Technology to Empower Patients with Chronic Conditions

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Abstract

This paper describes two projects that use technology to help patients manage and improve their own health. The first is a tool for identifying triggers of a patient's chronic condition. This tool can also be used to predict an impending outbreak so that evasive actions can be taken. The second is a nutrition monitoring tool to help dialysis patients limit their sodium and fluid intake to acceptable levels.

Motivating Scenario

A 20 year old woman has pain in her lower jaw. She goes to her dentist who takes x-rays, but cannot find anything wrong with her teeth. She is sent home with painkillers and the pain goes away in a couple of days, only to return a few months later.

Over the next 10 years, the pain comes at more frequent intervals and lasts for longer. The woman cycles through dentists, is checked for a variety of dental related problems (e.g. teeth grinding and TMJ) and takes Vicodin whenever there is a flare up. Full of frustration, the woman insists that she has the suspected tooth removed during a particularly painful attack. Less than a month later, the pain is back.

The woman spends the next few years keeping sporadic diaries, trying to figure out what might cause the pain. At first, she speculates stress. It takes a year to eliminate that, at least as the sole cause. Next, she speculates misalignment of her body. After a year of expensive chiropractic and osteopathic visits, she has her most severe flare up yet that lasts for over a month.

Finally, a new doctor suggests that she might have a chronic condition called trigeminal neuralgia (TN) and she sees a neurologist to confirm the diagnosis. She learns that the pain associated with TN is so severe it has been dubbed the "suicide disease" [8]. The woman is relieved to finally have a diagnosis that fits and to know that what she had been experiencing for years was not in her imagination.

Her neurologist describes the standard treatment: drugs until they no longer work, and then surgery. The drugs are no picnic either: anticonvulsants. The woman is not eager to start down the medication path and is determined to find another solution.

She stumbles across some information on the Internet that her condition is related to migraines. Her mother had suffered from migraines for years and had recently discovered a connection between her migraines and chocolate. Desperate, the woman completely gives up refined sugar. Within 2 days, the current flare up recedes to the point where she only needs Vicodin to sleep. Within 2 weeks, she takes her last Vicodin ever. She is now pain (and sugar) free.

Imagine if there had been technology in place to help her keep track of her nutrition, her stress levels and other possible triggers. How many years of pain and frustration could she have saved to determine that she needed to remove sugar from her diet?

This is a true story. This is my story. This is the reason I started applying my expertise in computer systems to empowering people to manage and improve their own health.

In this paper, I describe two projects that use technology to empower patients with chronic conditions. The first is a tool for helping patients identify triggers (e.g. stress and nutrition) for their condition. This tool may also be used to help predict an episode of a condition, giving the

patient time to take defensive measures (e.g. take a migraine pill). The second is a nutrition monitoring tool to help dialysis patients limit their sodium and fluid intake.

Both of these projects are in conjunction with nurse researchers in the School of Nursing at Indiana University-Purdue University in Indianapolis (IUPUI).

Tool for Identifying Triggers

Many people spend enormous amounts of time and energy to attempt to identify triggers for their chronic condition, be it allergies, migraines, epileptic seizures, pain or anxiety. Methods typically include keeping track of a certain suspected cause with a diary. Success is limited by the accuracy and completeness of the diary, and nearly impossible if the condition is caused by a combination of factors.

The primary difficult with diaries is that it is hard for the patient to remember to write everything down. We are developing a toolkit that assists in the recording and analysis of various factors. The toolkit combines a PDA with a variety of recording methods:

- **personal monitoring sensors** to automatically recording data from on-body sensors such as EEG, EKG, stress and heart rate [7]
- **bar code reader** for easy entry of nutrition for packaged foods
- **experience sampling method** to periodically prompt the patient for information relating to their daily activities [2]

A patient may still want to monitor only a few variables at a time. The toolkit allows the patient to specify what factors to monitor.

