Design of a Paired Patient-Caregiver Support Application for People Coping with Cancer

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Abstract. Smart medical interfaces have the potential to address the unique health needs of each individual user. However, they must be carefully designed and tested to provide a supportive and non-stressful experience for users who are ill or overloaded. This paper documents a design methodology used to develop such an application, describing issues that can be encountered during the development process. The paper also illustrates the use of patient-entered data to drive multiple processes, showing how a smart medical interface can mediate among multiple stakeholders.

Keywords: smart medical interface, human-computer interaction, iterative design, cancer, web-based intervention, symptom management.

1 Introduction – The Design of Smart Medical Interfaces

As the public's access to powerful computer resources grows, so does the effort to create computer-based tools that can intelligently customize themselves, based on the unique needs of their users. The design of smart medical interfaces is particularly promising for the area of consumer health applications because the health needs of individuals are affected by many different factors, and must be uniquely addressed [1, 2, 3]. However, computer-based applications for use by patients and their families must be carefully designed to provide a supportive and non-stressful experience. This is challenging because illness touches people from all walks of life, leaving them distressed and vulnerable. Therefore, it is important to apply iterative, user-centered development methodologies to the design and implementation of such interfaces [4].

This paper describes our *Pathways for Caring* project, which involves the creation of an application that serves as a mediator between patients suffering from cancer, their primary caregivers, their medical providers, and medical researchers looking for better ways to provide care. This system, known as the *Patient-Caregiver Management System* (PCMS), guides both cancer patients and their caregivers through an assessment of their symptoms and needs on a weekly basis. The information entered by the patients and caregivers is captured by the PCMS and used

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to produce customized guides for both the patient's symptom self-management and the caregiver's stress self-management. These guides are drawn from database repositories of self-help information, known as the *Symptom Management Toolkit* and the *Pathways for Caring Guide*, that have been developed in cooperation between Indiana University Purdue University at Indianapolis (IUPUI) and Michigan State University (MSU) [5, 6]. The PCMS also uses the gathered information to determine if the patient's provider should be notified about any developing problems, sending a HIPAA-compliant notification to the provider if this is the case. Finally, the PCMS captures non-identifiable patient and caregiver information, such as how much time these users spend looking at each page of their care guides, and how highly they rate the information in the guides. This growing repository of behavior and experience data will help medical researchers develop better care methods for the future.

Given the sensitive nature of these functions, it is important that the design team follows best practices in human-computer interaction [4]. In this paper, we describe the methodology we are using in hopes of providing guidance to developers of other patient-facing health interfaces, thus contributing to health practice in this area.

The paper begins with the user needs that drive development of the PCMS. This is followed by a description of the methodology used to design the application. Following this is a section detailing design and implementation of the pilot testing process. The paper then provides a walk-through of the most significant application interfaces resulting from our design process, and concludes with a discussion of the implications for the design of patient-facing smart medical interfaces.

2 Background – The Needs of Patients and Caregivers

Cancer is one of the most prevalent chronic illnesses in the United States affecting both patients and their family members. Cancer patients experience a number of distressing, life altering symptoms during treatment. Management of chemotherapy-related symptoms is a significant burden to both cancer patients and their caregivers. As they face these distressing symptoms during treatment, cancer patients and their families have significant needs for 1) help with symptom management, 2) communication and coordination of care, and 3) help with the burden of caregiving [7]. Provision of cancer-related information helps patients and their caregivers to improve symptom management and manage stress, thus increasing overall quality of life. It is this set of needs and opportunities that provides the impetus for the PCMS.

3 Design Methodology

One key for successful interface design is an iterative development process. Our design methodology begins with extensive information gathering and needs assessment, followed by a period of conceptualization and discussion within the design team. Many rounds of coding, internal testing, and heuristic inspection eventually yield a working prototype. At this point, we conduct several rounds of

formal usability testing with external recruits, who are demographically similar to the intended application users, and who role-play being application users. Finally, once all identified usability problems have been corrected, the application is ready for a full-scale pilot test with real patients. At the conclusion of the pilot test the overall results are examined, desired improvements and elaborations are identified, and the design process begins again with a needs assessment for the new features. To date, we have successfully used our process for both the Phase I Symptom Self-Management interface and the Phase II Care-Giver Self-Management interface.

