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Design for Healthy Living: Mobility and the Disruption of Daily Healthcare Routines

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This paper reports on how people express health concerns as they move around their homes and travel between their homes and workplaces, stores, gyms, restaurants, friends' homes, hotels and other locations. We gathered stories from focus groups and in-home interviews with people with a broad range of health needs, and from these discussions, support for mobility emerged as a key issue for making health maintenance routines easy and resilient in the face of disruptions. The things people carry with them and access at strategic places help them maintain their health routines in the face of stressful and unforeseen situations.

Living with a chronic disease, such as diabetes, forces people to make difficult decisions on a daily basis, weighing the impact of otherwise small, incidental actions against unknown cumulative effects in the future. An offer of a piece of cake at a party can trigger an assessment of the pleasure of celebrating with loved ones against a fear of potentially serious health consequences. Continuous monitoring of one's health can lead to feeling overwhelmed, becoming depressed, and denying the need for behavior change. Our field study of people with health concerns showed that they carefully designed routines as a coping strategy to minimize disruptions to their healthcare practices. These self-care routines reduce anxiety by providing structure. Interestingly, practices for coping with disruption are closely linked to mobility. We found that individuals, and those close to them, deliberately design for contingencies by carrying a wide range of objects and accessing them at strategic places, arming themselves against the unexpected.

The Study

The aging population and epidemic spread of chronic diseases, such as diabetes, are driving healthcare issues to a prominent role in technology research. Worldwide, 171 million people suffer from diabetes, with 20 million people in the United States alone (http://www.who.int/dietphysicalactivity). Diabetes is incurable; instead people manage it through a combination of exercise, diet, and medications. With appropriate management, the prognosis for diabetics is good, and people live with their disease for decades by managing it on the daily basis. Even small improvements in the quality of life for people suffering from chronic diseases can have enormous impact both on the people with the diseases and on those close to them. The potential to make such a large impact has created strong business

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interest in developing products and services to address the world's burgeoning healthcare needs.

Our organization is interested in collaborating with other companies to translate healthcare research into business value, and we created this internal project to explore how to leverage our existing competencies in ethnography, Human-Computer Interaction (HCI), usable security, and ubiquitous computing in the healthcare domain. Discussions with medical practitioners interested in chronic disease management in the home shaped the scope, and we intended to use fieldwork to support the design of a device in the home to help those with chronic diseases monitor their health. Our organization had existing technologies that facilitate the connection of devices within the home and allow secure transmission of data. We planned to modify these technologies via in-home evaluation, similar to prior work in ubiquitous computing (e.g. Consolvo et al, 2003; Rowan and Mynatt, 2005). The medical professionals suggested diabetics as promising initial candidates for monitoring technology, a fit also noticed in HCI research (Frost and Smith, 2003; Mamykina et al, 2006), and grounded in worldwide need. More generally, our research aims were to: (a) comprehend people's perceptions about health in the home, (b) identify similarities and differences in the practices of those who monitored their health, and (c) highlight opportunity spaces for applications in home healthcare.

Method

To start answering these questions, we conducted an exploratory field study consisting of focus groups and in-home interviews. Twenty-nine participants recruited by a market research firm took part in the study, nineteen with diabetes at varying levels of severity, and ten others with a broad range of health goals (e.g. pain management, learning to maneuver a new prosthetic leg). We expanded the scope beyond diabetes to identify a broader range of needs and possibilities for technological intervention in chronic disease management. The fourteen men and fifteen women ranged in age from 28 to 65 with a median age of 48. Eleven of the participants were African-American, Asian, or Hispanic; the others were Caucasian.

Story-Collecting Focus Groups– The focus groups were designed to elicit open-ended narratives about health issues, and participants were encouraged to respond to each other's stories. We did not solicit opinions on proposed technology prototypes; instead we began by covering a table with index cards labeled with concepts we thought would be useful for triggering discussion, e.g. "relationships," "diet," "why bother?" and "treatment." Each person was asked to select a concept from a card that they wanted to discuss in relation to their health. There were also blank cards for recording concepts not represented. As the participants told their stories, the authors asked questions about how they gathered information, what happened when their strategy for taking care of themselves didn't work and things didn't go according to plan, and how they dealt with their health issues in public and with their families. Participants also asked each other questions, sometimes arguing, and

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exchanged notes about medical resources. Two of the 90-minute focus groups were only diabetics, and the third group was a mixed group of those with other health concerns. Audio from the sessions was transcribed.

