

Towards a Personal Health Management Assistant

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ABSTRACT

We describe design and prototyping efforts for a Personal Health Management Assistant for heart failure patients as part of Project HealthDesign. An assistant is more than simply an application. An assistant understands what its users need to do, interacts naturally with them, reacts to what they say and do, and is proactive in helping them manage their health. In this project, we focused on heart failure, which is not only a prevalent and economically significant disease, but also one that is very amenable to self-care. Working with patients, and building on our prior experience with conversational assistants, we designed and developed a prototype system that helps heart failure patients record objective and subjective observations using spoken natural language conversation. Our experience suggests that it is feasible to build such systems and that patients would use them. The system is designed to support rapid application to other self-care settings.

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1. Project goals and design requirements

For some time, we have been working on the specification and implementation of conversational assistants: computer systems that interact naturally and help human users solve problems. Our conversational assistant paradigm has been applied to settings ranging from transportation and relief logistics [1,2], to assisting with medication compliance [3], to collaboratively learning and executing novel tasks on the Web [4].

The first phase of Project HealthDesign was about developing a new, more patient-centric vision of personal health records. These PHRs would be integrated into patients' daily lives, collecting, analyzing, and delivering actionable information in an intuitive manner.

1.1. Project goals

Our goal in Project HealthDesign was to apply the conversational assistant paradigm to the problem of helping patients take care of themselves in their homes. It is well-known that demographic and epidemiological trends are leading to a huge increase in the number of patients suffering from chronic diseases. As a specific instance of chronic illness, we chose to focus on heart failure (HF) patients for two reasons. First, it is highly prevalent [5–7], resulting in significant costs in terms of hospitalizations [8], visits [9], and overall spending [10]. The estimated direct and indirect

cost of HF in the United States for 2010 is at least \$39.2 billion [11]. But equally importantly for our project, the underlying physiology of and best practices for heart failure are relatively well understood. It is considered very amenable to effective self-management for a broad class of patients [12,13].

Patient education has been shown to be a key factor in promoting self-care as a part of HF management. However, patient education alone does not result in effective behavior change for self-care and adherence [14–16]. The most effective educational interventions have included close home monitoring of patients with HF [17–21], resulting in reduced readmission rates and increased length of survival. These programs are very costly, however.

There is a growing body of evidence that even intermittent monitoring, usually by phone, can improve outcomes for patients with HF [22–24] and other chronic illnesses or conditions [25–27]. These programs have proven to be successful in reducing re-hospitalization, reducing costs, and reducing the pressure upon time available for face-to-face consultations. The evidence also shows that people are responsive and satisfied with phone-based case management. Our project can be seen as an attempt to adapt this style of interaction to an automated system. If successful, we would be able to obtain at least some of the benefit while significantly reducing costs and expanding access for patients.

1.2. Design requirements

Our design work began by analyzing the current state of heart failure patient self-care. We started from the patient guidelines

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used by the heart failure clinic at the University of Rochester Medical Center. From this we identified a number of elements that patients needed to track to follow the guidelines. These included both objective measures such as weight, and subjective measures such as chest discomfort.

We then worked with a focus group of nine heart failure patients to determine their current practices and identify roadblocks. Patients were racially diverse, and ranged in age from 35 to 82. All were classified as ACC/AHA stage B or C [28] and NYHA class II or III [29]. They also varied in how long they had had the condition. We obtained information from the focus group using self-care diaries and interviews. We also conducted a broader survey of 63 patients attending clinic (mean age: 54.8; mean years with HF: 8).

The most important conclusion from this study was that the patients all spend a significant amount of time and effort gathering and collecting the personal health information required to manage the disease. This included vital signs such as heart rate, blood pressure, and daily weight. These were generally recorded on paper, if they were recorded at all. Many patients said they had trouble keeping track of this information. Some patients used self-designed excel spreadsheets. None of our patients reported using an online, web-based system. The patients did not generally report recording the more subjective elements required to follow the guidelines. A few patients reported tracking the results of lab tests in an excel spreadsheet.

When asked about calling their provider, several patients indicated that they did not always call when they thought that maybe they should. On the other hand, some people called several times a day. From talking with providers, we also heard of cases where a visiting nurse might suggest that something be brought up with the doctor, but for whatever reason this sometimes waited until the next scheduled visit, possibly some time later.

