FIT2: Information Translations for Health Practices

Elizabeth Kaziunas
School of Information
University of Michigan, Ann Arbor
Ann Arbor, MI 48109 USA
eskaziu@umich.edu

Pei-Yao Hung
School of Information
University of Michigan, Ann Arbor
Ann Arbor, MI 48109 USA
peiyaoh@umich.edu

Mark S. Ackerman
School of Information
Computer Science and Engineering
University of Michigan, Ann Arbor
Ann Arbor, MI 48109 USA
ackerm@umich.edu

Abstract
The FIT2 project is investigating how to support health practices that gain their meaning by sitting at the intersection of a multiplicity of social worlds. We present our basic theoretical framework, early requirements based on a set of field studies, and our current prototype.

Author Keywords
health, health informatics, cooperative work, social computing, community health, patients, consumers.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI):

Introduction
The FIT2 research project aims to better support people when their everyday lives are disrupted by chronic illness. To do this, we needed to understand the practices that people rely upon to manage their health.

The project incorporates both technology and social-analytic studies, focused around the following research questions:

- How is "health" incorporated or separated from the activities of people's everyday life? What do they

do to garner "health" and when are these practices separate from, in conflict with, and augmenting medically-sanctioned practices?

- Are there distinct "health practices", and if so, in what ways might they be significant? If there are multiple meanings of health practices, how can we support people more fully understand their conditions?

- If "health" practices are seen as resources in people's lives, where do they come from? Furthermore, how might health practices differ among people from a range of social contexts? How do their different social worlds reinforce, bump up against, or argue with one another in terms of these practices?

- What practices do people believe will garner them "health" besides those sanctioned, directly or indirectly, by the medical community? In particular, how do people reconcile the social world of medicine (if it is even seen as one world) with their other social worlds and with their current set of practices? If they rationalize holding what would appear to be discrepant practices (in the view of medical or health professionals), how might we help them make sense of the "messiness" of their everyday health practices?

To understand these questions, we have engaged in a number of ethnographically-based studies and constructed application prototypes. We describe one line of studies and a system prototype briefly below. First, however, we describe our analytical stance.

Background

We base our analysis and understanding in symbolic interactionism and in Social Worlds theory, mixing in a Practice Lens perspective.

Social Worlds. In symbolic interactionist terms, people live in "social worlds" [6]. While Strauss is the person credited with "social worlds" as a conceptual construction, other second-generation Chicago School sociologists such as Howard Becker used similar constructions. The concept was present in even parts of the so-called first Chicago School with Parks' students, such as Cressey with his Taxi Dance Hall [2] and with Hughes' studies of work [3].

Because Chicago School micro-sociologists do not follow a strict distinction between process and structure, in the words of Becker:

> *Symbolic interactionists typically find that meaning is constructed in the process of interaction, and have always insisted that process is not a neutral medium in which social forces play out their game, but the actual stuff of social organization and social forces.... ([2], pp. 3-6)*

People's actions in a social world, then, closely follow the definition of a practice. They are bound to the meaning created in the moment, contextualized by the apparent actions of others. The actions cannot be separated, except analytically, from their contexts, which are the social worlds and the interaction. Thus, a social world has many of the same characteristics of Bourdieu's habitus.

People, of course, live in many social worlds simultaneously. Moreover, social worlds can share many overlapping characteristics; social world theory has the concepts of "subworlds" and "arenas" to provide a language for talking about the overlaps and distinctions.

Practice lens. Symbolic interactionism, while it examines human action at a micro-scale level and assumes that people's meanings are enacted in social interaction, has no construct for action-in-context. On the other hand, a Practice Lens perspective [5] focuses on action-in-context, but has no strong construct for context boundaries. We combine the two in our perspective. We follow others in the CSCW community, where there has been a growing interest in practice. Attention to practices can be found in a number of recent CSCW publications including research frameworks (e.g. [8]) and empirical work ([7]). Underpinning our work is a sense that practices are inherently social and represent collective patterns of action bound up within a range of contexts (i.e., social worlds), thus creating a useful framing for health practices that gain their meaning by sitting at the intersection of a multiplicity of social worlds.

Practices in Flint

We came to our theoretical perspective based on one of our ethnographically-based studies examining people living with chronic illnesses in Flint, Michigan, a largely impoverished community. In this study we conducted interviews with people living with diabetes, hypertension, and/or kidney disease, as well as conducted four focus groups with a variety of local health professionals (described in [4]). (While we talk below of 'patients' and 'consumers,' everything applies to the information needs of caregivers as well.)

One of these focus groups invited local diabetes educators (specially trained nurses and dieticians) to share their experiences regarding working with people living with these health conditions in Flint. Our findings showed there were a number of local contextual issues that impacted people's health management practices, including food preparation, exercise routines, and medication regimens.

