others; "words of wisdom"—how more experienced patients give advice and warnings, and highlight important things that diabetes patients need to understand as they progress in the treatment of their disease; and lastly, "I've been through that"—where more experienced patients provide examples of how they have dealt with similar situations.

The purpose of this analysis is to highlight the interactions that are observed to be critical in using others' illness trajectories to project what one might experience over time. Accordingly, the three categories do not fully represent reality. Rather, they are isolated for the analytical purpose of understanding how the patients are utilizing other patients' illness trajectories to address their individualized problems.

# **Upward Comparison**

According to social comparison theory, individuals evaluate their own desires, abilities, and opinions by comparing themselves with others (Dibb & Yardley, 2006). One of the concepts that is often discussed in self-help group

literature is 'upward comparison' (Festinger, 1954). That is, an individual compares himself with others who have been in a similar position and attempts to anticipate how he can become like the compared individual in the future. For instance, presenting a successful diabetes patient who overcame obesity could encourage obese patients to build positive attitudes about themselves and to work harder to be like the successful case. Such comparisons occurred in the support groups because members shared information about their condition in the past and how much they have improved over time. This inspired many members and had a positive impact on the group. One member posted his success story of reducing his A1C from 10.2 to 5.4, reducing medications, and losing 79 pounds. This member shared a detailed but concise history of how his numbers changed over time and what regimes he used to improve his situation:

I was unable to keep my weight down in the past. After the first concerns I decided to prove to myself and the Dr. I could not only make the lifestyle change...but keep the change to improve my bg numbers. Plus get off the meds.

My starting A1C was 10.2 and I was started on metformin 500mlg2xday. Plus lisinopril 2x daily for high blood pressure. [...] After cutting back on my portion size and carbs in each meal. My next A1C was 6.0. With this progress also came loss of weight. [...] By Christmas I had lost 50 lbs. This is when I had decided to start my exercise program. I live 1.3 miles from my job so it seemed a great idea to walk to and from work.

My gosh there went another 3 months by and my next A1C was 5.8. Now the Dr. reduced my metformin to  $250 \, \mathrm{mlg}$  2xdaily. I kept my diet pretty much the same. Changing off from a few meals that always seemed to get great results for bg readings. Kept walking to work and every where.

Another 3 months passed and the next A1C was  $5.6\,$  Plus the Dr. took me off the metformin. Also had lost  $72\,$  lbs at this time.

Now I wanted to really keep up with my new lifestyle change. [...] Just a short month later and just recently I went to the Dr. to have the normal tests done.

Well drum roll!!

My new A1C was 5.4

The Dr. didn't do the lipid panel this time..but the blood work up instead. Everything was spot on and nothing wrong. Even the FSB was 82. Plus as of July 29 I have lost a total of 79 lbs. (July, 2010. OC. Lyndew)

Lyndew not only shared the changing numbers, but also detailed the changes in her diet and exercise regime. Her success story inspired many—ten different members posted short messages sending her encouragement and telling how she inspired them:

Great report. You go girl!!! Proud of all you have accomplished. You are a source of inspiration. (Davidsondg)

I have to say your story should inspire many, sure it wasnt easy but it sure was worth it. (Furball64801)

What a great story! Congratulations on your success and hard work. You had a lot of good things working for you: a great attitude, stubborn determination to do something good for yourself, and a doctor who was willing to work with you.

What great inspiration for other diabetics struggling at the beginning of their journey. (Lightsinger)



What a wonderful success story. May you continue to remain well & so very very focused!

Figure 3: In response to Lyndew who successfully controlled diabetes in a year However, success stories and good examples do not always elicit positive responses from other members. In one face-to-face support group (FF2), a regular member, Nickey, called herself, "an example of a success." She regularly shared healthy recipes and exercise routines. While the group responded to her positively, by complementing her efforts or calling her a "food guru," an outspoken member of the group questioned her:

Nickey: I joined the gym. I go to the swimming pool. That made my bone spurs to be gone by doing swimming and muscle training.

Betty: Just by doing swimming? [with a face of doubt]

Nickey: You need to get away from the kitchen. I am an example of success.

[Other members wanted to go back to her history all the way back to when the support group began, but Nickey did not respond]

Betty: What is your A1C now?

Nickey: 6.5

Betty: What? The average of 6.5? Is it 200 each time? Can you [the nurse leader] get the chart for us? (June, 2010. FF2)

Support groups work best when members share common experiences and hardships that culminate in successful experiences. In Nickey's case, she did not share how she failed in the past, but only shared her success story, implying that it could happen easily for her. Just by going to the swimming pool she was able to cure bone spurs, and she talked about getting away from the kitchen as something that was a simple thing to do. By failing to share details about her past, she made it difficult for members to align their illness trajectories with hers. Knowing the past history of a successful example is critical in upward comparison.

In general, however, members with successfully controlled diabetes are hailed as sources of inspiration:

All the people in the last 10 years with this dreaded disease, we haven't lost anybody. I mean, the black lady, 90-some plus, Lowe's was 90, and you go on and on and on. [...] I mean it's just amazing that Olga and... although she is a newcomer relatively [they were all doing so well]. Do you remember Bill? The guy had all those bypasses. [He is doing well too] (I, P6)

#### Words of Wisdom

Seeing the success of others is not just a source of inspiration, but also a resource for learning. In addition to sharing success stories, more experienced patients actively share insights that they have learned over the years. Experienced patients warn less experienced patients about critical events they might encounter, helping them become more proactive about problems that they might not

anticipate otherwise. Experienced patients also attempt to correct practices of inexperienced patients which seem to need improvement and share potential consequences of various actions and events. Such sharing of words of wisdom allows patients to foresee things that they would be unable to anticipate as a newly diagnosed patient. However, receiving words of wisdom is one thing and putting them into action is another story.

Taking the initiative to go beyond taking medications by incorporating diet and exercise into daily diabetes management is a difficult thing for patients to do. An interviewee talked about how only two patients in his doctor's entire practice have attempted to change their diet:

He [his doctor] said two people in his entire practice that really, really understand it and can try real hard to work at it. Most people that got diabetes, what they want is a pill. And then they take pills and then eat and drink whatever they want. [...] (I, FF3 P2)

Not knowing what might happen after previously relying solely on medicine to take care of blood sugar levels, many patients can develop insulin resistance and gain weight as a side effect of using too much insulin and consuming too many carbohydrates. As illustrated in P1's quote above, many patients fall into the trap of relying on medications to control diabetes.

The following example illustrates experienced patients giving warnings to a new insulin user about the danger of depending solely on insulin to manage blood sugar levels, while suggesting that appropriate diet and exercise regimes also have to be incorporated into their daily diabetes management practices. The thread

began with Tinkerbell 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 as to whether insulin was something she could rely on for a long period of time:

Aside from the injection burn; and the nasty lows that can creep up on me; I think I just might be in love with insulin! I can eat pasta and rice and bread...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 spahghetti can garlic bread and 2 hours later a sugar of 99!! [...] My only concern is whether or not this will be harmful to my body I am a young typ2 2 I am 24 so would year of insulin hurt my body in anyway? [...] So what are some other opinions on this? (Oct, 2010. OC. tinkerbell)

Several patients replied to this, including a patient who also had a positive experience with insulin. Other members expressed concern about Tinkerbell's possible weight gain due to the increased use of insulin and the possibility that she might ultimately develop insulin resistance<sup>10</sup>. Members who replied to this thread included several who had experienced gestational diabetes and who enjoyed insulin in the beginning as Tinkerbell did—but their recommendations were to start thinking about incorporating appropriate diet change and exercise instead of relying solely on insulin:

I used it [insulin] for a short time but am not on it now after increasing my exercise and watching what I eat. I will caution to you that you can gain weight with the higher carb diet and insulin. Good luck. (Oct, 2010. OC. Panmat1)

<sup>&</sup>lt;sup>10</sup> A condition in which body cannot effectively use insulin.

Looks like you are doing great with insulin. Only thing to keep in mind that if you eat pasta/bread, you are taking insulin to process it and high insulin in body can increase insulin resistance (IR) in type-2. It is possible that not everyone will see increase in IR but something to consider. What this means is that over time you will need more insulin for same number of carbs. And of course as others mentioned, there is possibility of weight gain with higher carb/insulin. (Oct, 2010. OC. Shank us)

I've had the same reaction to insulin, Tinkerbelle. It allows me more freedom to eat a more "normal" diet. I still avoid the high carb stuff and watch what I do eat very carefully, but now I can have 1/2 cup of potato with my meal, or a small serving of my beloved pasta. My mood and outlook improved dramatically when I found I could have those small amounts...a little is a lot better than none! I did gain 3-4 pounds that I can't seem to shake off, so do be careful not to overdo it. (Oct, 2010. OC. Daisyrose2)

The more experienced members warned Tinkerbell about developing insulin resistance, which would require her to use more insulin over time. Using more insulin would leave her more prone to gaining weight, making it more difficult to control diabetes, thus creating a cycle of worsening diabetes management. Patients often cannot anticipate side effects that they might suffer over the years, since little information is given at the time of diagnosis and the foremost problem to be solved is lowering blood sugar levels. Accordingly, hospitals arrange support groups to educate patients and to help them become self-sustaining after receiving acute treatment. Those who choose to engage in support group discussions either face-to-face or online can get such advice—often from the successful peer patients—and potentially identify negative outcomes which they might have overlooked otherwise.

Other examples of words of wisdom include sharing information about interactions between medications and diet regimes (for example, Amaryl and the Bernstein diet), complications and exercise regimes (such as pneumonia and aerobics), how "frozen shoulder" (a condition that makes it painful to raise arms above the shoulder or bend them behind the back) develops over time, malicious websites on diabetes, dealing with predialysis and providing suggestions for avoiding problems. Members are able to share critical warnings and guidelines with less experienced patients. However, it can often be difficult for the advice givers to get people to listen and put what they learn into action:

I had one person to tell me "I am not talking to you because all it's going to do is upset me." [...] Cigarettes and alcohol can screw up your medication and not make them work properly. But you can't tell some people that. They won't listen. That's the biggest problem, people not listening. My girlfriend and I were teaching the self-help course for Arthritis Foundation for a while, way back. So we understand that some people really listen and some people really don't listen. And they don't want to know. (I, FF6\_P11)

The fact that people do not listen to sound advice is a classic challenge for healthcare in general. My analysis on illness trajectory alignment work builds on the assumption that the patients I observed are willing to learn and share. The analysis has been done in this way because the people I observed are those who have taken the initiative to come to a support group in the first place. Patients' lack of interest in learning and changing their behavior regardless of the information they receive from their peers will continue to be a challenge. The patients who have the hardest time changing their behavior are those who think they already

know what to do. Words of wisdom can be more useful in cases where patients feel uncertain and are seeking guidelines to follow.

Continuing with this theme of patients helping others with uncertainty, I now discuss how more experienced patients share "I've been through that" message with inexperienced patients. The experienced patients provide suggestions for possible short cuts and give ideas as to what the inexperienced patients can expect in the future. By sharing common experiences and demonstrating that "you are not the only one going through this," the process helps inexperienced patients achieve self-compassion—patients realizing that patients themselves are not the ones to blame for their disease (Neff, Kirkpatrick, & Rude, 2007).

### "I've been through that"

When advice and wisdom are coupled with shared experiences, this creates another unique form of help. That is, when experienced patients share "I've been through that" messages, the patients getting help are able to develop various tangible strategies based on the real life experiences emerging from the more experienced patients. Also, the sharing of stories about mistakes and successful strategies helps patients avoid making those same mistakes and reduce the uncertainty they might be experiencing.

Next, I describe cases that illustrate how patients provide solutions to the community based on their own experiences. I discuss how patients providing help disagree about which solutions are appropriate. This again raises the issues

discussed in Part I regarding how the community negotiates appropriate strategies when their personal beliefs and interpretations conflict. I then discuss the unique role of "I've been through that" messages—helping patients realize that they are not alone and increasing self-compassion by sharing common experiences.

Patient Ellalou73 had problems with Metformin<sup>11</sup>. She suffered bowel issues and sugar cravings after she started taking Metformin. While there were other community members who did not have similar experiences who responded with suggestions for improvement, there were also suggestions from members who shared common experiences with Ellalou73. Members who shared common experiences also explained how the situation has changed for them over time, giving Ellalou73 a sense of what she might anticipate. For example, Malproso shared how he also had the bowel issues but that they went away after the first few weeks. He suggested various strategies to help control her sweet tooth:

The main thing to do if you have an uncontrollable sweet tooth is to substitute Diet Coke or Coke Zero for the regular stuff. Not quite the same but still a sweetness. Also try Skinny Water or other drinks that are no carb (look out for Vitamin Water and Vitamin Water Zero as they have carbs). As for your candy bar craving, try the high cocoa-content bars like Lindt 85% Extra Dark. Four large squares (one serving) is just 8 grams of carbs. If you need it just a little sweeter try the 70% Intense Dark. It's just 13 grams. (September, 2010. OC. Malproso)

Another member relayed what he heard from people on the forum who had bowel issues with Metformin:

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<sup>&</sup>lt;sup>11</sup> One of the most popular diabetes medications.

You might ask your doctor about the "ER" or extended release form of metformin. Many on the forums say that solved the intestinal issues. (September, 2010. OC. Leadsinger)

Regarding the sugar cravings, another member shared how he had a similar experience when he had elevated blood sugar levels. He shared various conclusions he drew about the sugar craving issue and suggested a strategy he called, "test, review, adjust" that might help Ellalou73 identify the right foods to reduce her sugar cravings:

The more carbs I ate, the more carbs I craved. Often that craving was accompanied by high blood glucose levels. But sometimes the opposite was true and it was accompanied by low blood glucose levels which were reacting after highs. But I never got the cravings when my BGs were normal.

Maybe I'm different to you. But maybe I'm not. This will help you find out (click on the coloured text): Test, Review, Adjust. (September, 2010. OC. Alan s)

Another member concurred with Alan\_s, encouraging Ellalou73 to moderate her carbohydrate intake:

Alan you found the same exact thing that I did. I found the more carbs I ate the more I craved and I had non stop hunger. (September, 2010. OC. Furball64801)

As a result of this process of sharing information, Ellalou73 was able to better anticipate what she might be able to expect as she adopted various strategies. Ellalou73 learned that the bowel issues might be solved by waiting a few more weeks, and if the problem persisted she could ask her doctor whether she could try the extended release version of Metformin. She also learned that her sugar cravings might stem from unstable blood sugar levels, and that continuing to

control her blood sugar could help the situation while she satisfied her sugar cravings through diet pop products. Ellalou73 developed a near-term plan for proceeding with her treatment, thereby partially reducing her uncertainty about the future.

As members share solutions, conflicts emerge regarding which solutions are most appropriate for individual cases. Some of the processes described as part of the "breakdown of operationalization" in Part I can resurface. That is, conflicts in personal beliefs and differences in how patients react to various strategies can lead to conflicting opinions around problems. Members then have to negotiate these conflicting opinions to arrive at a consensus solution. For example, one member in dLife had trouble with tingling feet, and another suggested they take a B-complex vitamin. A third member challenged the suggestion by saying how B-complex vitamins include niacin, which could cause the same modest rises in glucose that he himself had experienced. This opinion was then challenged by another member, who pointed out that what B-complex vitamins have is niacinimide, not niacin, and that the particular experience of the third member could have been a unique problem. The original question poster ended up deciding to add B-complex vitamins to his daily vitamin intake.

Not only do members give practical tips, they also contribute by sharing their past experiences to show that struggling is normal for anyone, and by encouraging patients to accept their situation and to maintain a positive mindset about managing diabetes. In the following example, a member, Hsbearatl, posted

to dLife about how he continued to gain weight and feel isolated from the world. In response to his post, members encouraged Hsbearatl by sharing their own prior similar experiences. Hsbearatl was encouraged after hearing others' experiences about how they had handled the situation.

## Here is Hsbearatl's initial post:

Today I had my first check-in after my 'one day class'. I GAINED 8 lbs (oh, I am 6'5" 347 lbs) I am well, upset. My doc said we need to adjust my insulin (up to 38 units of Lantis) + glucophage. (he is adding Victoza). I just feel mad at the world, I want to crawl in my usual hole. A friend (tried) to reach out and I felt...patronized. (don't have a circle of friends)

As a BIG/obese gay man I feel utterly and totally invisible...so here I sit at home (with the great dog) watching netflix... (September, 2010. OC. Hsbearatl)

Various members responded, saying that what Hsbearatl was feeling is normal and that everyone goes through such a phase, encouraging him to keep a positive attitude and to continue to work hard at implementing his diet and exercise changes. They suggested that hard work would eventually result in benefits:

Oh, yeah, I know what you mean! I was the same way. Food was my drug of choice. "They" put me under all this stress dealing with a serious disease and "they" took away my release valve. It was awful. I cried for months. I was terrified. I just knew I wouldn't be able to control my eating and that I'd have all those horrid complications. But terror is a good motivator! I did learn to eat properly and in reasonable portions. I did learn to exercise, although I can't say I like doing it, haha! You can do it, too. The alternative is worse. Hang

in there, Friend. It gets easier. (September, 2010. OC. Daisyrose2)

Hsbearatl showed improvement in his attitude toward himself and his diabetes:

Holy crap folks...your replies almost brought tears to my eyes..thank you so very much. [...] So good to hear this is normal. Being alone does exacerbate this a bit. [...] think I am going to get off my tuckus and take the dog for a walk in the sunshine. Thanks folks...really. Nice to feel not a lone. (September, 2010. OC. Hsbearatl)

The cases described in this section illustrate how "I've been through that" messages give patients practical tips, and how possible solutions are negotiated amongst the members. It is important for patients to know that others have successfully faced similar situations.