By including usability as well as pilot testing in our process, we follow the recommended best practice for software development [4]. This is necessary in order for the methodology to find and correct both software bugs and poorly designed features. Many of these design issues can only be found through testing.

3.1 Design of the Phase I Symptom Self-Management Interface

Design of the Phase I Symptom Self-Management interface began with the creation of a focus group of common citizens who shared an interest in cancer treatment. We also met with a pre-existing group of nurses, and with an oncologist, to get the provider perspective. During several meetings with the focus group and the providers, we gathered their ideas and also used a card-sort technique to understand how members of the public and the provider groups conceptualized cancer treatment information. Additional background was provided by evaluation of a version of the application, developed at MSU [5], that used telephone technology, rather than web technology.

The needs assessment and conceptualization stages of the Phase I development process are documented in Newlon, Hu, Stratton, and McDaniel [6], which also shows screen shots of the resulting interface. Implementation of the prototype was expedited through revision and reuse of self-help content from the telephone-based application.

Usability testing of this interface applied a simplified version of the best practices methodology. The testers were demographically suitable recruits role-playing pre-scripted scenarios as patients. Each participant's demographic information and prior knowledge were collected via a pre-test questionnaire, while overall reactions to the application were collected via a post-test questionnaire. Task successes and issues were collected by observer notes and by videotape.

3.2 Design of the Phase II Caregiver Self-Management Interface

The Phase II Caregiver Self-Management interface was created using a similar process. However, instead of a focus group, needs assessment and caregiver self-help content development were accomplished through consultation with domain experts.

Due to the variety of interfaces in the Phase II version, usability testing was conducted individually on each type of user (i.e., patient, family caregiver, health care professional), and also on a patient-caregiver pair, to make sure both the individual features and the linked functionality worked as required. The testers were again recruits role-playing pre-scripted scenarios as patients, caregivers, and providers.

4 Pilot Testing of the Application

A second key for success in developing a medical interface is rigorous field-testing. In addition to the usability testing that occurs during the standard development process, a full pilot test must be run on each version of the application using actual patients while they undergo actual treatment. This pilot study requires its own methods and strategies. In particular, the recruitment of recently diagnosed cancer patients is a challenge. It is a process that is impacted by stringent regulatory oversight, the limited resources of the providers, and the personal struggles of the patients and caregivers.

4.1 Pilot Test Design

The Phase I pilot study employed a single group, descriptive design to evaluate the system in terms of feasibility, acceptability, satisfaction and usability. The study recruited participants who were receiving chemotherapy at an NCI-designated cancer center. Based on each week's symptoms, the original interface generated evidence-based information tailored to each patient and sent notifications to providers when the symptoms reached a threshold level of severity. The gathered data was examined to identify patterns in user and system behaviors, providing a picture of how users interacted with the system and used the customized self-care guides to manage their healthcare. These research findings were used in the design of the Phase II PCMS.

As of this writing, the Phase II pilot study is just underway. It employs a single group, descriptive design, recruiting cancer patient-family member dyads. We hope for a sample that is large enough to correlate symptom levels with self-management behavior for at least the most common symptoms. This may be a difficult task, because the results of the Phase I pilot study demonstrated that the sample size of the symptoms is much smaller than the sample size of the participants. Even for the most common symptoms, not every patient has every symptom in any given week.

4.2 Methodology for Pilot Test Recruitment

For our Phase I pilot, gastrointestinal cancer patients who were seen in the clinics, and who were found to be both eligible and interested in the study by clinic staff, were introduced to the onsite study recruiter. After confirming eligibility, the recruiter consented and enrolled patients into the study. However, we found that identifying eligible patients and determining interest in the study quickly overburdened the clinic staff and resulted in low study accrual of 14 patients from 1-2009 to 11-2009. In addition, one participating nurse left during the study (7-2009). As a result, the one remaining nurse had difficulty facilitating recruitment due to an increased work load.