In-Home Interviews– Of the twenty-nine focus group participants, five diabetics and five non-diabetics participated in 90-minute in-home interviews within a week of the focus groups. The participants captured the diversity of the focus group participants with a mix of genders, ages, and ethnicities. The group included people living alone, in couples, and with roommates. On the advice of the medical practitioners' Human Subjects Committee, none of the interview participants had children in their home. Participants included diabetes, someone with Crohn's disease (a gastro-intestinal disorder), a chronic back-pain sufferer, a middle-aged man trying to loose weight, a cyclist training for a 200-mile ride, and someone following a rigorous diet of natural food/herbal medicine. Participants were asked to show places in their homes important to their health and the tools in those places used for self-care. In addition to showing tools, participants were asked what information resources they used to learn about their health. After the tour, we asked the participants more questions about how they coped with exceptional events that disrupted their usual practices. We captured the interview on a mobile digital audio recorder, and it was transcribed. The important places and tools were photographed.

Analysis– The authors separately read through the almost 17 hours of transcripts and collated themes and concepts into spreadsheets. Following a grounded theory approach (Strauss, 1992), analytical concepts emerged from the body of data, which were then refined over a series of discussions.

Findings: Themes of Self-Care

The field study results showed that our initial assumptions about in-home health monitoring overlooked some important issues that people monitoring their health were concerned about: that is, the experience of living with the imprint of a health condition on the body and how that experience motivates healthcare routines including the placement of objects and artifacts in environments where people moved from place to place. We identified two key themes in the experience of living with a health condition: bodyscapes and objects used in daily self-care routines. Understanding these themes shifted the focus of the project away from the idea of introducing a single health monitoring device into the home towards a more holistic approach integrating objects that are not strictly medical and that could be a part of multiple environments.

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Bodyscapes

In exploring health and self-care narratives it was clear that the imprint of health concerns on the body takes an enormous toll. Our participants described their bodyscapes in different ways, including identifying a range of physical symptoms that made self-care challenging and describing how their health conditions impacted their image of their bodies. For example, the diabetics in our study talked about developing calluses and bruises from finger pricks and shots, getting cold sweats, and fearing falling into a coma.

> *You have to actually learn to sit there and just feel like you're going to die because you heart rate goes up really, really high. It actually kind of hurts, so you just sit there and keep telling yourself I will survive. I find with doctors they don't think diabetes–it's not a big deal. Every doctor I've ran into there is just like "Oh, you're okay," and it's so common, they don't think anything of it.* – 28 year old woman with diabetes.

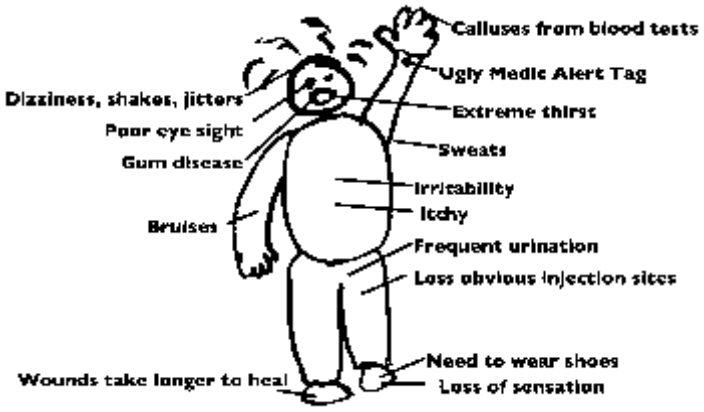

FIGURE 1. Imprint of diabetes on the body.

This imprint on the body contributes to the emotional charge of diabetes, and the diabetics told us that having diabetes is "a big deal," even though from a medical perspective it can be easily managed. In addition to its corporeal impact, diabetes also has an emotional and social impact. For example, diabetes contributes to clothing choices because subtly injecting a needle through clothing while seated at a table or desk produces the risk of blood spots on fabric that someone else might notice. The subtle seated injection approach was not a possibility for one woman when she wore a dress. She preferred to inject insulin into her abdomen, but in a dress, she explained, she needed to go to a bathroom stall to lift it up for her injection. Footwear was an issue for some participants as diabetics need to protect their feet from wounds and are discouraged from going barefoot. Medic-Alert identifying jewelry was derided as unattractive.