Sharing past experiences, present struggles, and expectations about the future enables members to encourage one another, find solutions, and reduce uncertainty. In the next section, I discuss how patients at varying stages collectively assemble a coherent story around a problem based on their varied experiences and opinions. The processes and the results are helpful for all individuals in the community, not necessarily only for newcomers or inexperienced patients.

#### **COLLAGING ILLNESS TRAJECTORIES**

I have discussed how members' illness trajectories are shared to help members establish expectations for the future. My analysis to this point has focused on following the linear trails of each illness trajectory as a form of help, where the transfer of experiential knowledge flows from patient to patient. Now I further analyze illness trajectories themselves as dissected multiple parts which are born with specific purposes of use. That is, the community collectively requests specific pieces from members' illness trajectories that are concerned with a specific problem, such as information about medications or diet and exercise regimes. Employing the parts of illness trajectories collected from its members, the community attempts to construct a coherent story around individual problems. Pieces of illness trajectories from different temporal points on each member's trajectory are collected and re-assembled to shed light on the individual differences of how one might experience medications or new diet and exercise regimes over time.

As members carry out the work of collaging illness trajectories, identifying individual differences helps them to not only find generic solutions, but also to find the right intervention for each individual, modify current interventions when possible, and anticipate the future. Rather than arriving at a solution that perfectly fits each member, awareness of individual differences helps members collectively understand various possibilities so they can adjust their expectations, practices, and decisions accordingly. Next, I describe a case that illustrates the work of collaging illness trajectories, specifically in building an understanding about long-term experiences of a medication.

Peljbl started a thread in dLife after it was suggested by his doctor that he start taking Victoza, a weight loss medication. Victoza was a relatively new

medication at the time, and he wanted to hear about other patients' experiences with the medication before he took it, to assess whether it would be an appropriate medication for him and also to anticipate what might happen as he continued to use the medication over time:

Went to the endo[crinologist] yesterday - a1c up to 6.2 from 5.9 - LDL up to 122 from 97, weight up 6 lbs - all other labs WNL. He suggested I try Victoza - to help to lose weight and help my numbers. I tried Byetta [another weight loss medication] in the past - got over the nausea within a week but had stomach pain so had to go off it after 2 months - I did lose 15 lbs. Here's the question - anyone on Victoza - I am always hesitant to use a new drug. Anyone have any experience with Victoza to share with me? (Mar, 2010. OC. Peljbl)

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 several weeks to a month. Some of them were pointing to the thread to update their experiences with the medication over time. Personal beliefs, past medical history, other medications being taken, 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, Rjack22 replied to the thread after his third day of using Victoza. In this post, Rjack22 informed readers what they might experience during the first few days of taking Victoza, such as gassiness, and shared his fear of

injecting medications. However, he was unable to anticipate what might happen with more protracted use of Victoza:

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, but then I am on the starting dose of .6 MG. I have noticed more "gas". More burping and more wind. Hopefully this will pass (no pun intended) in a week or two.

I was very frightened about starting a "injection" medication. I just could not imagine sticking myself with needle. And in fact I had a great deal of difficulty giving myself the first one. The nurse kept telling me I wouldn't feel it but I didn't believe her. Finally I screwed up my courage and did it...and do you know what? She was right! I didn't feel it. Pricking you finger for testing hurts far more. I have also lost one pound of weight already.

I am very hopeful that Victoza will work for me, the indications are that it will, but it is very early yet. (Mar, 2010. OC. Rjack22)

Rjack22 described his current symptoms and how he felt about the medication, and also reflected on how he initially felt about Victoza as an injection drug. He described how this perception changed over time, providing a helpful perspective for those who were considering Victoza, but worried about the fact that it is an injection drug. Rjack22 was able to describe what kinds of anticipation or uncertainty that one might experience in the early stages of taking Victoza.

A month later, Rjack22 offered information about how his Victoza experience changed over time. His blood sugar had returned to normal, his dosage increased to the normal dose of 1.2 ml, his weight decreased, and new medications were added to his medication plan without side effects. Hasbearatl was encouraged

by Rjack22's update, even though unlike most of the posters in the thread, Hsbearatl did not have very good initial results with Victoza:

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Thanks for your note (I know its old) was just given Victoza to try as well- gained 8 lbs and am feeling VERY...not happy (doc also upped my Lantiss from 30 to 38 so....) and reading your note actually gave me a tiny glimmer of hope... (Sep, 2010. OC. hsbearatl)
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Hasbearatl's response illustrates how members share various outcomes of a medication, allowing peers to better understand individual differences in how they might experience thatthe medication. In addition, being able to hear other people's testimonies about use of a medication over time helps members better understand their own situations and build expectations for the future.

The thread also discussed other issues, such as side effects, insurance, and a possible connection between Victoza and cancer risk. Shawnapedelty, for example, shared her doctor's advice to use Byetta instead because of Victoza's possible connection with thyroid cancer. This was important information especially for Shawnapedelty, who had survived breast cancer. Peljbl revealed that he also had a history of kidney cancer and was waiting for once-weekly Byetta to come out (at the time, Byetta had to be taken twice daily). When Rjack22 shared his positive experience with Victoza, Peljbl replied to say that he was still worried about taking Victoza because of the cancer risk despite Rjack22's positive experience:

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rjack - so glad you are having such good results with the Victoza - I keep thinking I will try it but I can't quite get past the cancer connection (having already has kidney renal cell).

What to do - what to do??? (Apr, 2010. OC. Peljbl)
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Having a history of cancer prevented Peljbl from selecting Victoza as his primary medication. His alternative was to wait until once-weekly Byetta came out, since twice a day Byetta was giving him stomach problems. He soon discovered that once-weekly Byetta was not approved by the FDA. Peljbl tried controlling his blood sugar levels without the help of Victoza for several months (revealed from his posts), but the risk was too high for him since his blood sugar was not being controlled. Moreover, he contracted pneumonia, which 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 his stomach problems:

I still haven't tried it [Victoza] yet because I was trying to control my numbers on my own but since I had pneumonia for the month of June - my numbers have been up - usually 130 or so in the morning where they were 100. So I am going to start the Victoza - hoping it helps with the numbers as well as weight.

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. Peljbl)

Through several months of discussions with other members of the community, Peljbl was able to develop a fuller understanding of Victoza and how it affected individuals differently. As a result of the information in the thread, community members were better prepared to make informed decisions before starting the medication. Also, as new challenges emerged throughout his progression of using Victoza, Peljbl was able to plan his actions appropriately for

the specific stage of Victoza use with what he learned from the community, as shown in the quote above.

There were other issues associated with Victoza that Peljbl did not have to deal with, but many others experienced. A major issue was how members could get their insurance providers to pay for Victoza, as it is an expensive drug.

Members discussed not only the effectiveness of the drug but also the institutional, social, and organizational issues surrounding the medication. Mish01 talked about her difficulty in getting Victoza approved by her insurance company:

Just had Rx for Victoza submitted to pharmacy, yesterday. Medicare D immediately turned it down. Pharmacy wanted to charge me \$375/mo or so. Today, Medicare D contacted me to say the MD is appealing decision at this time. I have been on Byetta since Jan. '10 and lost only 2 lbs, but this was 2nd attempt in 3-4 years. Also was taking Januvia which MD said was not needed with Byetta. Crossing fingers that Medicare D will OK Victoza. Would love to lose more weight! Any other weight-loss reports? (Apr, 2010. OC. mish01)

Similarly, another member, d\_dubois, discussed her difficulty in getting Victoza approved by her insurance company due to its cost. Liatris01 was also interested in switching from Byetta to Victoza but his insurance did not cover Victoza, and he was looking for strategies to help convince the insurance company to allow the switch:

i would love to switch from byetta to victoza but my insurance does't cover it, anyone have any advice on how i can make this happen? (Nov, 2010. OC. liatris01)

Lmeyers31 then suggested writing a letter citing the positive experiences noted in the present thread to the insurance company. That was what Imeyers31 did to get his insurance company to approve Victoza:

Perhaps you could write a letter quoting some of the posts here. I was taking Byetta and thought I was doing fine until I switched to Victoza. I can't believe how much better my numbers are. I've written a letter to my insurance company before and it was a positive outcome. Good luck! (Nov, 2010. OC. lmeyers31)

The discussions surrounding Victoza demonstrate how members of the support groups share pieces of their illness trajectories containing information on medication experiences, which are then used to generate solutions and anticipatable challenges involved in using a medication. Members share individual differences related to many aspects of a medication—effectiveness, insurance coverage, and side effects, among others. Through collaging partial stories from various points in time, members develop a rich picture of medication experiences and become aware of alternatives that may be pertinent to their own situations. Through this process, members adjust their expectations and practices.

In summary, collaging illness trajectories occurs when members attempt to learn more about individual differences and long-term effects around medications, share resources on diabetes management, and discuss important topics such as diet or blood sugar monitoring devices. In face-to-face support groups, members discuss a wide variety of topics such as their experiences with laser eye surgery, the shingles vaccine and its effect on diabetes, the progress of the artificial pancreas, light therapy, and the long-term effect of Vitamin D. This discussion helps patients

collectively assemble a more complete picture of what they may anticipate over time and appreciate individual differences in the experience of various resources, activities, and events.

#### CONCLUSION

In Part II, I discussed how members share stories of their diabetes management as part of the collaborative help process. The way in which the concept of illness trajectories is discussed here has many dimensions that help differentiate each member's illness trajectory from that of others. Illness trajectories differ in length, kind, and placement, where "length" describes the length of one's experience, "kind" describes individual differences of personal health, belief, and interpretations that make trajectories differ from one another, and "placement" describes the situated environment (including the institutional, physical and social context of a patient) in which one's illness trajectory is placed.

Depending on how these divergent illness trajectories are placed together, different kinds of help interactions are born. Apprenticeship is exhibited by matching points on the illness trajectories of two patients and following the more experienced patient's path of the trajectory backward in order to help the less experienced patient know what to expect in the future. Collaging illness trajectories happens by way of dissecting multiple illness trajectories into pieces, which are then collaged into a coherent thread that helps the community better understand various problems and interventions around long-term diabetes management.

This perspective of considering illness trajectories as objectified entities helps to move the analysis of CITF forward by further understanding the illness trajectory beyond its original conceptual use on the description of social organization of medical work around patients (Strauss & Fagerhaugh, 1997). Illness trajectories are encapsulated knowledge of patients' work that can be practically used as proxies with which patient-to-patient work of managing diabetes over time is more effectively established. I am also able to move forward the conversations around trajectory as anticipation in coordinated work (Ackerman & Halverson, 1999) by describing the aligning and collaging work of individual trajectories.

In Part III, I explain how operationalization and illness trajectory alignment work come together as support for individualized problems by further building community trajectories. I also discuss how illness trajectories as encapsulated knowledge of patients relate to the work of operationalization. I then briefly discuss differences between online and face-to-face settings of support groups and end the chapter with remaining questions and future work.

### Part III. Discussion

In Part III, I first discuss how operationalization and illness trajectory alignment work come together as seamless activities that patients perform as they participate in the community and manage their diabetes over time. To this end, I describe how the communities build common-enough understandings--the work that the patients are ultimately involved in as they participate in the support groups.

I then further examine the relationship between operationalization and illness trajectory alignment work—how the process of operationalization generates snapshots of illness trajectories at various points in time, providing potential implications for an automated system that allows for repositories of illness trajectories. I end the chapter with a discussion of the differences between online and face-to-face settings of support groups, along with remaining questions and future work.

### THE COMMUNITY'S BUILDING OF COMMON-ENOUGH UNDERSTANDINGS

The work of helping a peer community of patients discussed through operationalization and illness trajectory alignment stands out as distinct social activities for analytical purposes. In reality, these help activities are embedded in patients' everyday lives while they participate in support groups. The ways in which participation occurs in reality are that the members of the support groups regularly meet and discuss their ongoing struggles, point to critical events, or complain if they want to, regardless of whether the conversation would help result in solutions or not. Many of the core regular members come to know one another through years of sharing stories together. Newcomers slowly recognize the various roles that each member plays. Knowing one another takes some work of operationalization, such as sharing patient profiles, in addition to regular and ongoing casual social interaction. Members knowing and deeply understanding one another's everyday experiences through the sharing of illness trajectories allow

them to know who to ask for specific help, enrich the solution space by allowing participants to see various strategies practiced by different members, and further their understanding about diabetes through comparison. The mutual benefits of learning through ongoing member interaction are described by one interviewee:

You have to be a diabetic to truly help someone. That is why a forum like dLife helps me. I am talking to people who understand what I am going through. I understand what they are going though. (I, DL1)

Support group members go beyond the simple exchange of information. They conceptualize other members' roles, characteristics, and strengths through understanding one another's illness trajectories as part of the community. Members seek specialized help from different members. These benefits do not occur instantaneously; understanding one another is facilitated through illness trajectory alignment work, since knowledge about others can only evolve as a result of following their histories of diabetes maintenance over time. Regular updates and sharing one another's daily struggles, successes, and failures help members establish a network of people they can utilize for specific purposes. The implicit learning of others' practices gained by following one another helps enrich solution spaces for all participants.

Learning new strategies can be accomplished by directly asking members of the community how they addressed specific tasks. Such inquiry, however, sometimes requires knowledge that the asker does not yet possess. Often, patients do not recognize how they can improve their practices until they witness other

cases that offer them better examples. Casual sharing of members' practices can foster the emergence of new ideas, and gradually help patients build synergistic learning experiences. Patients, through continuous updating and sharing of daily practices, learn and enrich their solution spaces. The learning experience happens as members encounter new strategies, products, and recipes that they were previously unaware of. Members continue to attend to their peers' practices, constantly seeking ways to improve their own practices. Another important point is that advice providers are also able to learn whether their strategies work for others, which helps advice providers further understand individual or circumstantial differences in the strategy choices they make. Sharing experiences around common interventions helps members gain a deeper understanding of individual differences related to various strategies. This further helps members as they move into various phases of their diabetes condition over time.

Such knowledge, generated through being aware of one another's experiences over time, and all other help processes discussed in operationalization and illness trajectory alignment work becomes a foundation for the community's shared understanding about diabetes management. A community's commonenough understanding affords each member the ability to tailor solutions for themselves or to help others generate solutions for individualized problems. The community's shared understanding becomes a guideline, a reference, and a trusted experiential knowledge repository that patients seek out as an ultimate source of help. The community's shared understanding is not tangible in any way. Similar to

what Ackerman and Halverson (2000) saw in hotline, the community's commonenough understanding comes from continuous negotiation and agreement of strategies, elicitation of exceptional cases, and challenges that emerge out of operationalization, breakdowns of operationalization, and alignment of illness trajectories.

### OPERATIONALIZATION AND ILLNESS TRAJECTORY ALIGNMENT WORK

Now that I have discussed how operationalization and illness trajectory alignment work play roles in the help interactions taking part in the support groups and how they contribute to the building of community trajectories, I want to further discuss the relationship between operationalization and illness trajectory alignment work. Each member's illness trajectory, as presented to the support groups, is never complete. That is, only the parts that the members willingly report are visible to the community. Members introduce themselves and attempt to present their illness trajectories as completely as possible. Examples include introduction forums or the introduction phase in face-to-face support groups, and the instances when one has to describe one's history in order for a helper to give appropriate advice. Still, one's illness trajectory is in a constant state of progression, thus the community needs to be kept abreast of one anothers' illness trajectories over time in order to have a "complete" picture.

Operationalization helps complete patients' illness trajectories over time as members share their patient profiles, experiment findings, and current struggles as

part of their interaction with the support group. Operationalized knowledge becomes elements that comprise a story of one's illness trajectory. Illness trajectories as stories can be represented through the temporal sequence of operationalized knowledge modules that are chained together—such as patient profiles reported in posts over time. In the following message, as part of the process of helping a fellow patient find an answer to his problem, a helper looked up the patient's past posts to better understand his illness trajectory—how his numbers have changed over the years:

Four years ago you wrote this:

"When I take my fasting blood first thing in the morning it is around 150. 2 hours after eating it is around 185 for all meals. I test 4 times a day and my A1C is 6.3. My Doctor wants me to get my A1C down to 6.0 and keep my suger at 100 before and 140 after meals. I exercise 1 hour a day and eat good food so I do not get where he is coming from."

Obviously, things have progressed. [...] (September, 2010. OC. Alan\_s)

At any given time, shared illness trajectories are not complete. However, I argue that the modularizable aspect of illness trajectories—the fact that a trajectory can be represented through chains of operationalized knowledge—allows for additional context in systems that pull out the operationalized knowledge of a patient for use as a help resource. That is, utilizing multiple snapshots of one's diabetic situation at different points in time can foster understanding of one's illness trajectory, because it provides a richer context for patients' collaborative help processes.

Operationalized information and illness trajectories supplement one another. Illness trajectories are never completely articulated by the patients. Accordingly, illness trajectories, through stories and anecdotes about critical times or brief historical summaries, add some, but not complete, historical and situational context to patient profiles over time. In Chapter 6, I discuss the design implications of operationalized experiences working as modules of illness trajectories.