2. Prototype description

Based on the user study, our prototype effort focused on the first part of a self-care solution—collecting the data. Our prototype Personal Health Management Assistant engages its user in a short “daily checkup,” using spoken or typed natural language to gather information relevant to their condition. Clearly, spoken interaction will not be best for all patients, but it does hold out the promise of universal access for all those for which it is physically possible. As well, written (typed) language can be an effective form of interaction, whether in a chat style or via text messaging while on the go. The important common feature is that the interaction is treated as an ongoing dialogue between user and system, with the system trying to understand the user’s intentions and be proactive in helping them achieve their goals. Fig. 1 illustrates the system concept.

Our goal for this project was not simply a “paper prototype,” but rather a working end-to-end spoken dialogue system for the heart failure checkup task. Our previous work on such systems provides a high-level system architecture, as well as initial implementations of many of the necessary components [30–32]. Broadly speaking, the system components are divided among three main categories: interpretation, behavior, and generation. The interpretation components involve understanding what the user has said or done, the behavior components manage the system’s behavior (both reasoning about what to do and doing it or getting other agents to do it), and the generation components construct system contributions to the dialogue. Common knowledge bases allow sharing of information across categories. In this paper we can provide only a brief sketch of the system organization and function. Please see the cited articles for additional details.

The user speaks or types to the system in unrestricted natural language. Speech recognition produces utterance hypotheses,

which are then parsed into semantically-meaningful logical forms (typed input is parsed directly). These partial representations of the meaning of the utterance are interpreted contextually and disambiguated with respect to the discourse state and task model. A core collaborative agent pursues the system’s goals (e.g., obtaining information) while responding to user requests and responses. This agent’s behavior is driven by a general model of collaborative problem solving, augmented with the specifics of the HF self-care model. It also maintains the system’s knowledge, including its beliefs about the user’s beliefs. Finally, spoken or typed language is generated and graphical displays updated to accomplish the system’s communicative goals.

Our prototype system was also able to exchange information with the Project HealthDesign Common Platform. Elements from the common platform can become knowledge that changes the system’s behavior. Observations gathered by the system can be pushed to the common platform for further dissemination. The key to sharing knowledge in this way is an emphasis on the semantics of the information. We are not sharing arbitrary text captured on a web form. Instead the system is sharing its knowledge, which is derived from interaction and interpretation.

3. Testing/evaluation results

Evaluation was not a focus of our efforts in Project HealthDesign. We have, however, recently completed a separate project that evaluated the feasibility of a system similar to our Personal Health Management Assistant prototype. That study involved heart failure patients recruited from our clinic using the system for a simple one-shot checkup interview. The system’s output from the interview was its understanding of the observations reported by the user (e.g., weight, swelling, etc.). We also had healthcare providers listen to the interviews and fill out a web form detailing their observations. The purpose of the study was to compare the accuracy of the system compared to the human experts. The results of this study have not yet been published.

4. Discussion and implications

We draw three broad conclusions from our work on the Personal Health Management Assistant prototype. First, personal health records must support patient-generated observations, both objective and subjective since these are crucial to effective self-care. Second, supporting self-care requires going beyond simply storing and presenting this information. Patients want and need help making decisions and taking action, and applications need to enable that. And third, effective sharing and integration of information between personal health applications requires a more formal semantic characterization of the information being shared than is currently common. This would enable both the automated decision support necessary for proactive assistance, and the natural language understanding and generation involved in truly intuitive interaction.

As part of Project HealthDesign, we also had the opportunity to consider the ethical, legal, and social aspects of our technology. A few core questions are worth raising.

Ethical: Some critics of this type of technology have argued that it is unethical to replace human decision-makers with machines. Our belief is that the technology should be developed to complement and augment human decision-making, but inevitably there are cost-benefit issues involved in the details. How can we ensure that patients are involved in those details?