Consequently, during our Phase II pilot, we have sought to increase the effectiveness of our recruiting effort by allowing recruitment of patients with any solid tumor as long as participating nurses are caring for them. We also obtained a waiver of HIPAA authorization, for recruitment only, from the IUPUI Institutional Review Board (IRB). As a result, our clinic-based recruiters are now able to review the patient medical record for study screening purposes only, and identify eligible patients without burdening clinic staff. With permission from clinic staff to directly approach an eligible patient about the study, our clinic-based recruiters describe the

study to patient/caregiver dyads and obtain written informed consent. Clinic nurses sign an informed consent for the study in order to receive patient symptom alerts from the system. To avoid confusion, one co-investigator for our study is responsible for explaining the study to the clinic nurses and obtaining their written informed consent.

This appears to be working. In 12 weeks of recruitment, 12 nurses and 12 of 50 planned patient/caregiver dyads have consented. We have had 1 patient not eligible due to visual impairment, 3 patients refuse due to feeling overwhelmed, 1 patient refuse due to no caregiver, and 3 caregivers refuse due to lack of interest.

However, Phase II has also had other complicating factors. Our Phase II pilot is a multi-site project with recruitment at one site and interviews at another. This multi-site approach required the development of a web-based encrypted administrative site for patient-identifiable demographic information (e.g., name, address, nurse) and a secure, web-based data capture system REDCap, allowing investigators at different sites immediate access to data. [8].

Because we have multi-site, yet distinct, study activities; we were required to have IRB approval at both IUPUI and MSU. These multiple IRB approvals slowed the start of recruitment by 5 months. Also, because recruitment is limited to patients of nurses who consent to the study, we cannot enroll patients if their nurse has not consented. Two nurses have refused the study because they are not interested in participating.

5 Description of the Patient and Caregiver Interfaces

Now that we have completed the next iteration of our design process, and begun our recruiting, we are currently engaged in the Phase II pilot study of the PCMS with the new caregiver interface included. This interface allows caregivers to receive updates on symptoms reported by the patient, and also to manage issues of their own. Some of the modules included in the new, PCMS are listed in Table 1.

Table 1. User interface modules for *Pathways for Caring* project's PCMS

The PCMS has several user interfaces:
1. Patient Symptom Self-Management Interface
a. Symptom Reporting Module
b. Custom Information Module
c. Full Information Module
d. Symptom History Module
e. Evaluation Module
2. Caregiver Self-Management Interface
a. Concern Reporting Module
b. Custom Information Module
c. Full Information Module
d. Patient Information Module
e. Evaluation Module
3. Provider Interface
4. Administrative Interface

5.1 General Design

The graphics and user-interface elements for the PCMS have been created with the awareness that the application will be used by people who are very sick and/or dealing with the stress of a family member's illness. The reporting/evaluation requirements for the application are complex, so much thought has been given to streamlining the user interaction to ease the cognitive load for people who are not feeling well.

The application's system architecture is designed to serve caregiver-patient dyads. The design assumes that the caregiver may need help in receiving current information about the patient's symptoms, either due to physical remoteness or to communication difficulties. Therefore, the application is designed to bridge this communication gap, but in such a way that it will still function if one partner or the other needs to drop out for a while. For example, the caregivers are shown the symptom severity ratings their partners have reported earlier in each week's sequence. If the patient did not report symptoms during the current week, the last available symptom report is used.

All log-ins to the system are done via a common gateway, and participants are sent to the appropriate module, based on their role and/or the task assigned by the Messaging/Scheduling Module. The Messaging/Scheduling Module uses a nightly script to determine when it is time for a participant to log in and do the weekly report of symptoms or concerns. Participants are sent an e-mail message, with the URL and instructions to log in to the *Pathways for Caring* website. In the initial week of the study, the study participants only report symptoms/concerns. In subsequent weeks the participants do an evaluation of the previous week's results before reporting the current week's symptoms/concerns.