### ONLINE COMMUNITY FORUMS AND FACE-TO-FACE SUPPORT GROUPS

Before I conclude this chapter I want to briefly reflect on the differences between dLife and face-to-face support groups in terms of how the presence of health professionals and demographical differences influence the way the members interact in the communities. These two categories do not give a complete account of what occurs. Rather, the purpose of this section is to suggest future discussions around the issues of credibility of information and segregated patient groups, which I anticipate will be an interesting basis for future work.

## **Presence of Health Professionals**

The biggest difference between dLife and face-to-face groups is the presence of health professionals and their roles in changing the way members acquire information. All of the face-to-face support groups I studied are led by either a nurse or a dietician. This is not the case with dLife. The leaders of the face-to-face support group help members by "piping in" information that validates, confirms, or

adds to what is being shared by the members. There are 114 moderators in dLife as of April 2011, most of whom are diabetes patients themselves. Online communities such as dLife generally recruit active members as regular moderators to police conversations, ban members who flame, answer otherwise unanswered questions, and encourage members. These moderators do not necessarily identify themselves to other members as moderators and thus are perceived to be regular members. The piping in of information observed in face-to-face support groups also occurs among the members in dLife, but those doing so do not have the same authority over shared information as the leaders of the face-to-face support group do.

Although the exact number is unknown, dLife also has moderators that are certified dietitians or registered nurses. Out of the 1,400 messages I reviewed, there is only one acknowledged moderator who is a health professional. It may be that different moderators take charge of different parts of the forum, since my data come from the type 2 topic within the forum, and there are other topics such as type 1, type 1.5, prediabetes, gestational diabetes, ladies' room, and so forth. One moderator, who joined in 2005, had a total of 6,855 posts an average of 3.43 per day at the time of data collection. There is also an "expert Q&A" section where patients can directly ask questions of health professionals. Accordingly, dLife members have some opportunities to interact with health professionals on the site itself.

## **Demographics and Social Dynamics**

My goal in mentioning demographics is not to discuss gender and age effects on online community use as, many studies have discussed extensively (Adrianson, 2001; Herring, 1994), but to give a fuller description of the space in terms of who participates in face-to-face versus online support groups and how they perceive one anothers' spaces. Demographics of the patients participating in the two spaces—face-to-face and dLife—are quite different. The type 2 diabetes support groups that I observed consisted mainly of geriatric patients. On the other hand, many members of dLife are middle-aged or younger. Each member has a profile page, which contains demographic information including their age, although not all profiles are complete. Members talk about their children, school, marriage, and life routines in their posts, providing hints to the observer about their age.

When I asked the members of the face-to-face support group what they think about participating in online communities, they said online communities are filled with inaccurate information and too impersonal. The scale at which patients participate is too big, resulting in a perceived lack of intimacy. Very few people from the face-to-face support groups also participate in the online communities. Many do not know how to use computers and are hesitant to learn. In one meeting, a member came late and found that the group was discussing new software that would help blood sugar reading information be shared between doctors and patients. She immediately left, telling the group that she did not want to learn

anything new. On the other hand, during my recruitment of interview subjects, most dLife members preferred to converse by email rather than by phone, citing ease of communication as their primary reason. DLife members utilize online resources very well—some even regularly write blogs, articles, and create their own websites. They refer to a wide range of medical research papers and articles from MedlinePlus or government resources during their conversations. Interviewees from face-to-face support groups often rely on magazines, newspapers, and monthly meetings for updated news.

DLife members often talk about their lack of access to support groups and diabetes education resources in their local area. Often they either live in towns that lack medical resources or lack sufficient money to pay for education classes. Some members live in places where they have to drive a few hours to meet with doctors and some live on disability.

One assumption that emerged from discussion with face-to-face support group members was that people who participate in online communities may be busy people who do not like to be intimate with people. While such assumptions may be correct for some, there can be many other reasons—being on disability, not having insurance, living far away from hospital resources, insufficient income to afford education classes—that are not fully understood.

### REMAINING QUESTIONS AND FUTURE WORK

The people I observed and interviewed are those who actively come out to participate in support groups. Accordingly, these are people who are actively attempting to control their diabetes. As one interviewee's doctor said, where only two patients out of his whole practice are trying to incorporate diet and exercise regimes, there are patients out there that have very different notions about what managing diabetes can be. A new set of inquiries arises when we begin to think about how can we better support patients who do not want to be part of a support group. I interviewed one extremely obese lady who came only once and never returned to the face-to-face support group. Her perception of support groups was not positive. Her past experience with Weight Watchers, for example, was that people were there to vent and complain, and she felt like a loser being in that group. She assumed it would be the same with the diabetes support group. She knows what she needs to do—she just cannot put that knowledge into action, and that is not going to be solved through the support groups. Motivating patients with different needs is critical.

Another critical question is how members in dLife integrate what they learn from other help resources, such as face-to-face support groups they might be attending, or from their health care providers. Members come from all around the world, and the information they gather from their doctors can conflict. Doctors have different standards, definitions, and solutions depending on where they

received training. There are also cultural differences that should not be ignored.

How members can use information they receive from dLife with their health care providers is another question that needs to be answered.

Lastly, how my findings relate to online diabetes communities other than dLife.com and the face-to-face support groups for type 1 diabetes and support groups in other parts of the United States is unknown. Type 1 and type 2 diabetes patients have different sets of concerns and attitudes about diabetes. Type 1 diabetes patients have no control over their pancreas' inability to produce insulin. On the other hand, although there are still genetic influences to consider, type 2 diabetes comes from lifestyle and can be controlled by incorporating diet and exercise plans. Type 1 and type 2 patients need different kinds of support. Thus very rarely would type 1 and type 2 patients participate in same support groups. Even among type 2 support groups, depending on the group, when people with different demographic backgrounds are present, the content of the discussion changes. In Ann Arbor support groups, members are generally well-educated and proactive about their illness. There are former teachers, current professors, and many are college graduates. On the other hand, members in the support group in Macomb County generally have a lower level of knowledge about diabetes in general and their educational background did not come up during conversations. Leaders in Macomb County often offer information through games, a strategy that might not appeal to the Ann Arbor group. Finding the appropriate social

environment for support groups will be important as we design online communities for varying groups of patients.

# **Chapter 6**

## **Implications**

In my two research sites, the MythTV user community and the diabetes patient support groups, I observed three major implications for supporting individualized problems through collaborative help systems: (1) The operationalization of experiences into directly executable solutions can help knowledge transfer from one person to another; (2) The breakdown of operationalization is inevitable due to individual differences. However, the breakdown of operationalization also serves as an opportunity for the community to further understand individual differences; (3) Operationalization as a form of help has to be done within the larger context of overall management of the MythTV or diabetes care over time, which I call maintenance trajectories. Trajectories are used as resources for generating individualized solutions. Based on sharing of trajectories, the community as a whole often works on developing an agreed upon understanding of critical challenges and ideal ways to manage MythTV and diabetes.

In this chapter, I discuss the key findings from both studies to understand the role of collaborative help in solving individualized problems. I discuss how the findings impact the prior literature, specifically in collaborative help and research on health communities. I also discuss how the implications build on Strauss' continual permutations of action and Star and Griesemer's boundary objects. I then translate my findings into design implications for collaborative help systems.

# Common Findings

In this section, I summarize the common findings from the studies on the MythTV user community and the diabetes patient support groups. The common findings address how a community supports members in managing their individualized problems. I do not attempt to make any probabilistic generalizations. Rather, the goal of my dissertation is to act as an interpretive researcher (Strauss & Corbin, 1990) and to make theoretical generalizations on the situational representativeness of the study participants. My interpretation of the phenomenon will then provide explanatory theory for the experiences of other individuals who are in comparable situations (Strauss & Corbin, 1990). Popay et al (Popay, Rogers, & Williams, 1998) gives appropriate description about the aim of theoretical generalization:

The aim is to make logical generalizations to a theoretical understanding of a similar class of phenomena rather than probabilistic generalizations to a population (p. 348)

The following table provides a comparison of key selected findings from each study. I provide an item-by-item discussion of the connections between the findings from both studies. I end this section by explaining the differences in each site that did not fit into the common findings due to site-specific characteristics.

Table 1: Drawing connections from the two studies.

Comparison of the findings from the two studies	
MythTV User Community Study	Diabetes Patient Support Groups Study
(1) Configuration artifacts as help	(1) Operationalization of everyday experiences
(1-1) Configuration artifacts for contextualization	(1-1) Operationalizing diabetes condition for contextualization
(1-2) Configuration artifacts as independent solution	(1-2) Operationalizing strategies
(1-3) Breakdown of configuration artifacts as help	(1-3) When operationalization broke down
(2) Use trajectory alignment and negotiation work	(2) Illness trajectory alignment work
(2-1) Aligning future and past	(2-1) Apprenticeship
(2-2) Aligning experiences	(2-2) Collaging illness trajectories
(2-3) Community trajectory negotiation work	(2-3) Community's building common-enough understandings
(2-4) Negotiated solutions	

First, in the MythTV user community study, I identified configuration artifacts as analogous to operationalized experiences discussed in the diabetes patient support groups study. Configuration artifacts are essentially operationalized forms of experiences (and solutions) that members could easily share, execute or plug-in to the system and use ((1) and (1-2) in Table 1). Examples include Phil (Chapter 4 page 125), who created a script and shared it with his fellow Australian users so they could save and run the script in order to stream movies from ABC Australia on their MythBoxes without any additional effort. The script was an easy way to transfer knowledge from Phil to others just as Alan shared in a blog post

how to adjust diet to one's blood sugar test results. The blog post helped others to follow instructions and find individualized diet regimes appropriate for their health. In both cases, the solutions are black-boxed in that the users do not have to understand details of the solutions.

Configuration artifacts are also used to contextualize the problem, and so do operationalized forms of diabetic experiences ((1-1) in Table 1). Examples include patient profiles or experiment results that are shared to provide context to individuals' diabetic situations. For the MythTV users, outputs and error messages are shared to help understand the context in which the problem occurred. This way, configuration artifacts and operationalized patient experiences work as boundary objects that the members could use as references for facilitated communication.

Due to individual differences, these operationalized solutions and configuration artifacts often break down, meaning that the solutions do not work right away ((1-3) in Table 1). For instance, the case of Phil in the MythTV user community illustrates how a configuration file downloaded from the documentation did not work for his individualized needs. The community together helped him modify the configuration file to work for his particular needs. Similarly, Diabetes86's step-by-step instruction for checking blood sugar was not an appropriate strategy for everyone in the community. Together the community members negotiated what would be an appropriate way to check blood sugar depending on the situation. In both cases, operationalized solutions in the form of

configuration artifacts and step-by-step instructions fail to work as solutions due to individualized nature of the problems, and the community has to collaboratively find ways to resolve the problem. What is initially shared as a black-boxed solution does not work, therefore the solution has to be reopened for further modification.

During this process of witnessing breakdowns in operationalization and working around the breakdowns, members recognize individual differences in various circumstances. As the community attempts to solve the breakdowns, the help has to be given within the larger context of maintenance trajectories. These are the trajectories that explain how individuals' MythTV systems are maintained over time, including how the configuration settings (compatibility issues, hardware configuration, and performance) change and the user needs evolve over time. Similar trajectories also explain how patients manage their diabetes over time, including how patient needs and the diabetic condition (complications, medications, blood sugar levels) change over time ((2) in Table 1).

Sharing trajectories, whether it is use trajectory or illness trajectory, helps members to learn from others and reduce uncertainty about the future ((2-1) in Table 1). In the MythTV user community, any changes made to the system may cause unwanted or unexpected consequences. Users who have gone through similar events share their experiences to help other users reduce uncertainty about the future. Similarly, one of the major challenges in chronic illness is uncertainty about the future. The patients share their experiences so that the patients can infer

from others illness trajectories about what may happen in the future and any preventative actions they can take.

Sharing trajectories further allows the communities to compare different cases and experiences to construct coherent stories about what to expect from a problem over time, be it adopting a new capture card or switching to a new medication ((2-2) in Table 1). When conflict arises in deciding on the appropriate solution to a problem, communities often negotiate an ideal solution to the circumstances ((2-3) in Table 1). In the section on "Negotiated solutions" (Chapter 4, page 167), I discuss how the MythTV users found an ideal solution to setting up a wireless frontend. Together, the community negotiated the pros and cons of various solutions in terms of performance and applicability to certain physical configuration settings. Similarly, in the diabetes support groups standards, definitions and guidelines varied and conflicted at times (Chapter 5, page 228) and the patients attempted to come to an agreement on appropriate answers to questions (such as "Is diabetes curable? What does it mean to cure diabetes?") or an appropriate strategy for patients who are obese.

Through the continuous sharing of use and illness trajectories, the communities help members understand how individual differences affect experiences, anticipate unexpected consequences, experience common situations, and recognize exceptional cases. In addition to help that communities give to individuals, the continuous social interaction among members of communities and

their sharing of trajectories allows each member to understand how individuals can independently construct individualized solutions.

The concept of "community trajectories" in the MythTV user community and diabetes patient support groups' "common-enough understandings" illustrate how members develop a shared understanding of appropriate solutions and how personal member examples could inform the MythTV and diabetes support groups. The concept of how a community develops shared understanding about the problem and solution space is discussed in the community trajectory negotiation work (Chapter 4, page 164) and community's building common-enough understandings (Chapter 5, page 266). In both cases, it is important that the members understand the socially accepted strategies and agreed-upon understandings of how to address core problems in maintaining MythTV or managing diabetes. When members go beyond the initial hurdle of installing MythTV or learning the basics of managing diabetes, the members begin reinterpreting problems and solutions in their own ways, such as finding cheaper ways to install two capture cards or whether the 6-inch plate method is the right way for one to lose weight. During this process of finding one's own interpretations, the members need a variety of perspectives and a sense of consensus with other people in order to make informed decisions about how they would maintain MythTV or diabetes over time. Learning about the community consensus, exceptional cases, and contentious points is only possible through regular interaction with other members in the community.

I distinguished the community's negotiated understanding of solutions as "community trajectory" in the MythTV user community and "community's common-enough understanding" in diabetes patient support groups, because there are subtle differences in the ways in which evolution of community's negotiated solutions mean to each community. For the MythTV user community, the surrounding computing environment is rapidly evolving, creating a wide gap between early adopters versus those who are relatively late in adopting new technology (Rogers, 1995). Becoming outdated in maintaining a MythTV installation directly transformed into critical challenges in the long-term maintenance of their MythTV. Thus knowing what is outdated versus updated community knowledge and the ability to compare the two is critical in the MythTV user community. On the other hand, solutions deployed in diabetes patient support groups go through less change than the MythTV user community. What is even more important than understanding updated strategies is becoming aware of individual differences and exceptional cases, from which one can infer about hes/her individualized situations.

In summary, the two studies show common findings in that: (1) the members operationalize their experiences for easy transfer of knowledge, (2) the operationalization process breaks down due to individual differences, (3) and the operationalization has to be done within the larger context of sharing maintenance trajectories. The communities also develop community's shared understandings toward managing MythTV or diabetes, which is possible through continuous

negotiation. Before I discuss how these common findings theoretically generalize and provide implications for collaborative help, I discuss issues specific to each site.

# Findings Specific to Each Site

While the overall framework on "operationalization" and "trajectory sharing" works surprisingly well for both studies, there are findings that are specific to each site or emphasized in one site more than the other. Next, I discuss the notable differences in relation to the core issue I am addressing in my dissertation: the individualized nature of the problem space, collaborative help, and how solutions become available through negotiated social interaction.

First, there are subtle differences in how the two communities deal with individualized problems. Individualized problems in the MythTV user community are often specific to the technical challenges of customization and appropriation as discussed in the section on "navigating the customization and appropriation gulfs" (Chapter 4, page 138). For the diabetes patients, philosophy and belief play a big role in shaping the individualized nature of problems. Managing diabetes has a highly personal element that involves relationship with family and friends and spirituality. Another layer present in the diabetes patient support groups is the negotiating of conflicting personal belief and philosophies, such as "Is taking insulin cheating?" These conflicts make it even more complex to come to

agreement about solutions. The MythTV user community emphasizes efficiency and performance, making it easier to find appropriate solutions.

Second, the relationship between experts and novices is an interesting dynamic that influences the way collaborative help could be offered. In the case of MythTV users, developers are automatically considered the experts. Regular users, depending on how experienced they are, play as expert advocates in the areas in which they are experienced. In the section on "community trajectory negotiation work" (Chapter 4, page 164), I discussed how the developers and the users constantly negotiate to shape the development trajectory of the MythTV system. In this way, experts and novices often create parallel collaborative relationships with each other. In diabetes patient support groups, health professionals are the ultimate authority for medical information and the negotiations between the patients and the doctors involve the patients choosing from options given by the health professional. There are limits to how much patients alone can fix individualized problems. Beyond experiential knowledge, patients need to rely on health professionals for receiving and validating solutions to individualized problems.

Despite the differences, there are some interesting commonalities between the two research sites. Next, I attempt to derive a theoretical generalization from what I found in the two studies about the critical help processes and challenges in supporting individualized problems through collaborative help.

