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## **Designing Information to Facilitate Chronic Disease Management**

### **Clinician–Patient Interactions in Diabetes Care**

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One of the major trends in treating chronic disease is to provide people with the information necessary for keeping their conditions under control and enabling them to self-manage their diseases as much as possible. This is widely thought to be the most cost-effective, self-empowering treatment strategy for better outcomes and adherence. Patients with diabetes, who often struggle with their disease throughout their lives, form an excellent group through which to examine the issues in this current emphasis on disseminating information in chronic disease management. Anecdotally and in research findings, diabetes clinicians find that, as good as their communication of information for self-management might be,, in at least 40% of the cases, changes do not “stick” (Yong et al., 2002). For example, patients’ glycosylated hemoglobin levels (HbA<sub>1c</sub>) often decrease as a result of increased knowledge about diabetes and behaviors to manage it, but 6

months later many patients' levels creep up again. Even when patients are well informed about the causes of diabetic conditions and the positive consequences of self-care behaviors, and even when patients demonstrate an understanding, long-term self-management and motivation wane. What can we do to create information and communicative exchanges that work?

Information technologies are often assumed to be a prime solution. They are able to widely disseminate necessary information for managing diabetes, tailor it to user profiles, and alert patients. Specifically, educational, informational, and self-management Web sites as well as virtual clinics, advanced monitoring technologies, patient access to electronic health records, and online support groups all have been touted as necessarily leading to improved self-management (Toscos and Connelly, chapter 10, this volume; Anderson and Klemm, 2008; Armstrong and Powell, 2008; Armstrong et al., 2007; Bu et al., 2007; Cox et al., 2008; Eysenbach et al., 2004; Kroeze et al., 2008; Ralston et al., 2004; Strecher, 2007). We see the situation as more complex and problematic. Patients with diabetes face the information offered by such systems in an already overwhelming problem space. The information expands their factual repertoire, but it may not add to the patients's larger aim of dealing with their chronic condition based on their distinct needs and beliefs, acceptable trade-offs, lifestyles, fears, and priorities. It is commonly understood that for these aims information must be

personalized. But even with personalized information, patients have to integrate it into their lives to make difficult choices about self-management, lifestyle, and quality of life. Amid the uncertainty, ambiguity, and often contradictory demands from comorbidities, patients must struggle to determine which behaviors they should try to achieve immediately and in the long term. They need to consider not only “facts” but also complex causal relationships and the implications of their actions physiologically, psychologically, and socially.

In this chapter, we argue for the need to better understand how to design information that can enhance patients’ understanding of their diabetes *in relation to* potential complications, treatments, and socially situated behavior. On the one hand, health informatics specialists need to support patients with diabetes in easily receiving information that they need for greater knowledge and self-management. On the other hand, specialists need to ensure that information transfer and communication strategies support patients in contextualizing information into actions and rationales appropriate for their lives. A great deal of research in health information systems addresses the first goal—information delivery and reception—but much about the second goal is a black box. Little is known in health informatics about the communication strategies, content choices, and strategic framings that facilitate and foster the transformations of information into personal habits and knowledge that “stick.” It is well established in the research

that communications and interaction styles between patients and caregivers strongly affect patients' success in managing their diabetes (Zoffman & Kirkevold, 2005). However, optimal communications and interaction styles are difficult because individuals have nuanced and differing responses to interventions. Patients perceive and evaluate information provision differently, and their responses to such distinct interaction styles, as coaching, participatory problem solving, presentations of options by caregivers, and education for compliance, vary widely. Variance is tied to complex interacting factors—sociodemographic and health variables, cognition and learning styles, and the nature of the interpersonal relationships (Heisler et al., 2002; Montori et al., 2002; Whittemore et al., 2005). In fact, at present, convincing evidence of effectiveness in achieving optimal communications is missing (Kopp et al., 2002; Strecher, 2007). As Strecher (2007) emphasizes, “Internet-based health programming is still in its infancy... [and] one of the most egregious sins of this field has been to generalize Internet-based programs into one class of intervention” (p. 69).

The design of health information systems for information transfer that can foster sustainable self-care amid this variability often turns toward user-centered interactive health communications, tailored education, and expert counseling systems. But for any of these promising approaches, we argue that a fundamental step is to open the black box of “personalization.” Personalizing for diabetes or

any chronic disease is a complex problem. Health informatics specialists must understand and design for the actual ways in which information functionally behaves for particular groups of patients who seek to assimilate it and turn it into positive self-care actions. Toward this end—establishing a better understanding of the content, interactive framing, and resulting transformation of medical and personalized information—we studied the information needs and communication modes of a group of diabetes patients. Our findings provide important criteria on which e-health systems designs and evaluations should be based.