5.2 Symptom Self-Management Interface

The Symptom Self-Management interface is for the chemotherapy patient in the caregiver-patient dyad. The patient receives a reporting reminder from the system a couple of days before the caregiver is notified. This gives the patient time to enter this week's symptom information before the caregiver logs into the system.

Symptom Reporting Module. This module has changed little since its Phase I implementation was described in Newlon, Hu, Stratton, and McDaniel [6]. Patients are asked to respond to questions about the severity of nine standard symptoms, with the option of adding more symptoms if needed.

The significance of this interface is the amount of coordinated action that it drives. The symptom types and levels reported determine what self-management information the system pulls from its repository and presents to the patient. In addition, however, the symptom levels determine whether the system notifies the provider that the patient is having problems; also, they are displayed during the caregiver's subsequent reporting session, allowing the caregiver to request appropriate symptom management information from the system; also, they eventually become dependent variables for researchers examining the effectiveness of the application as an intervention.

The symptom reporting interface has also been designed to help the providers with their reporting requirements. Symptom details are reported using a combination of

numeric scales and multiple-choice descriptive statements. The descriptive statements in the multiple choice sections are intended to coincide with the National Cancer Institute Common Terminology Criteria for Adverse Events (CTCAE v3.0) [9] for each symptom, allowing the provider to receive the reportable toxicity level whenever the system sends a severe symptom alert to the provider (see Fig. 1).

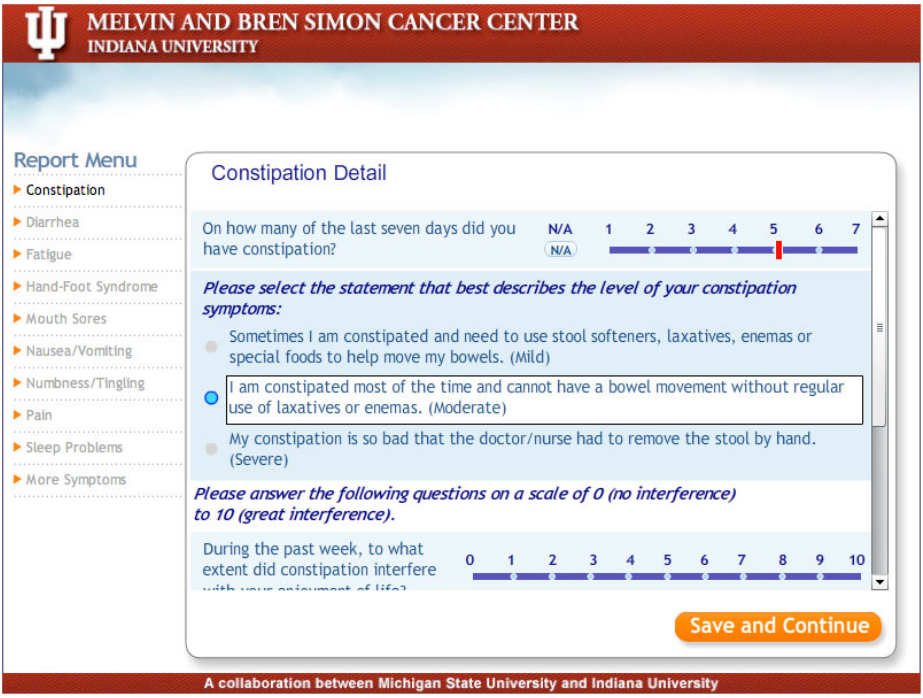

Fig. 1. The Symptom Self-Management interface's symptom reporting detail screen showing the toxicity criteria for constipation

5.3 Caregiver Self-Management Interface

The Caregiver Self-Management interface is for the caregiver in the caregiver-patient dyad. The caregiver receives a reporting reminder from the system a couple of days after the patient is notified. Again, this gives the patient time to enter the current week's symptom information before the caregiver logs into the system.