## Theoretical Implications

In the literature review chapter, I discussed the increasing need to support individualized problems, both from the technical help and personalized medicine perspectives. I also discussed the need to better support the transfer of knowledge, specifically when the knowledge is tacit (Polanyi & Sen, 1966), and for contextualization, especially in recording and reusing information (Ackerman, 1996; Ackerman & Halverson, 1998, 2000). My dissertation presents how operationalization, the breakdown of operationalization, and the notion of trajectory alignment and negotiation address tacit knowledge transfer and information reuse problems. In this section, I summarize how my findings contribute to the literature and further discuss how the concept of boundary objects and Strauss' continual permutations of action can be re-examined for implications for giving collaborative help.

### (1) OPERATIONALIZATION: TRANSLATING EXPERIENCES INTO SOLUTIONS

In chapters 4 and 5, I presented how operationalized experiences in the forms of configuration artifacts, patient profiles, step-by-step instructions, and experiment results act as proxies for easily transferring knowledge from one person to another. The operationalization process described here is similar to the work of standardization (Star & Griesemer, 1989) in that the common solutions to the problems arise from the multiplicity of information (Bowker & Star, 1999).

Information inherently resides in multiple contexts and is interpreted in multiple

ways. Thus standardization becomes a way to develop information systems that can find good ways to re-represent information and produce appropriate moral and political consequences (Star & Griesemer, 1989).

Operationalization in the MythTV users and diabetes patients acts in a way similar to the work of standardization. In order to convey situated experiences and context, the members develop standard ways to inscribe information. It is similar to what Suchman and Trigg (1996) called the "artful integration" of local constraints, received standardized applications, and the re-representation of information. When Hugh shared the script to stream movie files from ABC Australia, the script included local constraints to Australian users, but it was a standardized file that any person could run on their systems. It was a re-representation of Hugh's knowledge for adding the streaming feature. When Alan shared his "test, review, adjust" tactic used for figuring out an individualized diet plan, the instructions addressed each individual's health constraints, standardized ways of measuring blood sugar and nutrition, and re-representation of the practice that Alan developed over years of experience that others could easily follow.

In the communities I examined, the artful integration of multiple experiences into knowledge goes beyond re-representation of information. The operationalized experiences themselves are translated into solutions and guidelines so that others could execute or use them as solutions right away. It is not only about the objectification of tacit knowledge (Ambrosini & Bowman, 2002), but further operationalized so that the knowledge could be directly re-used. In ideal cases, re-

contextualization of the solution is unnecessary. Operationalization amplifies the material aspect of classifications in the sense that information and knowledge are inscribed, transported, and affixed to items (Bowker & Star, 1999). These items in a mobilizable and executable form of knowledge make it easier for members to share, compare, and critique experiences, and contextualize problems. The notion of embedded knowledge (Ackerman, Pipek, & Wulf, 2002) being encapsulated in material objects and how those objects can be used as tools for social learning further extends the Vygotskian relationship between material and concept in learning about the external world (Vygotski et al., 1978).

# (2) BREAKDOWN OF OPERATIONALIZATION: OPPORTUNITY FOR INTEGRATING MULTIPLICITY

Because of individual differences, operationalization often breaks down.

Operationalization strips away context and makes it difficult to deal with exceptions when operationalized knowledge is attempted to be used as solutions or guidelines. Operationalization inevitably fails to capture practices "simultaneously embedded in various processes" (Ackerman & Halverson, 2000) during maintenance activities. The fact that operationalized concepts lose context is a well-explored phenomenon. Gephart (1988), in his work on ethnostatistics, highlighted that researchers "should not expect or pretend that statistical rules are explicit." Rather, researchers "should expect to undertake ad hoc and post hoc interpretations of rules" (page 64). Similarly, studies on medicalization of society

(Conrad, 2007) stressed the importance of the context of stories by discussing how numbers strip away context and alter experience, politics, ethics, and economy. As such, operationalization as artful integration of representing information across multiple localities is a brittle practice that often encounters limitations.

Standardization efforts in information systems have shown that standards do not remain standard for very long, and that "one person's standard is another's confusion and mess" (Gasser, 1986; Star et al., 1991).

However, in the MythTV user community and the diabetes patient support groups, the mess, confusion, and inconsistencies brought about by the breakdown of operationalization provide the opportunity for improvements in dealing with individualized problems as a community. When the MythTV users and diabetes patients attempt to operationalize solutions for easier dissemination of knowledge, they often no longer find executable solutions due to individualized nature of the problem spaces. The community then has to collaboratively examine what makes the solution not work and find how the solution could be tailored to work for individualized situations. During this process, the community discovers the individual differences of the member. This helps each member to learn how to deal with individualized situations as they arise as shown from Bowker and Star's (1999) argument about multiplicity and its role in making information visible. The communities also continue to come to agreement through continuous negotiation on ideal solutions and standards and definitions. Through this process, the communities as a whole continue to build a shared understanding of how to

maintain MythTV or manage diabetes over time, and how these experiences vary in individualized contexts.

(3) COMMUNITY'S BUILDING COMMON-ENOUGH UNDERSTANDING THROUGH
SHARING INDIVIDUAL TRAJECTORIES AND THEIR CUMULATIVE MESS

I discussed individual differences as a dimension in creating messiness and confusion in the previous finding on the breakdown of operationalization. The messiness I describe here adds yet a temporal dimension that creates "cumulative mess" (Strauss & Fagerhaugh, 1997), which amplifies uncertainty as people manage issues over time. The cumulative mess in the accounts of the MythTV users and diabetes patients refer to uncertainty about the future, which is slowly shaped by the relationship between sequences of actions and reflections on the past. Similar to the social constructivist view of the accumulative of the historical-cultural context as a critical perspective in learning processes (Luria & Cole, 1976), the constant reworking of past events and ongoing events that shape the future context should not be lost when members share experiences and generate solutions.

Accordingly, it is important that operationalization as help takes place within the larger context of sharing maintenance trajectories in both communities.

Individual trajectories are the very foundation upon which communities' common-enough understandings are built. At the same time, community's common-enough understandings shape individual trajectories. The community's understandings are challenged by individual trajectories that show exceptions. In

this way, the communities continue to build messiness through new challenges and exceptions that dispute current agreement. This messiness is reduced as the community comes to agreement on ways to maintain MythTV or manage diabetes. Similar to what was observed in a hotline (Ackerman & Halverson, 2000), experiential knowledge and evidence are present in both the individual and community trajectories as they mutually build upon each other.

Bowker and Star's notion of trajectory was that the mess would decrease as the members go through the "naturalization" process. As a community comes together to routinize an object's use, the characteristics of an object's creation and its situated nature strips away over time. One example is light switches, which have become an ordinary part of modern life. Similar to the "cumulative mess" Strauss described in trajectories, my findings about the MythTV users and diabetes patient support groups show that the messiness around operationalized experiences remerges as challenges arise around exceptional cases and emerging problems. A strategy for checking blood sugar developed by an individual and largely adopted by the community cannot be sustained if individuals constantly challenge the strategy with negative experiences. The context of how the strategy is initially constructed has to be re-examined to fully understand who can use the strategy for which context. Then members of the community can begin tailoring and come to agreement on how to incorporate individual differences.

By comparing, connecting, aligning, and collaging pieces of individual trajectories, the members collectively expand their knowledge on how to maintain

MythTV and manage diabetes. The members are able to further understand the individual differences in those experiences and continue to build the community's common-enough understandings. Through continuous sharing of use and illness trajectories, the members are able to reduce uncertainty about the future, take preventative actions, and reflect on the past to revise their practices. The ability to reduce uncertainty has great value in managing chronic illness (Strauss & Fagerhaugh, 1997). I found the health-related notion of illness trajectory to also pertain to users' future projection of their use of technology.

#### BOUNDARY OBJECTS: EXAMINING TRANSPARENCY AND TEMPORAL PROPERTY

As shown in the three key findings above, the notion of the critical role of boundary objects—the products of the classification work by the MythTV users and diabetes patients in overcoming individual differences and generating solutions—emerges during the collaborative help process. In the cases of the MythTV user community and diabetes patient support groups, boundary objects help transfer information, especially when cutting across multiple contexts and interpretations that stem from individualized settings (e.g. the individualized MythTV system, individualized bodies, and individualized philosophies). How to interpret boundary objects and reuse them is a source of constant negotiation by the community members, as with Lutters and Ackerman's (2002) "meta-negotiation of boundary objects" in their study of aircraft technical support.

The original discussion around boundary objects refers to their emergence in the context of several communities of practice, rather than from individuals (Star & Griesemer 1989). I have expanded the discussion from the community level down to the individual or the level of individuals in groups. Beyond the canonical use of boundary objects as a common point of reference, my findings present how boundary objects transform from executable solutions to contextualizing aids and vice versa. For instance, the changing history of patient profiles over time, including information about new diet medications and weight changes, not only contextualized the patient's diabetic condition, but also informed the effectiveness of certain strategies. The patient profile could also be used as a conversation starter and an aid to encourage patients (Chapter 4, page 194). Next, I discuss temporal placement in trajectories and transparency as important properties of boundary objects in how members of the communities help one another.

# **Temporal property of Boundary Objects**

In the discussion of individual and community trajectories, I briefly mentioned Bowker and Star's notion of trajectory of boundary objects. Here I expand on the temporal property of boundary objects and their role in helping to transfer knowledge and contextualize problems.

Bowker and Star's (1999) notion of trajectory of boundary objects has been discussed primarily as a "naturalization" process "whereby the contingent and historical circumstances of the object's birth are made invisible and sink into the

community's forgotten memory" (pg. 299). The discussion of temporal in this sense is deeply tied to the duration of how long a practice-activity will take before boundary objects become naturalized in a community of practice. Beyond this duration, I saw how the temporal property of boundary objects plays a critical role in contextualization and the creation of reference points with which alignment work occurs. For instance, patient profiles that include temporal information in the form of signatures are helpful in informing the long-term effects of certain interventions and also contextualizing the patient's health status. Patient profiles are not just boundary objects independent from individual trajectories. Rather, they are important in recording the temporal changes of boundary objects for others to access and generate relevant interpretations. How-to pages on the MythTV wiki are useful for only a certain amount of time as the solutions rapidly become obsolete. However, the wiki pages lack the ability to record and show how temporal information relates to solutions. Accordingly, the solutions on wiki pages develop bad reputations. Solutions are labeled as "no longer useful" or "hot issue."

When boundary objects are used as contextualization sources, having temporal information allows for awareness of historical changes and facilitated alignment work of individual trajectories.

# **Transparency of Boundary Objects**

In the naturalization process, boundary objects were discussed as blackboxed objects, where the content and context of how they are created are increasingly hidden as the community routinize the objects into their practices. This shows the point of boundary objects—to facilitate communication and overcome multiplicity in hindering information transfer. For the MythTV users and diabetes patients, boundary objects often have limitations in fulfilling their original role because of individual differences. In order for boundary objects to become mobile and easily transferrable knowledge artifacts that could be used as exectutable solutions, they have to continuously incorporate exceptions stemming from those individual differences. This process of incorporating exceptions requires the members to examine the content of boundary objects and attempt to understand the origin of the content (the case of checking blood sugar: page 211). Members can then modify the objects to make them executable solutions (the case of Hugh's modifying xorg.conf: page 132). Thus the transparency of boundary objects is dynamic and constantly changing. Rather than constant progression toward a black-boxed object, boundary objects in the MythTV user community and diabetes patient support groups go through continuous overhaul.

Depending on the context in which boundary objects are used, transparency is also affected. When being used as solutions, it is not necessary that the content be shown. However, for contextualization purposes, boundary objects are often white-boxed to show the content. In this way, the context is still mobile because of its encapsulated form, but the content is visible as needed. In the cases of the MythTV users, complete information is not necessary. The content is "gray-boxed" (Huh et al., 2011; Wulf et al., 2008) by the members helping with the problem to

hide unnecessary information and to focus on the important parts, which is in a way like scaffolding (Cole, 1985; Mamykina, Mynatt, Davidson, & Greenblatt, 2008).

#### **SUMMARY**

Above, I addressed issues of tacit knowledge in experiences, specifically in its elicitation and transfer. I described how people, whether for technical or health-related help, operationalize their experiences into knowledge that can work as executable solutions or contextualizing tools. Operationalization addresses how the information bricolage process (Levi-Strauss, 1966; Turkle & Papert, 1992) can be facilitated, rather than acting as a hindrance to finding a solution. I also addressed one of the seminal problems in information reuse—contextualization (Ackerman & Halverson, 1998, 1999). Those communities address the breakdown of operationalization by re-contextualizing the solution and amending solutions to fit individualized situations. In these cases, the breakdown of operationalization was not necessarily a failure, but an opportunity for the community to learn about individual cases and try to come to agreement on conflicting individual interpretations of problems. Most importantly, I discussed the temporal notion of experiential knowledge and the critical role it plays in giving individualized help.

Trajectories are used not only as a means for contextualization but also as reusable information through which members can align themselves and follow (as discussed in upward comparison (Festinger, 1954)). Trajectories are also compared

and contrasted to one another to generate various meanings that can potentially work as individualized solutions. In this way, not only operationalized experiences but also experiences understood with time work as solutions. This finding contributes to ongoing work by showing that patient experiences are valuable knowledge resources for the daily management of personal health (Civan, 2009), rather than as detrimental resources that lack validity (Culver et al., 1997).

The key to producing individualized help is the ability to share individual differences and understandings linked to time. Because of the multiplicity provided by individualized settings, the communities continuously negotiate assumptions, norms, and ideals for appropriate maintenance strategies. The temporal aspect of the shared experiences is also important because much of maintenance activity involves looking to the future and examining current states as consequences of the past. The ability to look forward and backward through the experiences of others is a great opportunity for the members, especially for those dealing with long-term problems, such as chronic illness. Boundary objects, together with their placement in trajectories, play important roles in conveying temporal information and issues related to a particular place on the trajectory.

Through constant sharing of exceptions and commonalities, the community, as a whole, is able to develop a community trajectory by collaboratively collecting multiplicity, re-examining solutions, and attempting to come to consensus of what makes sense to the whole community. The community trajectory then helps individuals to understand how to manage diabetes and MythTV systems over time.

# **Design Implications**

In this section, I translate theoretical implications into design suggestions to develop collaborative help systems that can better support individualized problems. The general design suggestions are: (1) facilitate sharing of operationalized experiences that users can take to generate information helpful for individualized problems; (2) support challenging operationalized solutions to elicit individual differences; and (3) facilitate sharing of individual trajectories and reveal community trajectory and community's common-enough understandings. I revisit two scenarios introduced in the Introduction chapter, each representing technical-and health-related problems. In both cases where an individualized problem is present, I illustrate how, using the general design implications listed above, the suggestions can be implemented in online community systems.

#### SCENARIO 1: KYLE AND HIS APPLE TV

Kyle recently purchased an Apple TV. One of the things he wanted to do with the Apple TV was to see the photos on his computer on the large TV screen. However, when he tried to sync his photo files from his PC computer, it took almost one hour to sync his 25,000 photos. If this had only occurred once, it would have been fine. However, the problem persisted each time he synced his photos. Also, there was an issue where Apple TV tried to merge all folders into one folder while putting an artificial cap on syncing only 20,000 photos maximum. He called Apple but the response he received was "Too bad, we cannot help you."

He then started searching Google and read posts in various user forums. The design of the online forums made it difficult for Kyle to find the exact solution he wanted. He had to go through each topic and read the threads to figure out that the problem was not the same

as his. He eventually posted the problem on an online forum and he received several responses. One suggestion was to check his home network. Kyle had no problem with his Netflix so he knew this was not a networking problem. The second suggestion was to not use iPhoto and instead use Aperture. Kyle was using a PC, so this suggestion was also not helpful. Kyle did not find a solution to his problem, so he lived with the problems he had with his Apple TV.

This case illustrates how systems can produce individualized problems like Kyle's where system designers do not anticipate all the problems users could have with the systems in their computing environments. How could the findings from the MythTV user community and the diabetes patient support groups address Kyle's scenario? Next I walk through the three design suggestions.

# (1) Facilitate Sharing of Operationalized Experiences

In a hypothetical system that contains a repository of configuration artifacts and operationalized experiences of how a system is used, an individual like Kyle could find an individualized solution to his problem. He could search the user profiles within the repository to find a pool of users who match his situation. These would be users with PCs, the specific photo sharing software, and the specific version of Apple TV that Kyle uses. From the pool, it would be helpful for Kyle to find two groups of people—those who have syncing problems and those who have not. He could then compare the differences in their configuration settings to his own and troubleshoot what may be his problem. With this repository, experiences are recorded in operationalized forms with profile facets that users can analyze, browse, and search to generate individualized solutions.

# (2) Support Challenging Operationalized Solutions to Elicit Individual Differences

The repository system could provide the popular, hot, and most active searches as many community-based forums do, such as giving users the ability to search the most popular photo sharing tools used with Apple TV or which version of Apple TV had most problem reports. However, this type of information organization inevitably hides discussions around individualized problems that are uncommon. We could imagine the system giving users the ability to flag any experiences that showed exceptions. Whether an experience is an exception or not will become more visible as the users continue to contribute to the repository.