For a year, we observed and analyzed monthly group meetings in a diabetes outpatient clinic in a large research hospital. This group of diabetes patients was brought together and led by a particularly dedicated and gifted care manager, a nurse practitioner, and Certified Diabetes Educator with 4 years of experience writing curricula and team-teaching diabetes self-management classes. The care manager saw a need for a level of engagement beyond one-on-one help (which was becoming prohibitively expensive for the clinic to run) that was more tailored than predefined information dissemination via clinic-sponsored classes or booklets and electronic sources (which did not solve all problems that patients had). To fill this gap, she offered monthly group meetings to a hand-picked set of long-time patients with diabetes who were among her most motivated and knowledgeable patients; even they, she recognized, had trouble “staying on the

wagon.” Her goal was to help them personalize and act on information advantageously for their needs. This group was mixed in age, gender, and nationality; all had health insurance or were employed.

Through studying this particularly engaged and motivated group of patients, we have been able to delineate critical problems that even engaged and motivated people trying to take care of their disease necessarily face and issues regarding information transfer that “sticks” even after clearing the “hurdle” of motivating people. In the following, we detail the kinds of communication exchanges and uses of information in this group. However, first we present a literature review concerning potential treatment approaches, followed by a description of our site, data collection, and data analysis. We follow that with our detailed findings, and then we conclude with design implications.

## **Literature Review—Treatment Approaches**

Several health and medical research themes are relevant to our study. They are often overlapping, but occasionally colliding. We cannot completely survey these research themes; we concentrate on an overview of potential treatment approaches instead.

Clearly patients need help for them to successfully manage any chronic disease, diabetes being an important one. In traditional doctor–patient care

(described historically and critically in Callahan & Berrios, 2005), a doctor, or someone under a doctor's authority, prescribes treatment, and the patient attempts to adhere to that treatment. Appropriately, this is often termed a compliance approach (or sometimes the compliance regime). This treatment approach emphasizes a one-way information transfer. In one variant, there is actually little information transfer—the patient knows what the doctor says to do. In other variants, education or other structured information may be provided.

For a number of reasons, the compliance approach has been supplanted. For chronic care, this approach is too costly because it depends on trained personnel. In any case, the emphasis on compliance hides much what actually occurs with chronic care (as detailed in Charmaz, 1994). A number of studies have shown how patients exceed prescribed treatments to self-direct and manage their chronic illness for a greater quality of life. What we term the *chronic disease management approach* emerged in health care as a means to emphasize self-management along with compliance, primarily emphasizing inculcating both in a patient through education. In one variant, it is assumed that if patients are given the right information, they will understand their disease, be self-empowered, and self-manage important aspects of their disease. Patients must take ownership of their disease and understand appropriate management and treatments. In another variant, a clinical care manager who specializes in a disease serves as an

intermediary between patients and their doctors. Care managers keep in regular contact with patients, help them solve problems in managing their disease and in navigating the health care system, and attempt to educate them for greater self-management. Random control trials in diabetes care management show that this approach to care, compared with traditional care as usual, results in better patient outcomes and greater patient satisfaction (Bodenheimer, 2003; Wagner et al., 2001; Williams et al., 2004). Again, the information transfer tends to be one way, although there is some personalization and contextualization by the care manager. This may be a downside of care management (which we emphasize in this chapter)—gains often lapse once patients no longer receive care management and self-management education. Insights from education and an application of these insights to self-management techniques and behaviors do not seem to stick.

This problem in chronic disease management of long-term adherence has generated several potential solutions. Two relevant to this study include, respectively, (a) dissemination of important medical data back to the patients through health informatics systems, and (b) an adult-learning, community-of-peers approach to education for self-management. Each of these solutions has its own literature, often with variant emphases and research questions. In health informatics, one emphasis is making large amounts of often heterogeneous data available and intelligible to patients so that patients can make more informed



decisions. In diabetes, relevant technologies include monitoring applications and sensors that capture and deliver back to patients information on their diets, glucose levels, or blood sugar trends so that patients increase their awareness of interrelated behaviors and outcomes and improve decision making accordingly (Bu et al., 2007; Piette, 2007; Zrebiec, 2005). Many studies in health informatics examine the usefulness and usability of such applications and propose means to overcome the operational complexities that diminish usability and designs for improved usefulness (Mamykina et al., 2006).