A second study followed up with semi-structured interviews among seven diabetes educators, which used an early FIT prototype (below) as a design probe to unpack the design space around supporting health practices. We were particularly interested in localizing health information (presented in the form of short video clips) with the goal of contextualizing health practices. The design probe study in Flint revealed a number of insights, including:

- The importance of connecting patients to reputable national health resources and local resources. The health educators pointed out the importance or their patients:

  "National resources [e.g. American Diabetes Association], the content of those is what we're teaching. So those are respectable; those are the best resources in my opinion...You're probably better off pulling YouTube videos and then tailoring these little lists and pathways to the local [P-01]

and

"I often recommend Diabetes.org. Its the American Diabetes Association website and everything on there is going to be evidence-based research recommendations." [P-06]

- Strategies for integrating trusted health information from a variety of social worlds, such as local faith based communities. In Flint, in particular, churches are very important and central in people's lives. The diabetes educators focused on the patients' church-centered social worlds:

  "And with the community experts, I like that the pastors are there. Maybe there is a list of pastors in the community who they can refer to and maybe what their contact information is, or ways to email them or contact them. Because they do a lot in this community and people rely heavily on their faith and religion and their church. They're big support systems for them." [P-03]

- An overwhelmingly positive view of the accessibility of video as medium to reach low-literacy populations, as well as particular demographics. The health educators noted:

  "I love video. I think for this population [e.g. Flint] it it's really effective... It doesn't require reading." [P-01]

  The educators also stated that video was more appropriate for younger patients, and that video was less daunting:

  "I think videos that show people of the community... is important….Movies are, I think, not threatening. So the video content I think is good" [P-02]

- The necessity of "action steps" or practices that are generated for and by the local community. Helping people determine their next actions a is critical, according to the health educators:

  [Doctors] are trained to say, "This is the problem. This is the solution." And the part they leave out is how do you make that happen in somebody's life." [P-06]

- It is also critical to tailor and localizing the action plan to the patients' social context(s):

  "We tailor our stuff and our education and our support based on what we have in this area, so we can give ideas and insight as to where to find resources in the county. And maybe that's not needed in some other areas." [P-03]

  and

  "Food was a scarce resource in Flint. And then sometimes I'd even learn from the patients coming in, sometimes they knew the system better than I did or the dietician" [P-07]

Overall, the health educators pointed out the usefulness of incorporating *some* community voices:

The dynamic I see between participants [in group classes] is that sometimes it will be a person who

has had diabetes for a long time...and that person with experience will kind of reach out and take them [new diabetics] under their wing. "Oh, have you tried this? Have you had this new breakfast cereal? Or tried exercising at your lunch break at work?" And I think it makes it more real to the participants when it's another person living with diabetes who's saying, "I struggled with that too. I didn't have time for exercise, but this is how I did it." [P-06]

A central challenge is to understand how and under what circumstances clinicians feel comfortable giving a voice to community members, while at the same time, preserving autonomy and some control for the community members. We are actively exploring this question in our FIT2 prototype.

FIT2

Based on these understandings, we designed FIT2. It is based roughly on the design of our FIT1 prototype, but FIT1's goal was to support a patient's understanding of his medical test results; FIT2 is more focused on enabling patients' and caregivers' coping practices. In FIT2, we redesigned the application to provide different views that highlight the perspectives and knowledge within different social worlds, i.e. groups of people around the patients, so that patients could see different practices within their everyday social contexts. Potentially, they could more easily find and incorporate the ones they feel would be beneficial. As with FIT, FIT2 is video-based. As was found in the Flint educator study, video is more appropriate not only for illiterate people but also relatively young people.

For FIT2, we felt that information providers might include family members, relatives, community members, religious groups, local health personnel, and health professionals. Each would speak as part of their own social world(s). These people might contribute videos, and a number of videos are generally available. As people use FIT2, they might also find that they have comments on practices shown on the platform or that their own practices could augment existing ones on the platform. They can then add videos or record video themselves to attach their practice or knowledge to 'translate' the existing practice into a (more) contextualized practice. The videos, over time, would become less general-purpose information and more contextualized. Other people with similar social contexts (e.g., diabetes patients seeking healthy food in Flint area, who has access to local church resources) can then learn to cope with their own health issues within their social worlds.

Scenario and prototype design

Jerry, a 30-year-old new father, lives in the Flint area in Michigan. He just got diagnosed with Type II diabetes and is trying to figure out what he should do for himself. His diabetes educator, Daphne, thinks sending him to the Internet would be problematic. There may be just too much text and too much jargon for his taste, but more importantly, there is too much wrong information out there. She gives him FIT2, instead, loaded onto an inexpensive tablet. She also preloaded a set of potential videos for him to view, as well as a path through them.