# (3) Facilitate Sharing Individual Trajectories and Help Community Trajectories to Become Visible

As Kyle sorts the pool of users with similar issues, it would be helpful for the repository to contain historical information about each user's maintenance trajectory. Kyle could see how users went through various tasks to solve their problems, and then he could take shortcuts in troubleshooting. Seeing other users' trails of tasks performed can be facilitated through allowing users to follow other users' individual trajectories.

Also, if a core group of long-time Apple TV users had established communities of practice, it would provide Kyle easy access to updated problems and solutions. This would support the community trajectory and make it visible.

Currently, this notion of understanding community trajectories is performed by users searching online forums for relevant posts to their problems. If the forum could show topics over time, such as a visualization of title keywords, it would help Kyle understand the kinds of problems the Apple TV users have attempted to solve over time. Another idea would be to help users post references to past forum articles whenever new posts are made (by suggesting articles as users write a certain keyword). This way, as with literature review is being done in academic papers, just by reading a single post, community members, including newcomers, could potentially gain some access to community trajectory.

#### SCENARIO 2: MOLLY AND HER CONFLICTING DIET REGIMES

Molly is a 65 year old female who has successfully managed her diabetes for the last twenty years. In a recent visit to her doctor, she heard that she may be developing liver disease. The doctor suggested a diet plan that was the exact opposite to what she should be eating as a diabetes patient. The new diet plan recommended high-calorie food, reduced protein, increased intake of carbohydrates, and white bread instead of whole grain bread. As a diabetes patient, she should be eating low calorie, high protein, reduced carbohydrates, and whole grain products instead of bleached ones.

Molly became frustrated. She scheduled an appointment with a dietitian in two weeks, but she wanted to know what other people did in her situation until then. Knowing that her creatinine level is high, she also wanted to avoid dialysis and wanted to know what she could do to delay this as long as possible.

There were several individualized problems for Molly: she needed specialized treatment in managing her diabetes due to bad liver and high creatinine level. Many diabetes patients and other chronic illness patients have similar

comorbidity, health histories, and life styles that generate individualized problems. Their time with health professionals is limited and they need examples of how other people with the same problems get encouragement, which is a critical component in patient empowerment (Anderson et al., 1995). They also need to get ideas on how they can manage their complications. How could collaborative help systems, such as online community forums, give individualized help? I discuss the three general design implications for Molly's case.

## (1) Facilitate Sharing of Operationalized Experiences

Similar to Kyle's case, we can imagine a system with a repository of operationalized experiences in the patient profiles that includes experimental results from 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 also compare those who received dialysis and those who did not have dialysis for many years after being diagnosed with high creatinine levels. 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.

# (2) Support Challenging Operationalized Solutions to Elicit Individual Differences

A repository of operationalized experiences with shared diet regimes or experiences should also encourage patients to elicit any exceptions. Because a member challenged a strategy for checking blood sugar, the diabetes community was able to further understand the need for individualized strategies in checking blood sugars. For this reason, the repository 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 is 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.

# (3) Facilitate Sharing Individual Trajectories and Help Communities' Common-Enough Understandings to Become Visible

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 problem similar to hers and she could see many cases and exceptions that would help her anticipate the future.

In order to support the visibility of the communities' common-enough understandings, we could also imagine a system where patients post their problems 289

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 learn about each poster's problem within the larger context of how the community attempts to solve problems.

#### **SUMMARY**

Through Kyle and Molly's cases, I explained the implications for design in my findings. First, the general design implication is to help users reuse shared operationalized experiences as resources for generating individualized solutions and to get answers to hypothetical questions through collective experiences.

Second, because computational repositories tend to highlight popular, hot, and active objects thus inevitably hiding individualized problems, it is important to encourage users to elicit any exceptions and individual differences that will surface uncommon cases and make them easily accessible. Lastly, it is important not only to share a snapshot of a particular point in a user's temporal path, but to give users the ability to follow individual trajectories from the past into the future. This would help reduce uncertainty about the future and generate helpful information. Also, community trajectory should become visible so that conversations in the communities can be naturally embedded in the larger context of how the community understands and solves problems over time.

### Conclusion

In my dissertation, I observed communities that are increasingly dealing with individualized problems: the MythTV user community and diabetes patient support groups. The goal is to seek out help mechanisms with which people in both communities help one another solve individualized problems. I found that in both settings members are operationalizing their experiences to easily transfer executable solutions and context. However, because of individual differences, the process of operationalization often breaks down. At the same time, the breakdown creates opportunities for members to further understand individual differences and how solutions can be tailored accordingly. At the same time, operationalization has to be done within the larger context of sharing maintenance trajectories, be it about maintaining MythTV systems or diabetes over time. By sharing operationalized experiences, encountering breakdowns in operationalization, and sharing maintenance trajectories, the communities in both settings continue to build shared understanding about appropriate ways to manage MythTV system and diabetes over time.

The concepts around operationalized experiences, the breakdown of operationalization, and trajectory alignment work theoretically generalize, I believe, to other situations that resemble individualized problems observed from the MythTV user community and dLife.com. My findings apply to communities of

period of time. Maintaining multiple things generate individualized problems, and individualized problems require the collaborative work of tailoring existing solutions. During the tailoring process, knowledge transfer and information reuse become challenges, and the process of operationalization becomes a necessary one. Because the problem is long-term, sharing trajectories become critical.

My dissertation contributes in several ways:

- For theoretical perspectives in collaborative help, specifically around the issues of information reuse and contextualization: My findings address help mechanisms that support the easy transfer of context and the appropriate translation of information into executable solutions.
  Furthermore, I found sharing historical context in my field sites helps
  members to formulate shared understandings of problems.
- experiences and maintenance trajectories are critical in finding solutions to individualized problems. Current collaborative help systems are designed in a way that inevitably hides operationalized experiences and maintenance trajectories despite their importance. The design implications section describes examples of how operationalized experiences and maintenance trajectories can further become accessible for users.

For social constructivist and symbolic interactionist perspectives: The findings illustrate the active role of newcomers in communities of practice (CoP) beyond legitimate peripheral participation discussed in the original conversations around CoP. Through the discussion of building commonenough understanding and community trajectory, existing knowledge established by regular members continue to be challenged by newcomers with their exceptional cases and new perspectives toward the problems. I also further explored the notions of transparency and the temporality of boundary objects that help translate boundary objects from being communication facilitators to executable solutions.

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There are a number of issues that need to be further addressed that my dissertation does not fully cover. The participants in my dissertation are advanced technical users who participate in open source software projects and patients who voluntarily participate in support groups to improve their health. My observations are limited to MythTV users and diabetes patients participating in dLife and some support groups in near Ann Arbor area. How much of the operationalization process, trajectory sharing, and community trajectory building activities are happening in other technical user communities and patient communities is still in question. My future work then is to further find out how the implications emerged from my findings apply to users who are less technically advanced, patients that do not participate in support groups, and situations where finding operationalized

solutions and sharing trajectories are difficult—and find out how implications need to be modified in varying circumstances.

Individualized problems are everywhere. As we move into ubiquitous computing environments in which users need to continuously maintain multiple devices that need to talk to one another, users will further encounter individualized problems. Problems that people encounter in managing their health are inherently individualized, and patients increasingly turn to online settings to get health information from other patients. Collaborative help for individualized problems will continue to become critical in many aspects of our everyday lives.

# **Appendices**

# **Appendix A. Interview Recruiting Materials**

#### **MYTHTV USERS**

#### Informed consent

Consent to Participate in a Research Study
COLLABORATIVE CONFIGURATION IN MYTHTY COMMUNITY

Principal Investigator: Mark Newman, PhD, University of Michigan Co-investigator: Mark Ackerman, PhD, University of Michigan

#### Invitation to participate in a research study

Mark Newman, Mark Ackerman, and Jina Huh invites you to participate in a research study about configuration sharing in MythTV community. The study is funded by National Science Foundation.

### **Description of subject involvement**

If you agree to be part of the research study, you will be asked to talk about your use of MythTV mailing list for maintaining your MythTV.

#### **Benefits**

You will directly benefit from being in this study because with the findings, we are planning to devise a system that can support MythTV users to more effectively share configuration practices of MythTV.

#### **Risks and discomforts**

There are no risks associated with this study because the data collection is completely anonymous and the topic is not sensitive.

#### Compensation

You will be given \$15 Amazon gift card for participating in this study. The gift card will be sent to your email address used during the recruitment.

## Confidentiality

We plan to publish the results of this study, but will not include any information that would identify you. There are some reasons why people other than the researchers may need to see information you provided as part of the study. This includes organizations responsible for making sure the research is done safely and properly, including the University of Michigan, government offices or the study sponsor, National Science Foundation.

To keep your information safe, the researchers will remove all identifiable information from the data. Also, the data will be kept in a password protected storage.

Also, if you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies.

# Storage and future use of data

The data or specimens you provide will be stored in a password protected computer storage.

The researchers will retain the data/specimens for 3 years.

The researchers will dispose of your data/specimens by 5/1/2013

The data/specimens will not be made available to other researchers for other studies following the completion of this research study and will not contain information that could identify you.

## Voluntary nature of the study

Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. If you decide to withdraw early, the interview data will be discarded.

#### **Contact information**

If you have questions about this research, including questions about scheduling or your compensation for participating, you may contact Mark Newman at mwnewman@umich.edu.

If you have questions about your rights as a research participant, please contact the University of Michigan Institutional Review Board Health Sciences and Behavioral Sciences, 540 E Liberty, Ste 202, Ann Arbor, MI 48104-2210, (734) 936-0933 [or toll free, (866) 936-0933], irbhsbs@umich.edu.

### **Recruiting email**

Dear xxx,

Have you had trouble configuring MythTV or keeping it running? Has the MythTV community helped you make sense of your MythTV system?

We a university research group seeking to develop tools that will allow online communities can provide better technical support to their members and want to hear your experiences. We emailed you to see if you would be interested in participating in a phone interview with us. The interview will last roughly from 30 minutes to 40 minutes.

The only criteria in participating in this study would be that your age has to be 18 and over.

Please let me know if you would be interested in participating.

# **Appendix B. Diabetes Patients: Face-To-Face Support Groups**

## Informed consent (also used for participants from dLife.com)

Consent to Participate in a Research Study

#### BETTER SUPPORTING DIABETES SUPPORT GROUPS

Principal Investigator: Jina Huh, PhD candidate, University of Michigan Faculty Advisor: Mark S. Ackerman, PhD, University of Michigan Invitation to participate in a research study

Jina Huh invites you to participate in a research study about diabetes support groups. The study is funded by the National Science Foundation.

#### **Description of subject involvement**

If you agree to be part of the research study, you will be asked to talk about your use of support groups in managing diabetes.

#### Benefits

You will directly benefit from being in this study because the longer objective of this project is to implement systems that can better support diabetes expertise sharing among peer patients.

#### **Risks and discomforts**

There are no risks associated with this study because the data collection is completely anonymous and the topic is not sensitive.

#### Compensation

You will be given \$15 Amazon gift card as a compensation for participating in this study. If you decide to withdraw early, we will discard any data that was produced through the interviews, and half of the compensation will be given.

#### Confidentiality

We plan to publish the results of this study, but will not include any information that would identify you. There are some reasons why people other than the researchers may need to see information you provided as part of the study. This includes organizations responsible for making sure the research is done safely and

properly, including the University of Michigan, government offices or the study sponsor, National Science Foundation.

To keep your information safe, the researchers will anonymize your data as well as store interview data in a password protected place.

Also, if you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies.

## Storage and future use of data

The data you provide will be stored in a password protected computer.

The researchers will retain the data for 3 years.

The researchers will dispose of your data by 5/1/2013.

The data will not be made available to other researchers for other studies following the completion of this research study and will not contain information that could identify you.

## **Voluntary nature of the study**

Participating in this study is completely voluntary. Still, you can choose not to answer any of the questions for any reason. Even if you decide to participate now, you may change your mind and stop at any time.

# Audio taping of the interview

The interview conversation will be recorded to a digital audio file that will be stored in a secured laptop that only the PI has the access to. You can deny to be recorded. Even if you decide to allow for the recording, you can always request to either stop the recording during the interview or request later that the audio recording will be destroyed.

#### **Contact information**

If you have questions about this research, including questions about scheduling or your compensation for participating, you may contact Jina Huh at <a href="mailto:jinah@umich.edu">jinah@umich.edu</a> or call 734 645 3664, or Mark Ackerman at <a href="mailto:ackerm@umich.edu">ackerm@umich.edu</a> or call 617 290 6613.

If you have questions about your rights as a research participant, please contact the University of Michigan Institutional Review Board Health Sciences and Behavioral Sciences, 540 E Liberty, Ste 202, Ann Arbor, MI 48104-2210, (734) 936-0933 [or toll free, (866) 936-0933], <a href="mailto:irbhsbs@umich.edu">irbhsbs@umich.edu</a>.

## Recruiting flyer handed out during the support group meetings

Hi, this is Jina Huh, a doctoral student at the School of Information, University of Michigan. For my thesis, I am working on improving diabetes patient expertise sharing in both online as well as face-to-face support groups. I am interviewing patients with diabetes that use support groups to gain information about managing diabetes.

I am sending this flyer around to see if you would be interested in participating in a phone interview. The interview will last roughly from 30 minutes to 40 minutes, and I will compensate with \$15 amazon gift card or a check.

The only criteria in participating in this study would be that your age has to be 18 and over and that you are regularly managing your blood sugar level particularly for the concerns in having diabetes.

Please sign up below if you are interested in participating, and here is my contact email: <a href="mailto:jinah@umich.edu">jinah@umich.edu</a> or call 734 645 3664.

Name	Email	Phone

# Appendix C. Diabetes Patients: dLife.com

## Recruiting flyer for dLife members

Hi xxx,

This is Jina Huh, a doctoral student at the School of Information, University of Michigan. For my thesis, I am working on improving patient expertise sharing in both online as well as face-to-face support groups. I am interviewing individuals with diabetes that use support groups to gain information about managing diabetes.

I found you from dLife.com, and I am sending you this message to see if you would be interested in participating in a phone interview. The interview will last roughly from 30 minutes to 40 minutes. I will ask you questions on how support groups have helped you, for example. If the phone is uncomfortable with you, we can certainly converse through email or this messaging feature as well.

Please let me know if you would be interested in participating. Your input would be tremendously benefit the diabetes community as well as any health community in the future.

Thank you and I look forward to hearing back from you, Jina

# Recruiting flyer for dLife staff

Hi Zeneida,

This is Jina Huh, a doctoral student at the School of Information, University of Michigan. For my thesis, I am working on improving patient expertise sharing in both online as well as face-to-face support groups.

I found you from dLife.com, and I am sending you this message to see if you could enlighten me with what's going on in dLife.com among the members. The phone interview will last roughly from 30 minutes to 40 minutes. If the phone is uncomfortable with you, we can certainly converse through email as well.

Please let me know if you are interested in helping. Your input would be tremendously benefit the diabetes community as well as any patients' community in the future.

Thank you and I look forward to hearing back from you, Jina

# **Appendix D. Interview Protocols**

#### **MYTHTV USERS**

The following is semi-structured, thus the interview questions may change as the interview progresses.

When did you first started looking at MythTV?

How long have you used MythTV?

What do you use MythTV for?

How long did it take you to set up MythTV?

Please tell us about your maintenance activities with MythTV. Can you remember the last you had any problems with MythTV?

Are you subscribed to MythTV mailing list?

How often do you read the mailing list?

When was the last time you posted a question to the list?

When was the last time you posted answers to the list?

What is helpful in MythTV community?

What is not helpful in MythTV community?

What can be improved?

What needs to be retained?

What is most challenging in sharing configuration information about MythTV?

Any overall comments?

#### **DIABETES PATIENTS**

The following interview protocol will be semi-structured, thus specific questions can change and emerge in response to the interviewee's answers.

## For Participants Recruited from Face-to-Face Support Groups

1. When were you first diagnosed with diabetes?

- a. What medications, exercise plans, or diet plans are you using to maintain diabetes?
- b. Do you have any other ways of managing diabetes?
- 2. When was the last time you went to the support group?
  - a. What was most helpful?
  - b. What was not helpful?
- 3. Do you also go online for diabetes information?
  - a. Could you tell me the last time you went online to look for information on diabetes?
  - b. Which sites would you recommend me to look at?
  - c. How helpful were the sites? Why, and why not?
- 4. What is most challenging in dealing with diabetes?
  - a. What would be helpful in improving the situation?

## For Participants Recruited from dLlfe.com

- 1. When were you first diagnosed with diabetes?
  - a. What medications, exercise plans, or diet plans are you using to maintain diabetes?
  - b. Do you have any other ways of managing diabetes?
- 2. When was the last time you went to dLife.com?
  - a. What was most helpful?
  - b. What was not helpful?
- 3. Do you also go to face-to-face support groups or other online support groups for diabetes?
  - a. Could you tell me the last time you went to face-to-face support groups? Do you go to the support group regularly?
  - b. Could you tell me the last time you went online to look for information on diabetes?
  - c. Which sites would you recommend me to look at?
  - d. How helpful were the sites? Why, and why not?
  - e. What is in face-to-face support groups that online support groups don't have?
  - f. What is supported in online support groups that are not supported in face to face support groups?
- 4. What is most challenging in dealing with diabetes?
  - a. What would be helpful to improve the situation?