In adult learning approaches, the emphasis is on communication exchange among peers (patients with like conditions), sometimes with knowledgeable specialists, in areas related to the patients' disease and conditions (Fisher et al 2007). The goals are to deliver information in frameworks, modes (stories, examples, arguments, cause–effect explanations, factual explications, visual illustrations) and language that resonate with patients' needs and ways of knowing. In this way, patients can construct and internalize new knowledge and knowledge structures relevant to their situations and apply this learning to their choices and beliefs. Group visits exemplify this adult learning approach in diabetes and have improved patients' concordance with core diabetes self-care behaviors, metabolic control, psychosocial adjustment, quality-of-life modifications, and problem-solving abilities (Trento et al., 2001, 2004).

Relatively little emphasis has been given in the research literature to why patients find it so hard to stay with their self-management, understand the information they have been provided, and manage the tensions in adherence. The study presented here attempts to address this lack of empirical studies, particularly for these issues.

### **Site, Data Collection, and Data**

As mentioned, we report here on an empirically based field study of a single group of patients in the diabetes outpatient clinic of a large research hospital. Our goal here is not statistical generalizability but the recognition of important issues in patients' lives and their care. Therefore, we aim at theoretical generalizability (Strauss & Corbin, 1998), and the examination of such a group is not only appropriate but also desired.

The group was convened in 2005 and met monthly for a year. It was begun by a care manager, a senior nurse in an outpatient diabetes clinic whose job was to help patients one on one. She found herself becoming overwhelmed by her caseload while imultaneously internal finances argued against enough care for some. She decided to adapt the group visit methodology and offer to a group of patients a mix of education, support, problem-solving dialogs, and self-management training. The care manager hoped to continue helping her patients on

an ongoing, sufficient basis but also to reduce the time involved for any given patient. She was also able to include patients with minimal insurance and provide them with a floor of care.

She offered this group to a small number of her patients. Those who responded were long-term diabetes patients often with complicated histories. As such, they knew the basics of treatment—in fact, they were uniformly highly motivated and often highly educated. (The one exception was a patient in his early 20s who was still struggling with his acknowledgment of his disease. Even he, however, was highly educated about the disease.) These diabetics often had issues and questions that were beyond those of newly diagnosed patients. In fact, many had one form of the disease for more than 20 years, and most were middle-age fathers or mothers. As such, these people may not be “typical” diabetics, but for the purposes of our examination, they highlight information issues that are often typical but not always expressed. What this group lacked, as is seen in the following data, was an understanding of how to tie information together, to make sense of which information was pertinent and to be believed, and how to act in the face of conflicting or ambiguous information (including symptoms).

The group met once a month at the outpatient clinic in the evenings. The patients were aware of the researchers and gave consent. (In fact, there was no way to hide the two researchers scribbling notes on the side of the small room.)

The collected data were primarily field notes, although some amount of archival information was gathered as well.

We carefully examined our field data. We followed standard qualitative techniques in our analysis (Miles & Huberman, 1994; Strauss & Corbin, 1998), primarily searching for themes relating to information dissemination and use as well as care management. The analysis was informed by continued conversations with the care manager. In addition, this was part of a larger study on diabetes and depression care management, ongoing for 4 years now, and that larger study also informed our analysis here.

In our analysis, we abstracted common discussion events (episodes of information exchange). We attempted to understand the participants' understanding and their contexts through their discussions. Therefore, our analysis did not focus on separating discourse content into low-level sociolinguistic structures or code for subject matter topics. Rather we looked at participants' exchanges for insights into how information is personalized, especially with intention to act. Through their communicative and information exchanges, we looked at participants' expressed perceptions of the world they inhabit as diabetics and the psychosocial and medical contexts shaping their potential for better care and self-care.

We followed a dual theoretical stance in the analysis. Our analysis is based on discourse analysis (Cresswell, 2003; Roberts & Sarangi, 2005) and social interactionism (Strauss, 1991, 1993). A microsociological stance suggests that social interactions, including medical interactions, are formed in context—that what people believe to be the situation is, in large part, the actual situation for them. Social interactionists have been instrumental in viewing diseases, medical environments, and clinical interactions from the viewpoint of patients, as well as clinicians and other medical personnel.

As such, we note that the specifics of any given information exchange was almost always overlaid in multiple dimensions of conversation, and the categorizations described next are distinguished analytically rather than in practice. For example, one day's conversation found a participant asking others briefly about a new product:

It's supposed to keep you from wanting sweets. I got it on a newsletter. I don't know how it works. It seems interesting, but I don't know, what do you think?