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Body image– Self-perception of the body came through as an important concern for all the participants in the study, not only the diabetics. For example, twenty-two of our twenty-nine participants reported weight-loss as one of their health goals, and the connection between appearance, food, and healthy eating came up repeatedly. Two overweight people described the way others talked to them as "uncomfortable and hurtful," with one going on to say people talked to her as though she lacked intelligence or were a child. Medical diagnoses also changed the way some thought about their bodies. One participant said that being diagnosed with diabetes was helpful because it moved his struggle with his weight beyond concern with appearance and dating. Similarly, a woman described how chronic back pain had motivated her to lose weight in a way that her appearance had not. Two women described past struggles with eating disorders, one of which reported focusing on getting rid of "the pooch" in her lower abdomen area and dieting down to a low of 88 pounds (40kg). Appearance as connected to weight remained so important to this woman that even though she introduced herself as an amputee concerned with her ability to maneuver her prosthesis, all of her comments during the discussion about self-image were about weight, and being an amputee didn't come up. Having an amputee in the study was an interesting counterpoint to the diabetics' well-articulated fear of amputation as a complication of the disease, a fear motivating some to treat their diabetes. Although three diabetics had also had cancer, the consensus in their focus group was that amputation was worse than death.

Family history– The participants' families played a role in their body image in three ways: lessons about self-acceptance, foods associated with their family's culture, and perceived genetic predisposition to disease and body type. This study took place in the San Francisco Bay Area, a multicultural area, and some study participants found it necessary to explain their family's eating habits. Two people mentioned immigrating and one mentioned having parents with poor English language skills. Several people mentioned their culture in the context of food. For example, one woman announced that she's Hispanic and her family members are fat because "everything is cooked with lard and deep fried," and that her husband's Chinese family was "big on rice," a problem for her plan to avoid starch. Others talked about genetics, saying, "My family are my excuse. I come from a long line of little plump ladies." The genetic connection was particularly relevant for the diabetics, many of whom mentioned having diabetic grandparents, parents, siblings, or children. One man connected these themes:

> *I see it most prevalently with my sister … in my estimation is in total denial. She doesn't monitor her diet. I'm from the South, it's where she still is, Alabama. The colloquial diet there is fried food, a lot of fat, a lot of fat. I mean my family is all fat, I mean we're just fat people. But over the progression of her disease … her eyesight is getting progressively worse. They amputated a toe.* – 46 year old man with diabetes.

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Objects Used in Self-Care Routines

Our understanding of how living with health concerns impacted the bodyscapes of our participants was complimented by our finding that self-care entailed far more than following medically-based routines, such as being proficient at glucose monitoring for diabetics. Broadly, effective self-care involved the use of artifacts, information sources, emotional support, and planning for daily routines and emergencies. As participants took us on tours through their homes, we were particularly struck by the ways in which objects associated with people's emotional lives intersected with their healthcare routines. Again and again, participants showed us objects they used in health maintenance practices that addressed not only the body, but also the mind and the spirit. Moreover, certain objects such as mementos from friends embodied a source of strength and support, reminding people of their relation with others, whether as part of a family or spiritual community. We were shown silver-framed photographs of family members, boxes that held the ashes of beloved pets, and a videophone to communicate with young grandchildren. Our participants pointed out specific chairs, couches, beds, and candles that they used for meditation and relaxation exercises. Of the in-home interviewees, two of the diabetics had near-death experiences that had a significant impact on how they subsequently viewed their lives and health. There were alcoves that held religious icons and fresh flowers, and recordings of church sermons recommended by friends that they listened to while exercising.

> *[On the exercise machine] I kind of look out the window to see things passing by. Other times I use an audiotape, the one that's right beside you. [Responding to a question about what's on the tape] Believe it or not those are bible study tapes from Grace Church in Los Angeles, Dr. Reverend John McArthur. … I take care of my physical and spiritual needs at the same time. It's pretty cool that way.* – 50 year old man with diabetes.