#### Protocol for Email Interviews

Hello Kristine,

Thank you very much for allowing me to interview you. We can certainly converse through email or this messaging feature. I will include the questions below. You are not obliged to answer all of the questions, so please answer the ones that you feel comfortable with.

- 1. Please tell me about your day-to-day activities that are related with diabetes. What did you do today? (this can be about the food you tried to eat, checking your BG, taking medicine, checking dLife or other diabetes info, etc)
  - 1-1. Is this typical? If not, what is typical?
  - 1-2. What would be the exceptions?
- 2. Please think about when you were first diagnosed, and walk me through what happened.
  - 2-1. What had changed before and after the diagnosis?
- 3. Have you had any complications since the diagnosis? If so, please describe what you had to change in order to deal with the complication.
- 4. Please walk me through what you did with dLife.com the last time you came over to the site.
  - 4-1. Where in dLife.com do you read most of the time? Please give a specific example.
  - 4-2. What value do you see in the things that you do with dLife.com? Please give a specific example.
  - 4-3. What do the other members in dLife.com help you as opposed to what your doctor does to you? Please give a specific example.
  - 4-4. Please tell me about the last time you posted something to dLife.com. Where did you post it, what was it about, and what were you expecting to get out of them?
  - 4-5. What is NOT helpful (or less useful) about the support group / community in dLife.com?
  - 4-6. When did you first know about dLife.com, and what were you expecting to get out of the community?
  - 4-7. How has what you answered above in 4-6 changed over the years (or months, or days)?

- 5. Do you participate other support groups such as face-to-face meetings with individuals with diabetes or other online diabetes support groups? Please describe what they are, and what you get differently from them.
- \* Do you mind if I ask you follow up questions once I receive your answers? Your participation will be tremendously valuable for the diabetes communities as well as the health communities in general. Thank you very much. Jina

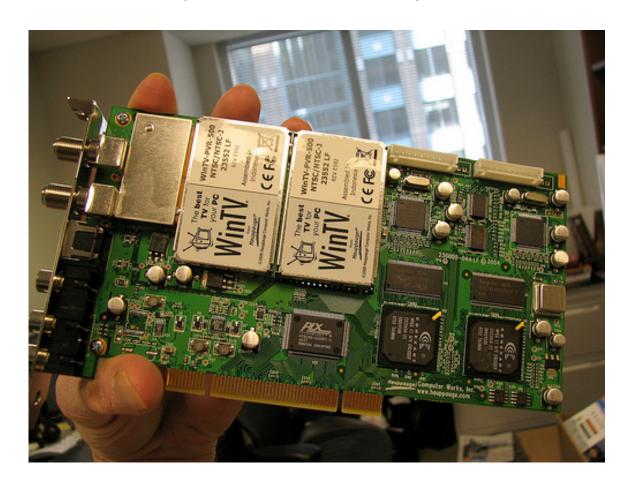
# Appendix E. MythTV system and User Community

# MYTHTV SYSTEM

# Configuration map



# Showing installation of two WinTV capture cards



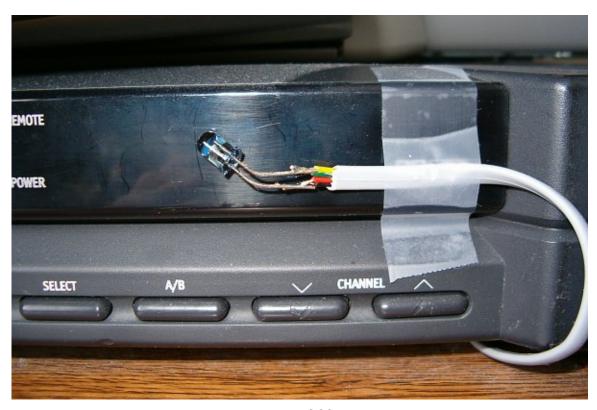
# MythTV installed in Nokia cell phone



# MythTV installed in a netbook



Installing remote control using IR Blaster



# MythTV connected to regular televison

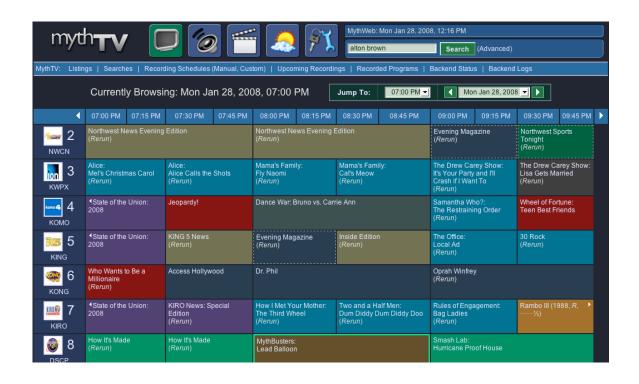


### **MYTHTV INTERFACE**

# The main interface (Note: There are multiple versions. The provided screenshot below is only one example)



### Overview of the TV channels



## **Setting up recordings**

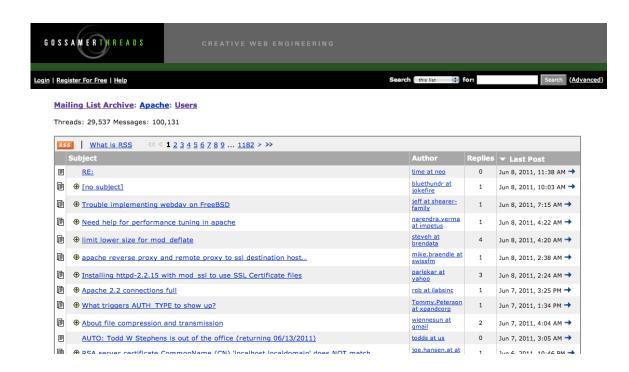


# MythWeather feature



#### MYTHTV USER COMMUNITY

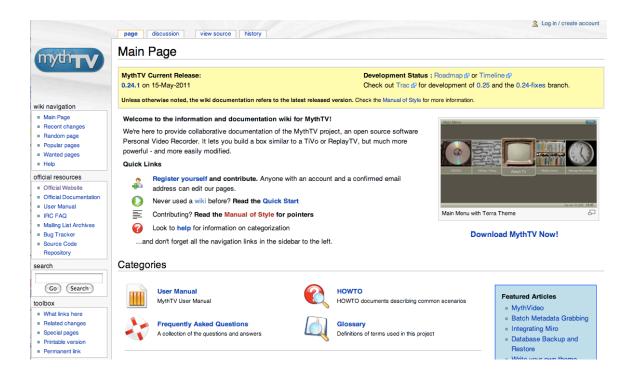
# Mailing list archive (Users-list) (http://www.gossamerthreads.com/lists/mythtv/users/)



# MythTV.org (Official homepage of the MythTV project)

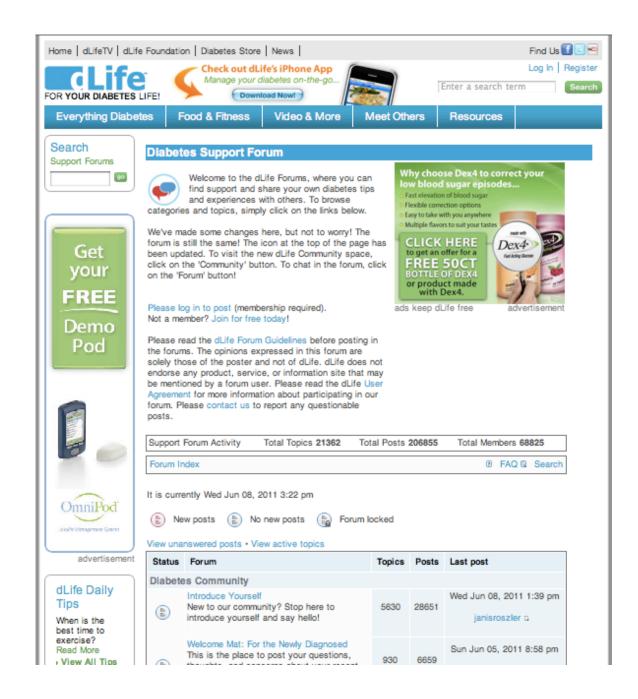


# MythTV Wiki (www.mythtv.org/wiki)



# Appendix F. dLife.com and Face-to-Face Diabetes Support Groups

#### DLIFF.COM SCREENSHOT



#### DISCUSSION TOPICS UNDER DLIFE FORUMS

Introduce yourself; Welcome Mat: For the Newly Diagnosed; Type 1 Clubhouse; Prediabetes Parlor; Type 1.5 (LADA); Type 2 Clubhouse; Gestational Diabetes; MomSpot; Ladies' Room; Mens' Room; The Senior Center; Parents Helping Parents; The dLife Family Room: Support for Friends and Family; The dLife Kitchen: Food Talk; The dLife Gym: Beginners to Athletes; The dLife Garage: Pumps, Meters, and Other Gadgets; Community Center: Diabetes Events and Fundraisers; Everything But the Kitchen Sink (Off-Topic); General Diabetes Discussion; Healthcare Professionals Network - FOR PROFESSIONALS ONLY; What's New at dLife.com; Talk About dLifeTV; dLife Feedback: Kudos and Complaints

SCREENSHOTS OF DIABETES PATIENT SUPPORT GROUP FIELD OBSERVATIONS

## Code lists and affinity diagram

#### MYTHTV USER COMMUNITY STUDY

#### Code-Filter: All

HU: collabConfig\_100611

File: [C:\Users\huhjina\Documents\mythtv\collabConfig\_100611.hpr5]

Edited by:Super

Date/Time: 06/08/2011 10:47:12 PM

\*:flag

\*:interesting comments

0: DESIGN IDEA

0:announcements

0:collaborative configuration--developers interacting

0:collaborative developmenet--call for collaborators

0:collaborative development

0:collaborative development--birth of a development

0:collaborative development--building devices

0:collaborative development--collective action

0:collaborative development--critiquing existing features/functionalities

0:collaborative development--death of a development

0:collaborative development--discuss

0:collaborative development--generating knowledge repository

0:collaborative development--learning from alternatives

0:collaborative development--negotiating what's appropriate design

0:collaborative development--negotiating what to develop

0:collaborative development--patches, packages, and scripts

0:collaborative development--reporting bugs/problems

0:collaborative development--setting values of new developments by group reaction

0:collaborative development--suggest ways to appropriate for new features

0:collaborative development--suggested improvements

0:collaborative development--test out

0:collaborative development--user-developer collaboration

0:conf as knowledge--adjusting solutions for one's conf

0:conf as knowledge--benchmarking

0:conf as knowledge--has anyone experienced this?

0:conf as knowledge--has anyone tried this?

0:conf as knowledge--inferred expertise

0:conf as knowledge--knowledge sharing between members with similar conf

0:conf as knowledge--negotiated minimal/additional information

0:conf as knowledge--non-transferrable solutions

0:conf as knowledge--object based expertise sharing

0:conf as knowledge--sharing objects

0:conf as knowledge--side-by-side comparison

0:conf as knowledge--similar personal configuration does not always give answers

0:conf as knowledge--stamping (this is how I do/did it)

0:conf as knowledge--this happened to me before

0:conf problem--comparison

0:conf problem--composition issues

0:conf problem--configuration-specific quiz

0:conf problem--downgrading

0:conf problem--inconsistencies

0:conf problem--instructions don't always work

0:conf problem--personalized configuration

0:conf problem--product/feature/program reviews

0:emerging issues

0:emerging issues--adding/replacing components

0:emerging issues--backing up

0:emerging issues--environmental changes

0:emerging issues--keeping track of versions

0:emerging issues--keeping up with upgrades

0:emerging issues--limited space, requiring reconfiguration

0:emerging issues--major mythty system component change

0:emerging issues--obsolescence of technologies

0:emerging issues--obsolete solutions

0:emerging issues--projecting future use

0:emerging issues--rebuilding mythtv

0:emerging issues--system upgrade and the broken state

0:emerging issues--unprecedented problems

0:emerging issues--waiting for fixes/updates

0:follow ups

0:follow ups--challenge the helper

0:follow ups--clarifications

0:follow ups--confirm the problem

0:follow ups--didn't follow up

0:follow ups--follow on problems

0:follow ups--follow on question

0:follow ups--I've already tried but didn't solve

0:follow ups--promise to follow up

0:follow ups--providing further details

0:follow ups--reporting decisions

0:follow ups--reporting self-diagnosed problem & solution

0:follow ups--reporting success results

0:follow ups--reporting trials and/ results

0:follow ups--reporting trials and/ results--didn't work

0:follow ups--reports the plan

0:follow ups--thanks for your help but that wasn't helpful

0:follow ups--unsuccessful result

0:future projection--asking what to do

**0:future projection--concerns** 

0:future projection--plans

0:future projection--providing suggestions

0:future projection--what happens if

0:future projection--will this come out

0:gathering evidences

0:gathering evidences-- the living evidence that it works

0:gathering evidences--counter-evidence

0:gathering evidences--providing evidence

0:gathering evidences--requesting information from a specific configuration

0:gathering evidences--test results

0:help mechanism--alternative solution

0:help mechanism--clarifications

0:help mechanism--critiquing

0:help mechanism--critiquing--customized scripts and codes

0:help mechanism--critiquing--plans

0:help mechanism--diagnosis

0:help mechanism--diagnosis--assumed causes & solutions / try this

0:help mechanism--diagnosis--multiple diagnosis

0:help mechanism--diagnosis--replicating problems

0:help mechanism--diagnosis--requesting further info

0:help mechanism--diagnosis--teaching how to diagnose

0:help mechanism--did you do this?

0:help mechanism--enlighten

0:help mechanism--expertise grounded on personal experience

0:help mechanism--failure stories

0:help mechanism--I heard / many people...

0:help mechanism--if A then B

0:help mechanism--in theory solutions

0:help mechanism--indirect help

0:help mechanism--known problems

O:help mechanism--laying out possibilities
O:help mechanism--pointers to conversations / patches / links

0:help mechanism--pointers to existing method

0:help mechanism--pointers to the appropriate experts

0:help mechanism--procedural instructions

0:help mechanism--product reviews--with personal experience

0:help mechanism--ruling out possibilities

0:help mechanism--sharing know hows

0:help mechanism--voluntary knowledge broadcasting

0:help mechanism--warning

0:help mechanism--warning--announcements

0:helpers' interaction--building up on each other

0:helpers' interaction--challenging suggestions

0:helpers' interaction--conflicting solution

0:helpers' interaction--counter-evidence for the solution

0:helpers' interaction--diverse strategies

0:helpers' interaction--head butting expertise

0:helpers' interaction--second with additional personal experience stories

0:meat-forum--communication breakdown

0:meta-forum

0:meta-forum--appropriate way to convey information

0:meta-forum--appropriate way to use the forum

0:meta-forum--assumed knowledge

0:meta-forum--cumbersome tracking of who said what

0:meta-forum--defensive words

0:meta-forum--developers listening in

0:meta-forum--direct member interaction

0:meta-forum--evidence based discussions

0:meta-forum--flaming through conflicting expertise exchange

0:meta-forum--forum boundaries

0:meta-forum--how membership is defined

0:meta-forum--keeping the warmth of the community

0:meta-forum--legality

0:meta-forum--member categorization

0:meta-forum--meta-mythtv

0:meta-forum--more info once I get home

0:meta-forum--motivations for help

0:meta-forum--open and share

0:meta-forum--outsiders peaking in for info

0:meta-forum--personal use of mythty

0:meta-forum--playing between humble and knowledgeable

0:meta-forum--politeness for ignorance

0:meta-forum--promythtv/proopensource/prolinux-unix

0:meta-forum--ranting as a way to earn membership

0:meta-forum--reactions to new comers

0:meta-forum--reactions to RTFM

0:meta-forum--reask allowed, only in the case there are new things

0:meta-forum--relationship between developers and users

0:meta-forum--result reporting culture

0:meta-forum--setting the rules

0:meta-forum--shared understanding about distro characteristics

0:meta-forum--shared vocabulary

0:meta-forum--shared vocabulary--how it becomes

0:meta-forum--showing incentives for answering Qs

0:meta-forum--staying on track

0:meta-forum--structured question

0:meta-forum--thank yous and encouragements

0:meta-forum--the jokes

0:meta-forum--the way developers can react to the users

0:meta-forum--typical threads--fading away to the background

0:meta-forum--user-developer war

0:meta-forum--value of the community

0:meta-forum--WAF

0:meta-forum--who can ask clarifications for shared vocabularies

0:misc

0:Q mechanism--can this be done?

0:Q mechanism--critiquing--questioning existing practice

0:Q mechanism--diagnosis--symptom description

0:Q mechanism--how do i

0:Q mechanism--reporting series of trials

0:Q mechanism--request for critique

0:Q mechanism--watching out for the updates on a problem

0:0 mechanism--where to get

0:Q&help mechanism--diagnosis--requesting/providing interpretation

0:Q&help mechanism--historical story sharing

0:Q&help mechanism--hypothesis

0:Q&help mechanism--is this normal?