In this simple conversational turn, the participant asks for help. It appears straightforward: she has seen an announcement but cannot verify its efficacy. Therefore, she asks other group members for their thoughts. At one level, this was simple information exchange, the kind one sees in everyday conversation as well

as online forums—had anyone used this product? At the same time in the same conversational turn (through the ambiguity of her language), the participant was also asking whether people had a way to think about these kinds of products. Would they in general work? What was a general model for thinking about this kind of product? Indeed, she may have even been asking whether such a product was possible.

There were other layers to that conversation as well. At the same time, the participant was telling the other group members that there were online and e-mail newsletters for patients with diabetes and that they too could get additional sources of information to monitor. Perhaps most important, the participant was likely soliciting emotional support: The craving for sweets was difficult to manage, and others must have understood, if not shared, that feeling.

This episode shows some of the inherent ambiguity and superimposition in everyday conversation. Shared understandings are partial, conversational goals are negotiated, and social activity and communication are a process rather than a simple outcome. Accordingly, although we focus here on information exchange, we must necessarily include support, action, and specific context as important considerations in our discussion.

## Findings

Before we describe the information use and communication exchanges that distinguished these participants, we must acknowledge that much of what we observed could be described as “straightforward” information transfer. By this, we mean information transmitted from a clinician to a patient, with the patient accepting the material rather passively. This occurred frequently, as might be expected. For example, one of the goals of the group was to provide advanced education about diabetes, and accordingly, we saw the straightforward transfer of educational material. For example, the care manager spent approximately 30 minutes speaking about exercise and its importance. She went through aerobic and anaerobic exercise, for example, saying:

[CM] If you're training to do anaerobic exercise, and you're not doing exercise yet, it takes about 2 weeks [to get the effect]. That's not a lot, they take 10 days to change over on car assembly lines, they shut down the factory for the change-over. It's about the same.

She continued with a discussion of how the body changes in those 2 weeks and why this was important for patients with diabetes. The group sat fairly silently during the presentation. Afterward, however, there was a lively discussion, some

of which is described next, as the group attempted to fit the information to their own situations.

However, we also observed how traditional information delivery to provide “factoids” of interest and guidelines to apply to expectations and behaviors is insufficient in generating motivated and sustained self-care intentions and actions. Group members’ comments on the difficulty of staying motivated and obstacles they encounter attest to needs that are deeper than “objective” information alone can satisfy:

Why can’t I get myself motivated now? In the past, something caused it to happen, but now I’m out of reasons.

It can be a full-time job. I could stay home every day and just manage my health care [Others nod]

I have to convince myself. Don’t you have to do that every day? Wake up and say, “I have to control myself.”

Therefore, aside from the “straightforward” information transfer we observed, we found five important types of contextualized and personalized information transfer—or rather communication. We believe these types to be critical in patients’ ability to self-manage their disease over time. Patients were looking to understand diabetes, its manifestations, and its potential trajectories as embodied in their own situations and literally in their own bodies. This contextualized and



personalized information exchange, then, served important “glue” functions in the lives of these patients and important grounding for self-care attitudes, strategies, and behaviors. That this was not the “straightforward” information transfer was obvious—the patients came alive. They were animated and excited in their tone, engaged in back and forth with the clinician (and other guest speakers), as well as in mutual conversation. We describe each of these critical types of contextualized and personalized information transfer in turn.

Then beyond the “straightforward” information exchange were:

- speaking to everyday complexities of the patient’s diabetes and comorbidities, as well as the ambiguities in those conditions;
- obtaining the necessary levers to construct sufficient mental models to weigh those complexities and potential actions;
- verifying their understanding of their conditions, especially when the understanding was formed through self-directed research and study;
- contextualizing their understandings, especially for sociofamilial and medical settings; and
- learning how to learn about what they would actually be able to do for self-management.

We discuss each in turn.

## Speaking to Everyday Complexities

Clinicians, especially in specialty settings, often provide information as if it were obvious but it is not. However, a patient's situation is often ambiguous and complex, especially as his or her disease progresses. Diabetes with its comorbidities, along with their innumerable manifestations and symptoms, is inherently complex to a patient (Charmaz, 1994). Patients in this group, despite being motivated and intelligent, often did not understand the complexities of their situation or many ambiguities. Other patients might not even understand that their conditions are inherently complex and ambiguous.