Our participants had a far more extensive definition of tools for self-care than we expected. What was especially surprising was the prevalence of mundane objects that people associated with self-care at home. In response to a request to show tools used as part of their health practices, we were shown a colander (for rinsing fresh fruit and vegetables), a shoe insert (for correcting fallen arches), and an iPod (for playing motivating music to aid workouts). They pointed out special herbs, spices, and many kitchen utensils and recipe books; artful ceramic containers for syringes, and bookmarks saved in their Internet browsers, among other things. There were small stuffed animals placed on dressers near medical kits, and exercise machines in prominent places such as living rooms.

Self-care routines– Just as health practices thoroughly permeated living spaces and affected what objects people wanted around them, health concerns also infused daily routines. The placement of meaningful objects in the home and ephemeral experiences such as meditation sessions represented anchoring moments on the Sisyphean slopes of chronic disease. In addition to helping people meet their goals, self-care routines provided

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comforting stability in the face of the emotional drain of managing health concerns. Some described routines designed to avoid tempting or difficult situations, for example always buying low-fat mayonnaise and diet soda so that regular mayonnaise and soda are never in the refrigerator to enable breaking a diet. Routines consolidate decision-making and align the outcome with high-level goals, instead of responding to the pluses and minuses of a specific situation. One person described how she made a decision to bike to work every day and just had to put on a rain suit if it rained without making an individual assessment of the weather saying, "If I had to decide every morning, I'd get kind of lazy and think 'Oh I don't feel like it today.'" Other routines focused on detailed preparations to enable healthy behaviors.

> *I've got a system where I just repack the bag as soon as I get home. If it's a gym bag with icky clothes, I just take the dirty clothes out, put the fresh clothes in right away. Or the swimsuit. I hang the swimsuit to dry and I remove the wet towel. And put a fresh towel in there, and then when the suit's dry the next morning, I just put the suit right back in the bag.* – 38 year old woman with Crohn's disease.

Disruptions and emergencies– Routines and the objects that support them act as a buffer against the unexpected, making people resilient against disruptions in their healthcare routines. The participants' potential disruptions ranged from inconveniences of minimal consequences, such as an overweight person leaving for work without their healthy lunch; to the socially traumatizing, such as the Crohn's disease sufferer vomiting or going to the bathroom on herself in public; to the life-threatening, such as a diabetic whose pancreas doesn't make any insulin (Type 1) and who will die if stranded without injection supplies. Example stories of disruptions generally took place away from home, and strategies for coping generally involved carrying extra supplies. Carrying extra supplies to plan for contingencies was so important that six of the ten in-home interviewees specifically mentioned bags (purses, backpacks, gym bags, and travel bags) as tools they use to take care of themselves. Not only was the content of the bags revealing, but also the context of how and when items in them were used clearly demonstrated the nuanced and more holistic way in which people viewed their health. For example, a chronic-back pain sufferer showed us a large bag she took on business trips that held a yoga mat (so that she could do yoga in her hotel room) and a heavy binder of food measurements to which she could refer when traveling. Bags even followed people around the house, such as a purse with a blood-sugar monitor in it going downstairs after lunch to be handy when its owner reads with a cat on her lap. One woman used pockets for keeping track of her daily pills to ensure they were at hand.

Direction: From Home Monitoring to Supporting Mobility

Although the project started with the idea of looking for opportunities to modify our existing home networking technology to support in-home health monitoring, the fieldwork identified a different unmet need: support for mobility to limit disruption in self-care. This change in research direction from in-home monitoring to mobility support

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changed the way we position healthcare research within the organization and guided us to a different group of potential outside collaborators.

We had planned to use participatory design methods to incorporate the end-users' feedback into rapidly changing prototypes; the fieldwork was basically intended to be a matchmaking exercise between the lab's technical capabilities and the needs of people managing health concerns. The findings from our study changed the dynamic of the project. From the fieldwork we gained an understanding of how the participants deliberately structured their environment and routines, practices that are visible in their design of the things they carried with them. Because strategies for limiting disruption were so varied and individual, we began to view the participants–not the technologists–as designers. Like the Portable Effects project (http://www.portablefx.com), our discussion of what people put in their bags and where they took them showed us that our participants were acting as designers. Acknowledging the participants as designers changes the relationship of power between them, the field researchers, and the technologists (Dourish, 2006) and gives them greater agency to accept, modify, or reject technological additions to the kits they use in their healthcare practices.