Upon opening the app, Jerry sees several health issues that he has: diabetes, hypertension, and general fitness. He chooses diabetes and is presented with a

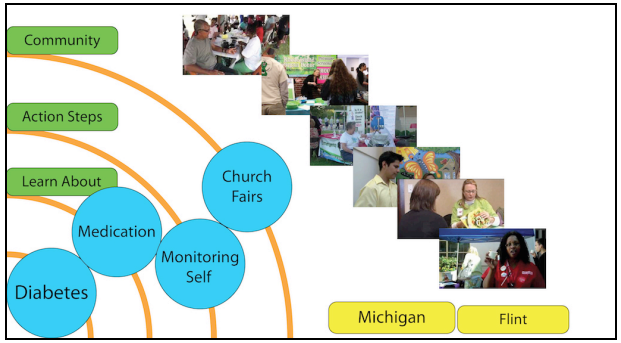

Figure 1: FIT2's navigation will guide users from health issues (e.g., diabetes) to action steps (e.g., Monitoring Self) while providing a social worlds perspective (e.g., Church Fairs) with videos. Our plan is to have FIT2 use location detection on mobile devices to automatically set where users are currently located, making the browsing experience more localized.

graphical prompt "Learn about …', along with several options surrounding the prompt: medication, nutrition, symptoms, and so on. (In subsequent versions, we will use video icons to supplement the text.) Jerry is concerned that the medicine he's been prescribed might affect his exercise, so he chooses medication. After he chooses, another prompt shows up, "Action Step", that will translate his information need into actionable goals. The prompt has the options Monitoring Self, the Usual Meds, Using an Insulin Pump, and so on. Because Jerry is trying to avoid medication, and thinks he may be able to control his blood glucose levels with diet and exercise, Jerry selects Monitoring Self, after which he is presented with several social contexts, including various churches, his Church Health Fair, community health groups, and so on. As a regular attendant of a local church, Seventh Avenue Baptist, Jerry looks to find some information and help he can obtain from people who he trusts because they are affiliated with the same church.

After he selects the 'Church Fair' option, FIT2 shows him several sequences of videos in thumbnail form. In these videos, people from within a social world talk about their experiences or their views about getting health guidance at a church-based health fair, as shown in Figure 1's wireframe. He is particularly interested in finding out whether his church can give him A1C and Serum Creatinine tests, so he doesn't have to pay for a clinic visit. Jerry clicks on one of the thumbnails, and FIT2 presents video sequences for him.

Some of the sequences have videos added by other users of FIT2. After watching the first video sequence, Jerry sees that the last video is added by another user to document her opinion of what she has learned at his church health fair so to attach more localized perspectives to the original three videos that are general knowledge. Jerry decides to explore more.

Current implementation and future plans

FIT2 is being developed as a mobile application using Adobe Flex. It currently consists of approximately 2000 lines of code, and can be run on an Amazon Kindle Fire and other devices that support Adobe AIR. FIT2 is currently available in prototype form, and has been redesigned to provide the ability to: (1) add videos, (2) comment, in the form of videos, on video clips, (3) share video clips with friends, family, and communities (e.g., church members), and (4) annotate, either explicitly or implicitly, clips.

We are currently designing several other views to examine the usefulness of highlighting a variety of perspectives for users about the different practices available. For example, a 'people' view will guide users, by highlighting the practices suggested by people in specific social worlds, such as health professionals, community health experts, people with similar health issues, or even family members.

We are currently examining the usefulness of a tool like FIT2 for caregivers of pediatric bone marrow transplant (BMT) patients. With pediatric BMT, caregivers have more limited information needs, but need to review recommended procedures and to understand what may be coming emotionally. Both are well suited for video. We are also exploring FIT2's usefulness in depression management. Once the work on FIT2 has advanced, we plan to test the application with users.

References

1. Becker, Howard S., and Michal M. McCall, eds. *Symbolic interaction and cultural studies*. University of Chicago Press, 2009.

2. Cressey, Paul Goalby. *The taxi-dance hall: A sociological study in commercialized recreation and city life*. University of Chicago Press, 2008.

3. Hughes, Everett Cherrington. *Men and their work*. Glencoe, IL: Free Press, 1958.

4. Kaziunas, Elizabeth, Mark S. Ackerman, and Tiffany CE Veinot. "Localizing chronic disease management: Information work and health translations." *Proceedings of the American Society for Information Science and Technology,* 50 (1), (2013): 1-10.

5. Schatzki, Theodore R., Karin Knorr-Cetina, and Eike von Savigny, eds. *The practice turn in contemporary theory*. Psychology Press, 2001.

6. Strauss, Anselm Leonard. *Continual permutations of action*. AldineTransaction, 2008.

7. Tixier, Matthieu, Gérald Gaglio, and Myriam Lewkowicz. "Translating social support practices into online services for family caregivers." In *Proceedings of the ACM 2009 international conference on Supporting group work*, pp. 71-80. ACM, 2009.

8. Wulf, Volker, Markus Rohde, Volkmar Pipek, and Gunnar Stevens. "Engaging with practices: design case studies as a research framework in CSCW." In*Proceedings of the ACM 2011 conference on Computer supported cooperative work*, pp. 505-512. ACM, 2011.