In the observed exchanges, various clinical specialists continuously oriented patients to conceive of their health-related symptoms or experiences from a systems perspective. For example, a guest speaker who was an exercise physiologist covered effects of exercise and indicators of potential problems for patients with diabetes by taking a systems view and integrating cellular-to-symptom dynamics. She tied the ways in which mitochondria burn fat and sugar to larger physiological dynamics of burning fat when oxygen is present (aerobic exercise) and burning sugar if it is not (anaerobic). She related this burning of sugar to the risk of insulin reaction in anaerobic exercise due to insulin keeping sugar under control, and she brought together these micro- and macrophysiological dynamics with long-term risks such as neuropathy and

retinopathy, why they occur in physical activities the group members may commonly perform, and signals that indicate something may be going wrong.

This comprehensive micro- through macrolevel view prompted one participant to proclaim:

[Abdi] I've had stress in my muscles for 5 years and doctors never knew how to deal with it. I've seen 12 doctors about the muscle problem. No one ever thought to relate it to diabetes. I learned more here than talking to all 12 doctors.

Another patient elaborated further, revealing the effects of this systems perspective on her intentions for self-care:

[CM] If you have background retinopathy, you exercise like normal every day, then one day you decide to run a 5K [race], can that throw you into...

[Sue] My ophthalmologist never told me anything. Now I have PR and now I need laser surgery. That's the reason I'm asking!

[CM] Now, before you get started—going down the path with anything that adds pressure in your eye, you want to do it smart. Don't do power lifting all at first, say, lift 10 or 25 pounds over your head. PR can be caused by many things, exercise can make it worse.

[Sue] I didn't know to ask. I would never think to ask my eye doctor if I can do sit-ups.

[Second person] Yeah.

[Abdi] It could be lifting up a bike—or kayak on top of the car—or suitcase. I'm going to ask, I'll see what they say.

Another example of this systems view can be seen in the group's discussing the relationships between nutritional intake and cell development and survival. The clinician tied cholesterol and consumed proteins to cell wall cohesion and to amino acids that build new tissue and foster absorption of minerals and vitamins. She wove in recipes and heuristic guidelines to personalize the science so that participants would move from a single-factor view to a multifactor view that was within their control:

[CM] Once you take protein away from your GI track, it won't come back. You won't absorb minerals and vitamins and may have more perforation in the GI tract. Missing meals, fasting is very bad on the system. It's not just how much you eat. It's how much do you absorb.

Ultimately, a systems perspective seemed to offer participants an understanding of their interacting, complex issues amid the uncertainty that affected their health

and lifestyle activities. One powerful insight that participants seemed to draw was that autonomous self-care can come from asking questions that anticipate and address this complexity.

### **Obtaining the Necessary “Levers” to Construct Sufficient Mental Models**

In order for this group of patients to understand their condition, the care manager continuously needed to provide key levers to aid the patients’ understanding in critical ways. Sometimes these exchanges consisted of just a few words from the care manager, allowing a patient in this group to form a framework that could then lead to an effective mental model or a plan of action for a situation. Often the lever was nothing more than naming things in different ways, a small shift with large consequences. The clinician said:

[CM] Words like “pass” and “fail” sabotage.

[CM] I’d make recommendations. It’s changing language. I don’t have anyone “test” their blood sugar because test is a pass or fail. I use “check” or “monitor.” Or instead of pass or fail it could be “Did I achieve it partially?”

[Tim] How about “try again” instead of “don’t achieve.”

[Another group member] I like that.

Levers also included visual diagrams that patients seemed to internalize more readily than verbal explanations, descriptions, or physiological concepts. The clinician drew sketches on the board freely, for instance, illustrating how fiber works to get rid of cholesterol and how insulin works as an anti-inflammatory agent in blood vessels and implications for comorbidities between diabetes and heart disease or retinopathy. Notably, the diagrams were cartoonish rather than scientific, using such images and pictures of a “car” for transporting away cholesterol.

### **Verifying an Understanding of One’s Condition**

Another type of critical exchange allowed the patients to double check their understanding. We repeatedly observed patients, who had spent considerable time researching and coming to an understanding, questioning the care manager. A patient does not necessarily know whether his or her interpretation, especially of their own situation, is correct, and we observed patients struggling to determine whether their interpretation was correct.

[John] I'm on beta-blockers so I've got a maximum heart rate so I can't use a rate monitor, right?

[CM] Yes, you have to do with breath rate and comfort level.

[John] That's what I've read, so I should exercise until I can't still carry on a conversation?

[CM] Yes.

This patient wanted to exercise correctly and had done considerable reading about what she could do and what she should avoid. However, for her, knowing that she had a correct understanding was critical because she had a cardiac history. A misunderstanding could have led to serious problems, thereby impeding her progress toward self-management.