0:Q&help mechanism--request for/explain background info

0:trajectory---1:technology proof-of-concept

0:trajectory--0:installation

0:trajectory--1:stabilizing mythtv

0:trajectory--2:appropriation

0:trajectory--2:appropriation--extending functionalities

0:trajectory--2:appropriation--using existing functionalities to achieve a new functionality

0:trajectory--3:performance tuning

0:trajectory--4:updating/upgrading

**0:trajectory--considering alternatives** 

0:trajectory--preventative maintenance

0:trajectory--transition to alternatives

SJ: adding a new device to the ecology / replacing old ones

SJ: adding new features

SJ: appropriation / customization/ extension

SJ: archiving / backup

SJ: Beginner troubleshooting

SJ: better understanding

SJ: bugs / identified problems

SJ: comparison of mythTV with other products

SJ: component Qs

SJ: composition issues

SJ: development ideas

SJ: downgrade

SJ: emerging issues

**SJ: EVENTS** 

SJ: future projection / review-comparison

SJ: meta forum

SJ: obsolescence

SJ: performance tuning

SJ: potential users of mythtv

SJ: regular troubleshooting

SJ: setting up / installation

SJ: sharing practices

SJ: system changes

SJ: themes

SJ: upgrades / patches

SJ:transcoding problem

zzz:expertise sharing with configuration

#### DIABETES PATIENT SUPPORT GROUPS STUDY

Code list: dLife.com

#### **Code-Filter: All**

HU: diabetes forumstudy3

File: [C:\Users\huhjina\Documents\diabetes\diabetes\_forumstudy3.hpr5]

Edited by:Super

Date/Time: 06/08/2011 10:48:54 PM

0.misc--humor//

0.misc--ill-working gadgets

communciation layer--breakdown using the forum//

```
communication layer--context around numbers
communication layer--messages redirect//
communication layer--participation--when lurker becomes a poster//
communication layer--private problems//
communication layer--redirecting for expertise//
connecting with face to face support group
connecting with other online communities
connection to health care--policing//
connection to healthcare--a doctor who understands//
connection to healthcare--alt. medication solutions
connection to healthcare--alternative solutions to doctors
connection to healthcare--asking for police//
connection to healthcare--bleeding to doctors
connection to healthcare--categories of doctors//
connection to healthcare--clarification (object)
connection to healthcare--collaborative policing--differing interpretations//
connection to healthcare--collaborative policing//
connection to healthcare--complex doctor-patient relationship//
connection to healthcare--conflicting experiential evidence towards what we know
connection to healthcare--conflicting need with doctors//
Connection to healthcare--diagnosis--not coming from similar personal experience
Connection to healthcare--diagnosis--specific name
connection to healthcare--doctor differences//
connection to healthcare--exchanging doctors' opinion
connection to healthcare--health care plan/
connection to healthcare--how to manage doctors
connection to healthcare--maximize doctor's visit
Connection to healthcare--medical expertise, without source info
Connection to healthcare--medical information clarification
connection to healthcare--outdated doctors//
connection to healthcare--side conversation--challenging authoritative resources
connection to healthcare--side conversation--common sense driving health management
connection to healthcare--side conversation--how to win doctors
connection to healthcare--side conversation--my belief apart from authority
connection to healthcare--side conversation--my belief with the doctors
connection to healthcare--side conversation--validating info from the doctor's office
connection to healthcare--side conversation--vent
connection to healthcare--side conversation--what they don't get from the doctors--enough
consultation//
connection to healthcare--side conversation--what they don't like the doctors to know
connection to healthcare--supplementing information gap
connection to healthcare--using authoritative resources--asking for references//
connection to healthcare--using authoritative resources--conflicting authoritative evidences
connection to healthcare--using authoritative resources--giving authoritative resources
connection to healthcare--using authoritative resources--personal experience against
authoritative results
connection to healthcare--using authoritative resources--summarizing authoritative resources
connection to healthcare--when to contact the doctor (when is it severe enough)//
connection to healthcare--wrong doctors//
design idea--challenge flag
design idea--facilitating environments for sharing experiments/buddy systems
design idea--showing past posts with the current post
design idea--suggested products and vote//
design idea--visualizing different symptoms for medications, keywords
design implication--composition of patients at different states
design implication--creating artifacts
design implication--friends and foes//
```

```
design implication--health-technical gap
design implication--helping to share personal notes//
design implication--history hard to know
design implication--matching hidden profiles
design implication--motivating people to participate in the buddy system
design implication--repetitive sharing of useful links
design implication--sharing nutrition info collaboratively//
design implication--terminology problems
design implication--works for both personal and social in terms of motivation
discussion leading to exchange of medical information
discussion seed--controversial issues
Encouragements--for people that are not doing well
Encouragements--good luck
Encouragements--no new info
help-giving--community-based--collaborative health management
help-giving--community-based--collaborative health management--newcomer
help-giving--community-based--collaborative knowledge gathering
help-giving--encouragements--conflicting cultures for differing encouragements
help-giving--encouragements--welcoming newcomers
help-giving--information--search results
help-giving--meta-ing--referring
help-giving--motivations for giving help
help-giving--this may be relevant to me
help-receiving--askers feedback--clarification
help-receiving--askers feedback--progress so far
help-receiving--askers feedback--promise to follow up
help-receiving--askers feedback--share profile
help-receiving--sharing concerns
hypothesis discussions
managing the forums--drive out ads//
Member roles--dominating person's help given
Member roles--mixed role//
Member roles--moderator--breakdown--don't see the thread all the way in//
Member roles--moderator--clarify//
Member roles--moderator--moderating//
Member roles--pipe in information//
Member roles--the role of the leaders
Member roles--the role of the leaders--secondary leader
offline management--also has resources
operationalization--breakdown--changing numbers//
operationalization--breakdown--conflicting numbers//
operationalization--breakdown--decontextualized//
operationalization--breakdown--each body is different//
operationalization--breakdown--hard to untangle//
operationalization--breakdown--inconsistent findings//
operationalization--breakdown--invisible information revealed through technology//
operationalization--breakdown--knowing how to play around with numbers for my body--
operationalization--breakdown--no easy magic answer//
operationalization--breakdown--of definitions//
operationalization--breakdown--operationalize everything//
operationalization--breakdown--personal interpretation of numbers//
operationalization--breakdown--resolve--explain//
operationalization--breakdown--resolve--failed//
operationalization--breakdown--resolve--taking sides//
operationalization--breakdown--situatedness of numbers//
operationalization--breakdown--unknown facts//
```

```
operationalization--contextualization--asking further question
operationalization--contextualization--digital artifacts as signals
operationalization--contextualization--extra info/
operationalization--contextualization--lab results//
operationalization--contextualization--profile
operationalization--contextualization--profile--signature
operationalization--contextualization--providing more details/
operationalization--contextualization--snapshots//
operationalization--contextualization--what to contextualize//
operationalization--contextualization//
operationalization--equation--additional factors//
operationalization--equation--asking for one//
operationalization--equation--confirm hypothesis//
operationalization--equation--for understanding diabetic experiences//
operationalization--equation--to get a rough sense//
operationalization--equation--unintuitive//
operationalization--equation//
operationalization--goals//
operationalization--information--experiment findings--unexpected//
operationalization--information--experiment findings//
operationalization--information--facts//
operationalization--meta--learning to operationalize//
operationalization--meta--measuring tools//
operationalization--meta--what's the most appropriate way to operationalize//
operationalization--meta--what is trustful info
operationalization--meta--why operationalize--contribution//
operationalization--meta--with appropriate language//
operationalization--modification--knowing how to play around with numbers for my body//
operationalization--modification--of one's operationalized strategy//
operationalization--modification--of related strategy//
operationalization--negotiation--accept others//
operationalization--negotiation--ask professionals for clarification//
operationalization--negotiation--coming to agreed appropriate strategy//
operationalization--negotiation--contextualization//
operationalization--negotiation--finding out how much to make effort//
operationalization--negotiation--operationalizing differences//
operationalization--negotiation--weighing//
operationalization--negotiation--what is normal/low/high--what my doc told me//
operationalization--negotiation--what is normal/low/high//
operationalization--negotiation--what makes sense to me//
operationalization--negotiation--when to stop worrying//
operationalization--negotiation--workarounds//
operationalization--PIM//
operationalization--solutions--artifact
operationalization--solutions--artifact--books//
operationalization--solutions--artifact--product//
operationalization--solutions--artifact--recipes//
operationalization--solutions--artifact--relevant links//
operationalization--solutions--by giving one's practice/
operationalization--solutions--determining whether the problem is urgent enough to see a
operationalization--solutions--executable artifacts//
operationalization--solutions--finding individualized solutions//
operationalization--solutions--general rules of thumb//
operationalization--solutions--key tips-abstracted//
operationalization--solutions--personalized solutions//
operationalization--solutions--product suggestions
```

```
operationalization--solutions--sharing knowhow/information that may be helpful/
operationalization--solutions--solution kit for helping Ds//
operationalization--solutions--start up kit solutions for new comers//
operationalization--solutions//
operationalization--understanding doctors' workflow//
question--asking for good product
question--asking for interpretation of results
question--asking for workaround
question--association questions
question--diabetes and everyday life
question--diagnosis
question--experience of a medication
question--factual question
question--has anybody experienced this
question--is this normal//
question--rare problem
question--reviews
question--situational problems
question--wanting a magic answer//
role of the forum--a place with people to talk to//
role of the forum--I'm not the only one//
role of the forum--people with commonalities//
role of the forum--success
role of the forum--supplement the time gap until the doctors' visit//
SES info
socially constructed appropriateness--being honest
socially constructed appropriateness--biased towards who does well
socially constructed appropriateness--black duck
socially constructed appropriateness--falling off the wagon
socially constructed appropriateness--it is allowed on when you made efforts or have
appropriate reasons that are not related to your own will
socially constructed appropriateness--maintaining assumed ethic
socially constructed appropriateness--newcomer can be a sicker patient?
socially constructed appropriateness--one reveals and everyone will open up
socially constructed appropriateness--stating efforts for healthy efforts
socially constructed appropriateness--thread specific culture
standards--gaging what is severe
TAwork--aligning--attitudes towards diabetes//
TAwork--aligning--best way to manage diabetes//
TAwork--aligning--reasoning//
TAwork--aligning--understanding interventions//
TAwork--aligning--understandings towards facts
TAwork--aligning--what's doing well//
TAwork--being aware of each others' beyond diabetes specific issues
TAwork--being aware of who are in the group
TAwork--collaging--"I will let you do the research and decide"//
TAwork--collaging--associated past//
TAwork--collaging--collaborative interpretations of numbers//
TAwork--collaging--hearsay
TAwork--collaging--many find...
TAwork--collaging--medication experience
TAwork--collaging--opposing experience//
TAwork--collaging--possibilities//
TAwork--collaging--product experience
TAwork--collaging--reviews of a new intervention//
TAwork--collaging--reviews of a resource
```

```
TAwork--collaging--solution over common problems//
TAwork--collaging--stories of others//
TAwork--collaging--symptoms/
TAwork--collective action--social creation of knowledge--experiments
TAwork--community trajectory--values
TAwork--connecting with patients--certain profile elements don't matter whether it's similar or
TAwork--connecting with patients--experience with med, resource
TAwork--connecting with patients--guru//
TAwork--connecting with patients--location
TAwork--connecting with patients--personal correspondence
TAwork--connecting with patients--similar stages
TAwork--connecting with patients--socializing
TAwork--connecting with patients--technical member//
TAwork--connecting with patients--that are similar
TAwork--critique
TAwork--inform news
TAwork--informing self--body changes//
TAwork--informing self--critical events//
TAwork--informing self--events
TAwork--informing self--filling in the blanks
TAwork--informing self--future plans
TAwork--informing self--future projection
TAwork--informing self--history
TAwork--informing self--history--as counter evidence//
TAwork--informing self--history attempted//
TAwork--informing self--how my body reacts
TAwork--informing self--inform changes in practice
TAwork--informing self--numbers over time
TAwork--informing self--progression
TAwork--informing self--reflection
TAwork--informing self--reporting decisions//
TAwork--informing self--reporting doctor's visit
TAwork--informing self--reporting experiences//
TAwork--informing self--routines
TAwork--informing self--the cracks
TAwork--informing self--unsurfaced profiles
TAwork--informing self--update
TAwork--keeping accountability
TAwork--keeping accountability--buddy system
TAwork--keeping accountability--buddy system--goal setting
TAwork--keeping accountability--buddy system--registering
TAwork--keeping accountability--buddy system--status update
TAwork--keeping accountability--buddy system--support for above and below
TAwork--keeping accountability--role of leaders--help the thread to stay on track
TAwork--keeping accountability--self monitoring results
TAwork--knowing from various communication channels
TAwork--knowing how each others' bodies are different
TAwork--knowing what to highlight
TAwork--need--a magic answer//
TAwork--need--adopting new interventions//
TAwork--need--current struggles
TAwork--need--frustration and anger//
TAwork--need--knowing subtleties//
TAwork--need--meeting the goals//
TAwork--need--new goals//
TAwork--need--new issues//
```

```
TAwork--need--not knowing what to do//
TAwork--need--to maintain under certain threshold//
TAwork--need--too little control//
TAwork--need--trying to make sense of ambiguity//
TAwork--need--uncertainty about the future//
TAwork--need--uninformed positive possibilities
TAwork--need--unknown issues
TAwork--need--what I have to do in order to...//
TAwork--parallelTA
TAwork--participation--informing absence
TAwork--participation--registering newcomer
TAwork--participation--two layers: visible and the invisible--becoming visible
TAwork--peripheral--diabetes and life
TAwork--peripheral--helping Ds//
TAwork--peripheral--insurance issues
TAwork--peripheral--life support group
TAwork--peripheral--self//
TAwork--perpheral--family//
TAwork--presenting common cases
TAwork--providing causes
TAwork--providing causes--providing opposing experience//
TAwork--routinized information sharing
TAwork--SerialTA--advices--improving practices
TAwork--SerialTA--being aware of potentials/more experienced knows more possibilities//
TAwork--SerialTA--breakdown--don't agree//
TAwork--SerialTA--can get good help
TAwork--SerialTA--different spaces of trajectories
TAwork--SerialTA--don't freak out//
TAwork--SerialTA--for new comers
TAwork--SerialTA--hypothesized diagnosis//
TAwork--SerialTA--I've been through that
TAwork--SerialTA--informing possibilities
TAwork--SerialTA--know-how//
TAwork--SerialTA--negative experiences
TAwork--SerialTA--sharing personal practice for possibilities
TAwork--SerialTA--success
TAwork--SerialTA--success--need to know the story behind for learning//
TAwork--SerialTA--to know one's history over time//
TAwork--SerialTA--upward comparison
TAwork--SerialTA--warning
TAwork--SerialTA--what's important to know
TAwork--social learning--are there anything I'm missing//
TAwork--social learning--comparison--By seeing similar cases often happening comfort//
TAwork--social learning--comparison--comparing with own experience
TAwork--social learning--comparison--confirm the good ones//
TAwork--social learning--comparison--how I am doing
TAwork--social learning--comparison--operationalized//
TAwork--social learning--comparison--practices
TAwork--social learning--confirm hypothesis//
TAwork--social learning--conflicting discussion is part of learning//
TAwork--social learning--decisions made to select is unclear//
TAwork--social learning--from situational expert//
TAwork--social learning--indirect learning
TAwork--social learning--inferring from one's experience//
TAwork--social learning--it's common
TAwork--social learning--me too
TAwork--social learning--new ideas//
```

```
TAwork--social learning--not me
TAwork--social learning--try out what other people do
TAwork--social learning--want to know if what works for me works for others as well//
TAwork--social learning--what do you do in this circumstance//
TAwork--social learning--what helps//
TAwork--stage--acceptance
TAwork--stage--back to zero one//
TAwork--stage--beginner
TAwork--stage--controlled prediabetes//
TAwork--stage--dangerous prediabetes//
TAwork--stage--denial
TAwork--stage--fell off the wagon//
TAwork--stage--gungho/funk/
TAwork--stage--long been diabetic but has no idea//
TAwork--stage--maintaining reverted//
TAwork--stage--new critical events//
TAwork--stage--plateau//
TAwork--stage--reverted//
TAwork--stage--stabilization
TAwork--stage--trail medication//
TAwork--want to follow for progression
Trajectory--against compassion//
Trajectory--connecting with patients
Trajectory--values--admitting obesity leading to diabetes//
Trajectory--values--against medications//
Trajectory--values--non-commercial//
Trajectory--values--respecting variety//
Trajectory--values--self compassion//
Trajectory--values-changes over time//
Trajectory as help--building consensus//
Trajectory as help--contextualization--requesting for trajectory info//
Trajectory as help--contextualization--story of one's diabetes over time//
Trajectory as help--experienced past informs//
Trajectory as help--matching points (similar problems)//
Trajectory as help--to learn about strategies//
varving beliefs
varying beliefs--beliefs driving understanding facts//
varying beliefs--doctors' preconception towards patients//
varying beliefs--opposing strategies//
varying beliefs--style of research
varying beliefs--we need to be more independent//
varying beliefs--what's appropriate approach towards diabetes//
varying definitions and standards
varying definitions and standards--definitions//
venting
w.personalized problem
w.personalized problem--everyday environment
w.personalized problem--everyday practice
w.personalized problem--how body reacts
w.personalized problem--how body reacts--kinds of bodies//
w.personalized problem--medical
w.personalized problem--one solution may not work for another person//
w.personalized problem--personal preference
w.personalized problem--random, unexpected
w.personalized problem--rare
w.personalized problem--situational challenge
w.personalized problem--solution--it's common
```

w.personalized problem--solution--work arounds
w.personalized problem--tangled multiples//
w.personalized problem--task specific challenge
w.personalized problem--unanswered--no experience
w.personalized problem--unique profile//
w.personalized strategy--helping to find personalized solution
w.personalized strategy--modification
w.personalized strategy--resolved strategy//
w.personalized strategy--what works best for them
w.personalized strategy--you have to find your own--start from mimicking//
w.personalized strategy--you have to find your own//
w.varying privacy