Even though our interviews took place in the home, discussion of mobility came up in two interconnected ways. It came up naturally as bags (purses, backpacks, etc.) embedded in the home triggered narratives about what people carried and where they went. Additionally, a section of every interview dealt specifically with how people handled disruptions to their routines. Incidents of disruption generally took place outside the home, e.g. at work, a relative's house, or on a trip. These questions were to help identify what parts of people's home routines worked well so that a technological intervention would not disrupt them, and to provide examples of situations where people needed extra support. From participants' responses the home emerged as a base from which people prepared and energized themselves, bolstered by favorite objects, before going out into the world where disruptions threatened their self-care routines.

Self-Care at Home, In the Community, and Anywhere in the World

This study suggests that practitioners interested in developing products and services to support home healthcare and chronic disease management would benefit from incorporating mobility into the scope of their projects and from exploring ways to include non-medical objects in self-care routines. The remainder of this paper describes examples of home-based healthcare practices to share them with practitioners.

Our participants moved across multiple landscapes. Especially striking was the fact that the resources they needed to take care of their health were not only available in specific places, but across a constellation of different locales. People planned for contingencies by designing what they carried with them and by leaving caches of emergency supplies in key places. For example, insulin-dependent diabetics visiting other diabetic family members

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talked about their relief at knowing there would be extra insulin in the refrigerator. One diabetic quite casually described having one testing kit on a centrally located dresser, another in his backpack, and a third in his "back-up drawer" in his apartment. Supplies needed to be carried wherever people went, whether traveling on holiday or business to Russia, Mexico, or small towns in the Midwest.

> *Well, what makes it hard for me is that some of the trips are to very small towns where the choices are extremely limited, like there is probably a McDonalds and a Pizza Hut and Wendy's or something. And there is always a grocery store, but there isn't always a refrigerator in your hotel room, so just eating the right foods is sometimes hard.* – 56 year-old woman with chronic back pain.

The following graphic shows some healthcare practices mentioned in the interviews organized by the kind of environment where they take place: home, community, or anywhere in the world. These practices are offered as a few examples of successful strategies employed by people with healthcare concerns, listed here because they suggest practices that could be amplified by technology, as we are beginning to explore.

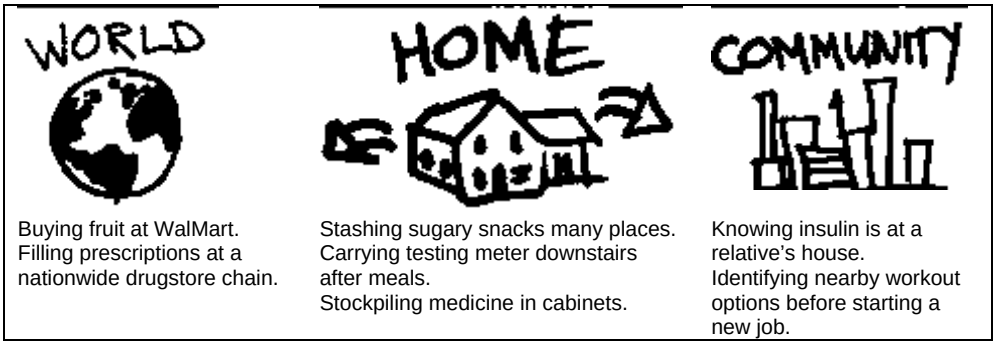

FIGURE 2. Practices supporting self-care in different environments.

People interested in designing healthcare products and services could learn from what our participants carry with them and what they value access to outside the home. People carry items, such as blood monitors, around their homes. They pack gym bags for routine trips to work and bring exercise diagrams on business trips. They also make sure that resources would be available at their destination to avoid any disruptions to their self-care. Our respondents showed creativity and resilience in how they protected themselves from disruptions, in effect designing their environments for healthy living.

Summary

This paper reported on a preliminary field study intended to inform the design of home health monitoring technology. Instead, the findings showed that our participants with

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a broad range of health issues had additional concerns about how disease impacted their bodyscapes and how the objects they used in self-care could support their health maintenance routines. As a result of these findings, we shifted our focus to explore the connection between mobility and support for those routines in the face of disruption. Our participants carefully designed the things they carried with them and left at strategic places to help them maintain their health in the face of unforeseen situations.

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Web Resources

Portable Effects: A Survey of Nomadic Design Practice http://www.portablefx.com

World Health Organization: http://www.who.int/dietphysicalactivity

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