Comorbidities often sparked patients' needs to understand interpretations that involve trade-offs. One patient, for example, described being unsure of her own knowledge in trying to care well for both her cardiac and diabetic conditions and sought confirmation from the group.

[Patient] I went to cardio rehab and cardiac rehab people didn't know anything about diabetes. I watched my blood sugar before exercise, and they said: "The higher the better" and that's not right.

[Sue] Cardiovascular was awesome and changed my whole being, but they didn't understand diabetes. They would not let me leave until my blood sugar was 150. I felt like a 2-year-old. That's extremely hard to do.

[Patient] What it comes down to is, I can either listen to cardiology or diabetes, and there's no crossing.

### **Contextualizing Understanding, Especially for Sociofamilial and Medical Settings**

In many of their exchanges, these participants contextualized their needs based on their current understanding of their condition, as well as their specific situations and problems, and this played a big role in their discussions. One participant, for example, started a conversation by identifying his extreme fear every time he would “go low” in blood sugar in the middle of the night. Discussion followed about combined eating strategies and exercise routines that could help ward off “going low.” Another evening, extensive conversation revolved around the new food pyramid, focused on individually making sense of it by personalizing for their own habits what it might mean in their daily lives to go from counting carbs to customizing portions by grams and their composition at various levels of the food pyramid (“How do you get through the grocery?” or “If I throw away the yolk from the egg when I eat it, am I getting rid of B12—could that be contributing to my B12 deficiency?”).



One important contextualization was their sociofamilial context. As an example, around Thanksgiving, there was a discussion of holiday meals as well as the expectations and misapprehensions of family members:

[Maureen] You have to live in the real world, that's what's killing me.

[Sue] My family will just snatch that piece of pie out of my hands.

[CM] Enjoy that food. If you have a special food, eat that food. Don't eat food you can get every day. Enjoy it but in moderation.

[John] If they're asking, they're ready to accept it. They're thinking about it.

### **Exchanging Information About Medical Contexts**

Another important contextualization was medical institutions and routines. These patients exchanged considerable information trying to address and better understand how to interact with their doctors and medical institutions. This included understanding how to deal with nurses in inpatient wards (in which they would inevitably find themselves over time). The care manager began:

[CM] I get calls from patients. (In a telephone voice) I'm in the hospital room. The nurse won't leave me alone until I take 4

packets of sugar. Her blood sugar is up because of the stress level of dealing with it.

One of the patients in response concurred, framing it personally and contextually:

[Patient] I said I felt a little low [to the nurse]. She ran to get some juice, and she came back with the juice and a big gluco-gun. I said I really don't need that. She said "Are you...?" She looked really nervous. She ran in and out every 2 minutes.

Patients all too often experienced similar types of situations. Recentering such situations so as to act more autonomously was clearly a high value to many of the group members. Several members, for example, roundly encouraged another member to cease going to a doctor who was filled with discouragement and blame. This doctor told the patient, as they talked about the patient's depression after a heart attack, that he was lazy.

[several group members] [in near unison] Then you need to see another doctor.

[Vera] Anyone who wears an insulin pump and lives with 40 years of diabetes is not lazy.

[Patient] But he saved my life.

[Vera] But he's a doctor. That's his job. If he's not emotionally satisfying, you dump him.

[Maureen] He said something hurtful, and I bet you didn't let him know.

[patient] No, I didn't let him know.

[CM] The question is: "Is the doctor a partner for my health care?"

Acting autonomously with health care institutions returns to speaking of the complexities and subtle contextualizations necessary to frame the shifting or reconceiving of perspectives. In this instance, the reconception involves shifting to partnership notions of doctor–patient relationships and an unwillingness to passively accept giving up or being unfairly chastised.

### **Learning How to Learn**

For the participants in this group, knowledge and action intersected in nonobvious ways. To handle their conditions adequately, people must be trained in how to understand and reflect on knowledge and self-knowledge derived through *action*, and these participants were no exception. In organizational studies, this is termed *double-loop learning*—the learning that allows learning (Argyris & Schon, 1974). Indeed, one might consider this as *double-loop action*—learning how to act to

learn how to self-manage. Moreover, as the group members' recounting of their experiences revealed, sufficient motivation for any continued action often required them to deal with alternatives and trade-offs with sufficient self-knowledge about what alternatives were personally practical and possible. As patients' exchanges showed, one of the main aspects of self-care in diabetes—setting realistic goals—is charged with double binds, tensions, and trade-offs. Thus, setting and working toward goals provides fertile ground for double-looping learning. Information exchanges among group members focused on situations in which, implicitly, this learning how to learn occurred, as did learning how to apply knowledge to choices advantageously in order to learn. For example:

[Sue] You can change your goals. It's a conscious effort all the time. People go out to eat. They chow, they pig out, and nobody says a word. We [this person's family] went to dinner and they gave me 2 pork chops. Right away, I ask for a take-away before dinner begins. I get a carry-out. It makes you different.