Legal: If there is clinical decision-making involved in these home-care and self-care systems, regardless of how basic, how do we address the liability issues? Does this type of technology require FDA approval as a “medical device?” What has happened

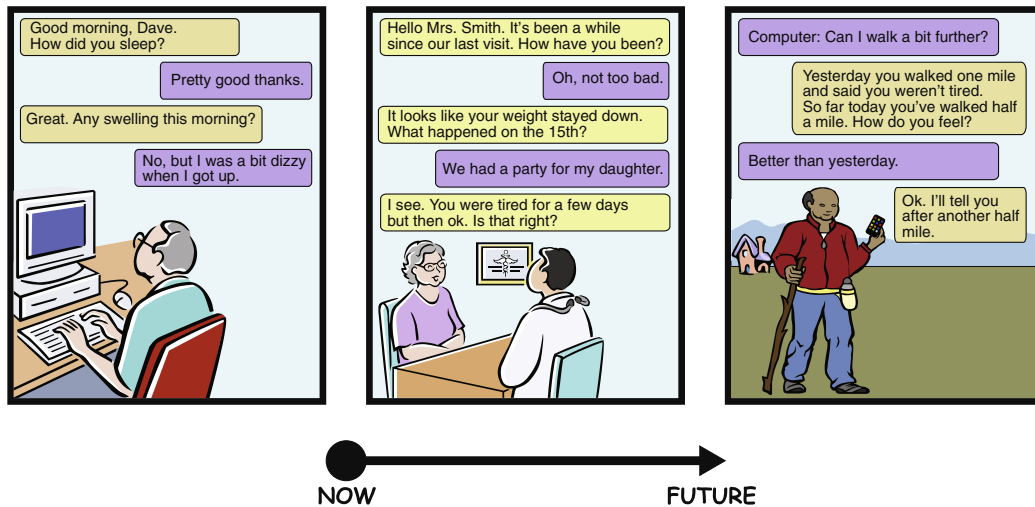


Fig. 1. Personal Health Management Assistant system concept: (a) conversational self-care checkup; (b) longitudinal data shared with providers; (c) intelligent context-dependent assistance. Only (a) was implemented as part of our prototype.

when other medical technologies have trickled down to the consumer? What is the effect of the changing consumer technology landscape on the medical legal system? The Project HealthDesign ELSI group produced an excellent white paper on this subject [33] that discusses the ELSI issues involved in using decision support systems for self-care.

Social: Two aspects of social implications have come up so far in our work. First, chronic diseases such as heart failure tend to lead to social isolation. As we develop the technology for self-care of chronic disease, can we build on the patient's relationship with the system to link them to a broader social community (*c.f.* [34])? And second, our prototype is a fairly limited system with which the patients will interact only occasionally and usually in private. The goal of the project was to see whether patients find spoken interaction useful, effective, enjoyable, *etc.* But the broader vision of intelligent assistants for home- and self-care involves a deeper involvement in people's social and personal lives. For example, Ref. [35] describes the use of statistical models of user activity and context to improve medication prompting. Refs. [36,37] apply similar techniques to assisting cognitively impaired users with directions. More general consideration of the role of context in effective human-system communication is presented in [38]; application to home health care is described in [39,40]. Finally, the integration of contextual awareness with reasoning about user activity for assistive systems (specifically, generating reminders) is presented in [41–43]. The challenge is to integrate these models of context and activity with the interpretation and generation of language for conversational interaction.

A key issue for personal health records that cuts across all of these dimensions is the implications for physicians. Will clinicians be able to trust the information in the record if it did not come from a clinical system? Is information gathered via natural language processing any more or less accurate than other user (patient) interfaces? Will clinicians be able to trust that the system will provide adequate and safe information even for patients with complex conditions? Our approach is to start small, validate the accuracy of the system under controlled conditions, and focus on the early stages of disease. Our experience suggests that there is plenty of scope for automated assistance with data collection and analysis in support of prevention and early detection of change, where the system's performance is not necessarily a matter of life and death.

Finally, one issue has arisen frequently from our patients over the last ten years. Although they are positive in general about intelligent systems for self-care, they are also very concerned about the

privacy of their data. This is an important potential barrier to the acceptance of this type of personal health application. Recognizing this, our vision of self-care is based on the idea of patients owning their data and sharing it in an informed manner. This is an area where action is urgently needed if the vision is not to be left on the curb as new technology is rapidly deployed by various vested interests.

5. Overview of implications

The prototype Personal Health Management Assistant illustrates the feasibility of building spoken language interfaces to personal health records for gathering observations of daily living from patients. The patient-users involved in our project generally saw the system as an alternative to “using the computer.” The integration of natural interaction with data collection and analysis is a powerful tool, but significant ethical, legal, social, and technical challenges remain.

6. Disclosure statement

The authors declare that there are no conflicts of interest.

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