## Code list: Interviews with dLife.com participants

#### Code-Filter: All

\_\_\_\_\_

HU: diabetes\_forum\_interview

File: (C:\Users\Jina\Documents\diabetes\diabetes\_forum\_interview.hpr5)

Edited by: Super

Date/Time: 02/23/2011 05:20:09 PM

being poor affecting diabetes practice

connecting with members--bringing out beyond diabetes

connecting with members--similar age

connecting with members--those who you listen to and those who you don't

design implication--interface changes social interaction

doctors--explained well

doctors--he doesn't know

doctors--how doctors made her

doctors--not compassionate

doctors--not much choice to choose in a small town

doctors--not understanding how my body reacts

doctors--sharing information they received from the doctors

doctors--too little information

doctors -- what he doesn't agree with the doctor

doctors--won't take uninsured patients

forums differ--culture of participation

forums differ--how forums get picked

forums differ -- in accountability

forums differ--participation one is taking

hard questions to answer--having no experience

hard questions to answer--inappropriate topic

hard questions to answer--not well understood by the majority

hard questions to answer--too specialized

hard questions to answer--type 1 vs type 2

information aggregation--accidental finding

information aggregation--active collection

information aggregation--have go-to sites

information artifact--videos

information gap in doctors--doesn't tell you that

information gap in doctors--experience answers

information gap in doctors--little things

liability in forums--I am doing fine in my numbers without dietitians

main members versus lurkers--possible difference in opinion

medical--personal diagnosis

members--a nursing student

members--role--expertise

members--role--help people active

members--role--humorous

members--role--well researched

members--to avoid--fight inducing

operationalization -- artifact used as boundary objects with which they can discuss with other people

operationalization--documenting critical incidences

operationalization--grounding professional information into daily practices

operationalization--modified strategies

operationalization--operationalized strategy

operationalization--patient profile contextualizing diabetes situation

operationalization--practice

operationalization--pushing recapped information to others

participation -- changes over time with learning curve

participation--clearer memberships

participation--knowing fight inducing members

patient challenge--not knowing until going through

patient challenges--everyday challenges

patient segregation--can't be put into boxes

patient segregation--life style differences (email vs phone)

patient segregation--type 1 vs type 2

personal belief for appropriate help

personalized--can't relate

personalized--finding personalized strategy--experiments and iterations

personalized--nearly all answers are like that

personalized--need information that is related to me

personalized--our bodies are different

personalized--patient profile

personalized--personal beliefs

personalized--personal preferences

personalized--personalized strategy

personalized--rare

personalized--strategies that work for me

personalized--understanding one's body

role of support groups--can't participate because it's type 2

role of support groups--not helpful

role of support groups--supportive people

role of support groups--too shy to participate

role of the forum--accountability

role of the forum--bridging professional articles

role of the forum--confirm knowledge with others

role of the forum--exchanging real life experiences

role of the forum--for tight control

role of the forum--gain knowledge for handling things better

role of the forum--giving help helps

role of the forum--knowing people that are out there

role of the forum--place to share concerns

role of the forum--rapport is a basis for beyond Q&A help

role of the forum--right combination of knowledge and emotional support

role of the forum--unknown problems surface

role of the forum--vent

satisfying

self-diagnosis

signalled participation--ongoing problems

signalled participation--personal beliefs driven participation

trajectory--adding layers to the understanding

trajectory--being diagnosed

trajectory--being updated

trajectory--changes in determination

trajectory--changes in regimes

trajectory--changes in the past

trajectory--collaging

trajectory--continuous searching for the magic answers

trajectory--critical incidences

trajectory--critical incidences--lessons learned

trajectory--diversity helps

trajectory--emotion management

trajectory--future plan

trajectory--gaining control over time

trajectory--helps to be informed (not having a set of questions)

trajectory--lingering questions

trajectory--others become the reminder

trajectory--prepare for changes

trajectory--sharing what you've gone through

trajectory--shifting from asking to advising

trajectory--stage--diagnosis

trajectory--stage--settled with strategies

trajectory--unrelated

trajectory--unsolved mysteries

trajectory--wanting to know commonality of a problem

trajectory--warnings

trajectory of forum use--come and go

unanswered question

values--getting off of meds as much as possible

what draws participation--conversational not factual

what draws participation--looking for places I can give input

what draws participation -- not the same questions over and over again

what makes a forum successful--active participation

what makes a forum successful--interface what makes a forum successful--making friends what makes a forum successful--whether there are advertisements

#### **Code list: Field observation**

#### Code-Filter: All

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HU: diabetes\_f2f\_field

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advices--alternatives

agenda

agenda--activity

agenda--activity--collective mini experiments

agenda--collaborative decision of speakers

agenda--conversation themes

agenda--for next time, preparation

agenda--invitation of experts

alternative medicine

challenge--finding people with matching beliefs

challenges--information taken only for those relevant

challenges--not enough people

challenges--trying her head out of sand

challenges--unable to carry out plans throughout the month

collaging--bringing in information from other resources

collaging--collecting information about an event, object

collaging--inserting warnings

collaging--understanding individual differences

collaging--what's going to happen over time

communication--multiple threads concurrently

connecting patients

design idea--collective gathering of error rates

different from forums

different from forums--automatic filtering of similar patients

different from forums--can demonstrate

different from forums--face to face

different from forums--how conversations are structured

different from forums--leader roles are centralized

different from forums--little issues

different from forums--number of members

different from forums--selective information per week

educating--critiquing

educating--empowerment

educating--filling in

educating--learning by seeing how others get tailored strategies

educating--reinforcing

educating--rethinking concepts

educating--strategies

educating--through hearing others' questions

educating--through quizes

educating--through scenarios

experience--samples

experience--show and tell

experience--tasting recipes

experiential knowledge

experiential knowledge--critical incident

experiential knowledge--experiences of a symptom or complication

experiential knowledge--learned over time

experiential knowledge--location-based

experiential knowledge--medication experience

experiential knowledge--new information

experiential knowledge--personal experiments

experiential knowledge--testimonies

gaging what's severe

highlighting important information

how well one's doing--I do well

how well one's doing--using falling off the wagon as a humor

hybrid--medical professional who is diabetic

introduction--names

introduction--patient profile update

knowing who are in the group

laymen knowledge

me too

members--characteristics

members--expertise

members--new comers

members--successful one

members--value

members--who knows what they are doing

object that coordinates conversations

operationalize--a strategy

operationalize--a strategy that needs to be inferred

operationalize--collective strategy building

operationalize--dealing with store, institutions, insurance, etc

operationalize--everyday strategies

operationalize--gathering practical resources

operationalize--gathering strategies

operationalize--how to operationalize

operationalize--information resources, an artifact

operationalize--magic answer

operationalize--most people...

operationalize--patient profiles as knowledge

operationalize--rules refined over time

operationalize--situate in everyday setting

operationalize--standards

operationalize--translating to laymen way of executing practices

operationalize--what to do

operationalize--workarounds

participation--selected people talk

participation--who participates

personalized--circumstances

personalized--individual differences

personalized--medical

personalized--personal preferences

personalized--rare

piping in information

```
piping in information--added comments
piping in information--clarification
piping in information--suggested ones
questions--beginner
questions--clarification
questions--collective gathering of problems, leading to generation of knowledge
questions--cracking the myth (is it true that...)
questions--diagnosis
questions--gray area questions
questions--magic questions to experts (operable)
questions--requiring executable answers
questions--requiring experts
questions--spontaneous questions
questions--that are not necessarily solved by medical professionals
questions--trying to understand everyday objects
questions--what to do
relationship to medical care--aligning expectations
relationship to medical care--empowered patients, not depending on the doctors
relationship to medical care--lack of information given
relationship to medical care--maximize doc visit
relationship to medical care--unsatisfied with the quality
role of experts--clarify social aspect of medical practices
role of experts--control the atmosphere
role of experts--disseminating patient cases
role of experts--encouraging and redirecting behavior
role of experts--help tailor strategy
role of experts--medical expertise behind
role of experts--redirect to clarify
role of experts--respect patients' experiential knowledge
role of experts--specialty
role of experts--starting threads to gather knowledge for
role of experts--suggested by the expert
role of experts--synthesize
role of experts--updating medical information (research)
role of support group--help individuals to manage
role of support group--help self learning
role of support groups--maintenance
social atmosphere
social atmosphere--connecting as friends
social atmosphere--considerate of new comers
social atmosphere--humor
social atmosphere--silence
standards--varying in different medical practice
standards--varying in what's high or low (relative terms) and sharing them
story line--focusing on a member's issue, and expanding conversation from there
story line--organized through relevance, rather than by topic
support group lifespan--leader leaves temporarily
support group structure--unidirectional information
trajectory--comparison
trajectory--different space
trajectory--future projection
trajectory--learning history of a member
trajectory--sharing getting over a common point
trajectory--upward comparison
uncontrolled people
validate--through negotiation
validate--through research evidence
```

### Code list: Interviews with face-to-face support group participants

**Code-Filter: All** 

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HU: diabetes\_f2f\_interview

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being aware of the members--beyond diabetes

being aware of the members--different depending on the group

being aware of the members--their problems

being aware of the members--what they do

breaking of operationalization--numbers don't mean

community trajectory--accepted strategy at the time

community trajectory--diabetes cure changes over time

community trajectory--future

connecting with people--common in terms of how one might become in the future

connecting with people--gets connected everywhere

connecting with people--having common

connecting with people--meet face to face to help

connecting with people--similar generation

design challenge--for patients to keep updated during the off times

design challenge--transforming interface to help share experiences in a constructive way

doctors--comparing with other patients

doctors--dealing with doctors

doctors--managing information from multiple doctors

doctors--not giving detailed info

doctors--not happy with doctor's decision

doctors--not really helpful

doctors--participatory medicine

doctors--relying on doctors as final measure

doctors--share patient profile with him

doctors--what's a good doctor

doctors--what's a good patient for doctors

gadgets--changing your management behavior

gadgets--need detailed help

gadgets--working to make it work for yourself

good information--combination of fact and experience

help resources--readings, lectures

help resources--the Web

hierarchy in information-experiences exchange vs new and authoritative information

information aggregation--active consumption

information aggregation--from everywhere

information aggregation--passive consumption

information artifact--books and resources

information artifact--boundary object for doctors

```
information artifact--diabetes
information artifact--evidences
information artifact--experiment results
information artifact--patient profile
knowing the members of the group--not so much
medical--answers that one believes in
medical--conflicting personal opinion
medical--conflicting with patients' sharing info
medical--experiences are from patients, but solutions are from doctors
medical--measurements and standards
medical--numbers make decisions
medical--personal interpretations of things
medical--personal measurement of things
medical--varying interpretations by different health areas
online--vast space
online communities--hard to diagnose problems
online communities--what makes a good community to go to
operationalization--breaking of op--disagreed strategy
operationalization--breaking of op--number doesn't mean
operationalization--executing operationalized knowledge from the doctors
operationalization--operationalized knowledge
operationalization--pills
patient challenge--gap between reported information vs what actually happens
patient challenge--hearing information they don't want to hear
patient challenge--how easy or safe can I get?
patient challenge--life changes
patient challenge--maintaining good behavior
patient challenge--needs to be able to criticize
patient challenge--sick and tired of counting
patient challenge--to put into action after all the information
patient challenge--what to give up and what to not give up
patient challenge--willingness to change
patient segregation
patient segregation--education about diabetes
patient segregation--patients with differing level of diabetes
patient segregation--people with different strategies (or no strategies)
patient segregation--those not coming out to the support groups
patient segregation--those using online support groups
patient segregation--type 1 versus type 2 or pump vs
patient segregation--varying philosophy towards diabetes
patient segregation--well controlled patient
personalized--background
personalized--different philosophy
personalized--doesn't work for me
personalized--finding personalized strategy
personalized--how body reacts
personalized--knowing oneself
personalized--lingering unexplainable things
personalized--medical problems
personalized--not rare, but hard to find information
personalized--personal preferences
personalized--rare problems
personalized--related information
personalized--routines
personalized--workarounds
personalized--you just have to deal with it and handle it
reliable information--doctors
```

```
reliable information--government resources
reliable information--specializing in diabetes
role of leaders--fill in the gaps
role of leaders--hybrid of patient / health professional
role of leaders--monitor and direct conversations
role of leaders--personality and role
role of leaders--policing
role of leaders--preferred
role of leaders--specialized
role of members--being analytic
role of members--characterization of the members
role of members--expertise / who to talk to
role of members--helpful--regulars
role of members--living evidence
role of members--lurkers
role of support groups--a nice addition to the main health care
role of support groups--activity--games
role of support groups--become family
role of support groups--compare and be reminded
role of support groups--compare and feel better
role of support groups--depending on the support group you learn different things
role of support groups--discover hidden knowledge
role of support groups--diverse input
role of support groups--earn additional resources to get help from
role of support groups--first-hand experience
role of support groups--giving help helps
role of support groups--good examples and bad examples
role of support groups--having somebody to talk to
role of support groups--having the access to solutions
role of support groups--how to pick support groups
role of support groups--I'm not alone
role of support groups--information presented in f2f
role of support groups--keep one on the straight and narrow road
role of support groups--learn about patients' cases
role of support groups--learn something new
role of support groups--lectures, expert information
role of support groups--people with similar experiences
role of support groups--personal experiment sharing
role of support groups--reinstate
role of support groups--sharing everyday diabetes
role of support groups--sharing what to do about it
role of support groups--sharing what worked for me
role of support groups--small shared experiments
role of support groups--small shared experiments--lack of participation
role of support groups--support
role of support groups--triggers hidden information
role of support groups--update on the new and upcoming
role of support groups--where you can collectively reflect on the information you gathered
sharing experiences--hard when personal preferences don't match
sharing experiences--learning attitude
sharing experiences--location-based
sharing experiences--not medically sound
sharing experiences--picking up tidbits
sharing experiences--products
sharing experiences--relaying experiences with no cure or real conversation
sharing experiences--we all cheat
sharing experiences--within normal conversation
```

sharing experiences online--need feedback in order to continue stuff that you need to be aware of support group culture--being honest support group culture--differences support group culture--dominating person support group culture--quiet support group structure--unidirectional support groups--not learn something new traejctory--give it 6 months trajectory--agreed good strategy

trajectory--alignment--controversy experiences

trajectory--change in belief

trajectory--coexisting patients at varying trajectories

trajectory--collaging of trajectories

trajectory--critical changes trajectory--critical incidences

trajectory--critical incidences--everyday is diabetes

trajectory--current struggles trajectory--future anticipation trajectory--future plan trajectory--help to anticipate

trajectory--history for analysis

trajectory--individual differences thus not helpful

trajectory--informed about the disease trajectory--learning individual stories

trajectory--patient profile change over time

trajectory--peer social learning

trajectory--pipe dream vs goal to hope to get into

trajectory--slow revision of one's practice

trajectory--stage--acceptance trajectory--stage--grieving trajectory--stage--gung-ho trajectory--stage--settling

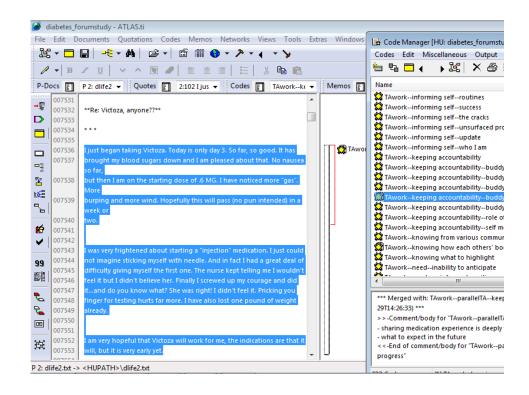
trajectory--this is what I did / this is how you get over the hump

trajectory--unknown anticipation trajectory--upward comparison trajectory--warning trajectory--wish I could've varying standards

what is severe

what makes a good support group

# A screenshot of Atlas.ti applications used for the analysis

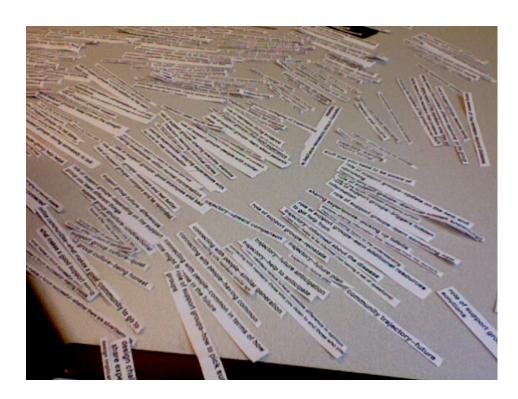


# AFFINITY DIAGRAMS FOR THE DIABETES PATIENT SUPPORT GROUPS STUDY

# Affinity diagram created for analyzing face-to-face support groups:



# Codes generated from all face-to-face support groups and dLife content analysis was aggregated together:



# Aggregated affinity diagram of all codes from dLife and face-to-face support group analysis:



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