[CM] One of the challenges is whatever goals [you] set brings attention to yourself.

[Sue] It makes it extremely difficult to achieve goals. I can't ever be just relaxed. No one would ever say to someone else, "Boy, are

you ever eating a lot.” But if you make conscious choices, they talk about it as a table conversation. I think people think twice about asking us out to dinner because it’s an issue.

...

[Tim] A person with diabetes is different.

[Sue] Always different. When you add complications from other chronic diseases, you’re adding exponentially.... [Given these binds] I set and achieve goals by looking at my weaknesses and truly attacking one. I don’t let the others fall off. I have an internal checklist: I’ll do this one thing and will make lifestyle changes to do this one. I personally can’t do more than one at a time. I become overwhelmed.

At some previous time, the first group member seems to have strived to reach many goals at once. As a result, she felt overwhelmed and perhaps too different from others. Based on information shared here, this participant arrived at her own process that fostered dynamically learning to learn and learning how to act. By tackling one goal at a time she learned, with steadily enhanced self-knowledge.

Indeed, action generates new self-knowledge and also brings new open questions. The effects of action may be complex and not always understood in

advance. Walking for exercise might be beneficial to some but cause problems for others:

[Vera] I have neuropathy so bad in my legs that I can feel only pain and cold, and the cold isn't always there. I'm worried about walking so much if I can't feel my feet. What should I do?

[CM] You could swim.

[Vera] I won't get into a pool in a bathing suit.

[CM] If you have hip, knees, or foot problems, walking might not be good. You should talk to your orthopedic podiatrist. Maybe you should get inserts. They'll balance you better and take off the pressure points so as not to give you ulcerative sores from walking.

These issues were not always clear cut. Part of what was taught was to work through the trade-offs and potential alternatives on an ongoing basis. For example, when a participant suggested that he might feel stigmatized when walking with a meter, the Care Manager responded with a suggestion:

[CM] You need to ... have a group walk. Everyone will be carrying a meter, that way you're not the odd man out.

Indeed, the most critical information shared by the care manager was to help group members understand possible reinforcement strategies that they could identify for themselves, psychologically as well as physically:

[CM] The whole idea is, “What are my choices?” Train yourself to like what your body likes.

Information about this double-loop learning—each person learning how to act, self-motivate, and self-reinforce for him or herself over time—gave the participants a way to self-manage. At that point, information was no longer “straightforward” and not merely contextualized. It was personalized for a continuing plan of action.

## **Discussion and Conclusions**

We began by wanting to understand the information needs of patients like the participants with diabetes in the observed group. This group of people had previously demonstrated receptivity to managing their diabetes for a productive life and lifestyle. As with a large proportion of patients with diabetes, however, sustaining this commitment was difficult. Similar to the complex needs of people with other chronic medical conditions, these patients’ sustained self-care was confounded by multiple physiological conditions, emotional and psychological

responses, social support needs, competing priorities, and varying competences in communicating needs to the medical community (Klemm & Wheeler, 2005).

Although these patients did not need constant attention and help, and although they were self-motivated and almost entirely well educated, the information resources that are typically provided did not seem to work for them.

Through studying this particularly engaged and motivated group of long-term patients with diabetes, we have been able to delineate critical problems that even engaged and motivated people trying to take care of a chronic disease necessarily face. Observing these participants, then, allowed us to see where standard information sources were lacking. This group may have been more motivated and articulate, but this served only to make more obvious the needs of what we believe to be true of all patients, in large or small part.

With these patients, we explored what we need to understand better about content and framing in information exchanges to identify possible approaches for evoking patient responsiveness and for fostering a reflectivity-for-action that may have sustained results. As the care manager who led this group said, the purpose of the group was to provide information for future action.

Our analysis shows that these participants engaged in personalized information exchanges to understand the trade-offs and alternatives they faced. This necessarily required them to understand the complexities and ambiguities in



their medical condition, as well as personalize and contextualize their models to their specific situations. Key levers were critical to the participants in obtaining a sufficient understanding. The substance and processes of these trade-offs, complexities, key levers, and personalizing needs are distinctive to patients who strive to live productively with their chronic diabetes.