In parallel, a desktop application is being developed to take the data from the PDA and help find correlations between variables and episodes of a patient's condition. We are also working with a researcher in visualization to find ways to present the data to patients in a more accessible format.

Nutrition Monitoring Tool

End-stage renal disease (ESDR) patients have lost all use of their kidneys. As such, they must undergo painful dialysis treatments 3 times a week. Since their blood is only filtered of the excess fluids and toxins every two days, they have highly restricted proscribed diets. A typical patient must limit their fluid consumption to 1 liter of liquid and 2 grams of sodium per day. Failure to adhere to their diets results in a variety of complications, including death.

Paper diaries are the primary method used for recording and computing a patient's nutritional intake. Studies have shown these diaries to be ineffective, with as many as 80% of ESDR patients *not* adhering to their diets [6].

Two major problems with this patient population is that they have a low literacy rate and have been shown to have difficulty performing the complex calculations involved with translating a food to its nutritional content [3].

We are developing a nutrition monitoring tool to help ESDR patients keep track of their dietary and fluid intake. The tool incorporates a PDA with a bar code scanner, a non-text based GUI for foods without bar codes, and a voice recorder for when the patient encounters problems [1]. The tool notifies the patient when their fluid or sodium intake is reaching dangerous levels, and allows the patient to experiment with "what if I ate ____?" Figure 1 shows how our nutrition monitoring tool works.

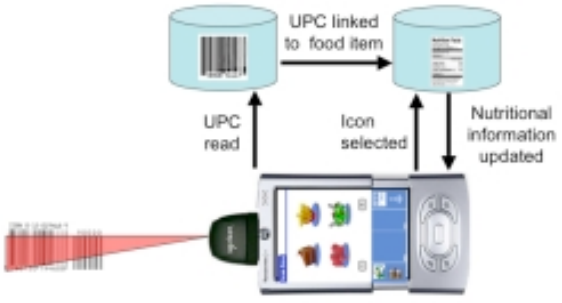

Figure 1: Nutrition Monitoring Tool

In conjunction with nurse researchers, we have a 6-week clinical study planned to evaluate the effectiveness of this tool.

Conclusions

There are a variety of HCI challenges that we are facing in these projects that are relevant to this workshop. Two of the most compelling have to do with the special needs of our target populations and the non-controlled testing environments in which we are deploying and evaluating the technology.

For the nutrition monitoring tool, our target population typically has poor eyesight as a result of advanced diabetes. An initial usability study on PDAs concluded that the largest default PDA icon size is not large enough for the majority of our patients [4].

Further, our clinical studies are being performed in an inner city dialysis unit, the demographics of which include a large percentage of patients who have not completed high school, who cannot read and who are not familiar with computers. All of these factors play an important role in how we design our tool.

Finally, we discovered early on that a dialysis unit poses far greater challenges than a traditional usability lab [5]. They are cramped with no place for the researcher to sit or place her things (wear a jacket with lots of pockets!). And even though the patients undergo dialysis for 4 hours, they become too uncomfortable after 2 hours to participate. This gives us only three, 2-hour timeslots spread out over the day to interview patients, making scheduling a challenge for larger studies.

These projects are both in an early stage: we are a year into the nutrition monitoring tool and less than 6 months into the trigger tool. It is my hope that attending this workshop will help inform our design and approach.

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Bio

Dr. Kay Connelly received her Ph.D. in Computer Science from the University of Illinois at Urbana-Champaign in 2003. She is an Assistant Professor in the Computer Science Department at Indiana University, where she leads the Security for Ubiquitous Resources Group (SURG). She is also a member of the Pervasive Technology Labs and an Associate Director of IU's Center for Applied Cybersecurity Research.

Dr. Connelly's research is in the area of Ubiquitous Computing, where she is developing a framework that relates, explains and predicts a variety of factors that play into user acceptance of ubiquitous computing applications. In particular, she is interested in privacy, trust, motivation, control and convenience of such applications as home sensor networks, health care management tools for laymen, and automatic configuration of mobile devices.