Several types of information exchange were also important for these participants to carry themselves toward action and eventual self-management. The capability to verify their understanding was critical not only to a conceptual understanding but also to being able to weigh alternatives, trade-offs, and potential risks. Furthermore, we observed the participants learning how to learn. They not only weighed potential actions, they also considered how to work out issues and problems that would necessarily arise in their planned self-management activities. They did so against a backdrop of feeling different and continuously judged with regard to compliance versus failure. They strived for self-care and self-centeredness in relation to their goals. This double-loop learning is essential to self-management because it enables patients to learn how to weigh alternatives, consider issues, and motivate themselves.

Two broad insights can be derived from these findings that are particularly important for information design. First, a process focus attuned to evoking responsiveness is equally, if not more, important to a focus on information

content. The importance of processes of communication and information exchange are well established in the research literature but have rarely been specified for the particular problem we examine: designing information exchanges in ways that “stick” to prompt and sustain better self-care and quality of life. We reiterate this insight here because our findings emphasize that it needs to be a consciously applied framework in information design and information system design.

The second insight, complementary to the first insight, better defines ways of framing information exchanges within this focus on communication process. Findings from our study underscore that patients are not immediately responsive or motivated toward double-loop learning when information is framed as instruction per se (e.g., what one should know about diabetes or how to perform exercises) or as exposition (e.g., objective explanations of the causes of retinopathy). Rather, exchanges in our study that triggered patients to reflectively consider the possibility of alternate long-term choices were framed as follows, with content being shaped by this framing:

- Conditional (“If...then...”) approaches accompanied by diagrams of conditional causes and effects in a systems world (be it systems of comorbidities or proteins to physical symptoms).

- Narrative approaches that include how one has been treated by others (family, health professionals) accompanied by examples and empathetic group problem solving.
- Language (terms and phrases) that encourages helpful and feasible actions (e.g., outlawing the term *fail*) or that vividly represents life in the world as a patient with diabetes (e.g., “snatched pie from my hands,” “dump him” [the demotivating doctor], or “that’s what’s killing me”).
- Question/answer formats that quickly become dialogs rather than reiterations of common self-care guidelines as patients introduce real constraints obstructing guideline compliance.

With regard to information system design, these structures can help in developing tailored information and education, user-centered interactive health communications, and customized electronic counseling or support. Findings from this study represent the communicative and informational structures, terms, and issues that diabetes patients demonstrably valued and explored with a trusted caregiver and with each other. The findings suggest that grounding design in well-established health behavioral change theories and adapting messages through user profiling or software agents are important—as current research in health informatics shows—but insufficient. Alone, conceptually sound tailoring of messages cannot achieve the information transfer, framing, and communicative

exchanges that resonated with the people in the group we observed. People wanted exchanges, not messages. In their exchanges, participants expected contextualized and evolving information based on the personal relevance of a question or problem at hand.

It is outside the scope of this chapter to propose specific designs or evaluate existing ones. Rather, findings from our study suggest categories by which to design and evaluate information transfers that may promote sustaining self-care. Findings reinforce results from other research with regard to the importance of vocabulary and language choices in the tailoring of information (e.g., Nijland et al., 2008). But our findings also enrich other research by showing that language choices extend to levers that help patients develop effective mental models and visual images. Additionally, our findings show that information systems for diabetes attuned to patients' expectations requires understanding and designing for patients' processes of double-loop learning amid multiple interacting and at times competing influences.

In this chapter, we have shown that information dissemination, exchange, and use are likely to motivate and foster sustained self-management over time. We recognize that our inferences about patients' responsiveness, indicating a reflective reconsideration of behaviors, choices, and attitudes that are likely to "stick," need to be substantiated if we are to draw definitive conclusions about the

success of these framings. We also realize that the influences of gifted clinicians such as the care manager in our group have to be better understood and measured. Nonetheless, the approaches to information exchange that we describe clearly reflect these patients' chosen approaches and kept them returning eagerly each month. The insights we presented here imply that intermediaries play vital roles and functions as "expert voices" who also are in touch enough with patients' challenges to know when and how to introduce certain framings such as diagrams or language awareness and how to moderate and modulate certain processes. We believe, therefore, that care managers or effective representations of this role will play a critical part in these kinds of information exchange. Our findings clearly can inform interpersonal approaches. They can just as readily inform digital approaches to crafting information resources to promote more long-lasting effects. Taking a process-oriented perspective in these digital approaches will require continued efforts to better understand—practically and theoretically—the relationship in self-care for chronic diseases among the communicators' intentions, processes of information exchange for self-care and coping, associated content and framing, double-loop learning, and outcomes.

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