Concern Reporting Module. The Concern Reporting Module asks caregivers to report concerns about both patient symptoms and caregiver-centric issues.

The first reporting screen displays the most recent symptom severity report from the caregiver's patient (see Fig. 2) and asks the caregiver to indicate which symptom management information is needed. The date of the report is provided so the caregiver has a reference to the time and knows if the report is not from the current week.

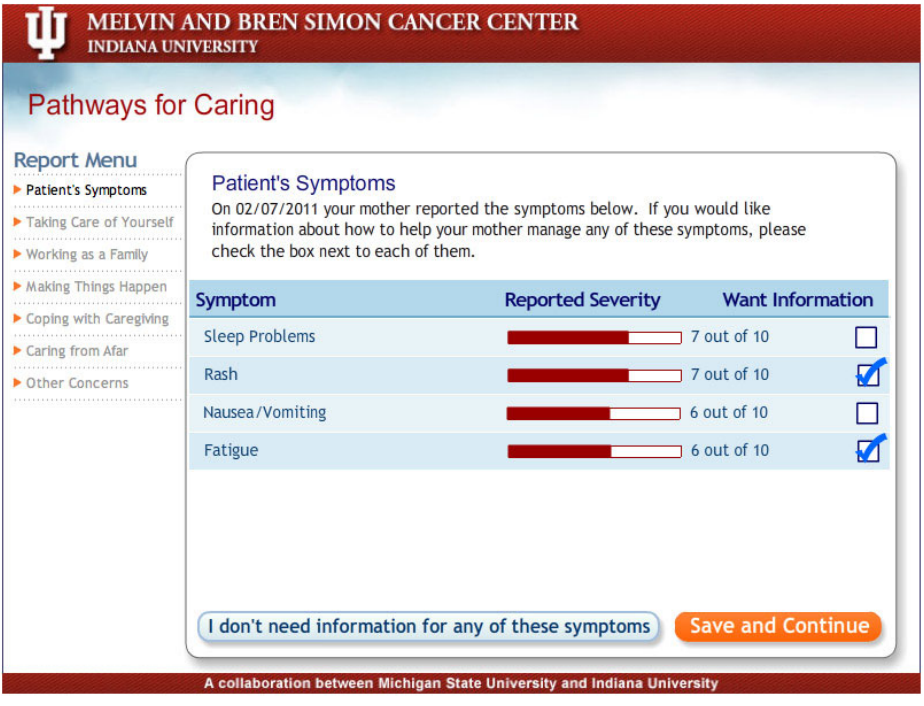

Fig. 2. The Caregiver Self-Management interface's Patient's Symptoms screen showing symptoms reported by the caregiver's hypothetical patient

On the next reporting screen, caregivers are asked to indicate whether they want or need information on various self-help topics. Caregivers living more than 50 miles from their partners also see a category for issues specific to long-distance care giving.

Custom Information Module. The PCMS records the caregiver's information requests and concerns and customizes information from the Symptom Management Toolkit and the Pathways for Caring Guide into a reference for the caregiver. The first section features any patient symptom information requests. In the following section, caregiver concerns that were ranked 3 or higher (out of 5) are displayed in order of highest rank to lowest. Each topic has practical advice and communication tips for friends, family, and health care providers. Fig. 3 shows an example of the Custom Guide.

5.4 The Provider Interface

The provider interface was designed to allow health care providers to respond to patient-generated alerts without the need to pass identifiable information through the alert e-mails. The alert tells the provider that a patient has generated an alert, but the patient is not identified. The project database keeps a list of each provider's patients, and patient alerts which have had no response. When the provider logs in, the patient list is displayed with outstanding alerts sorted to the top of the list. The provider can then click on the names to view the symptom reporting history for each patient.

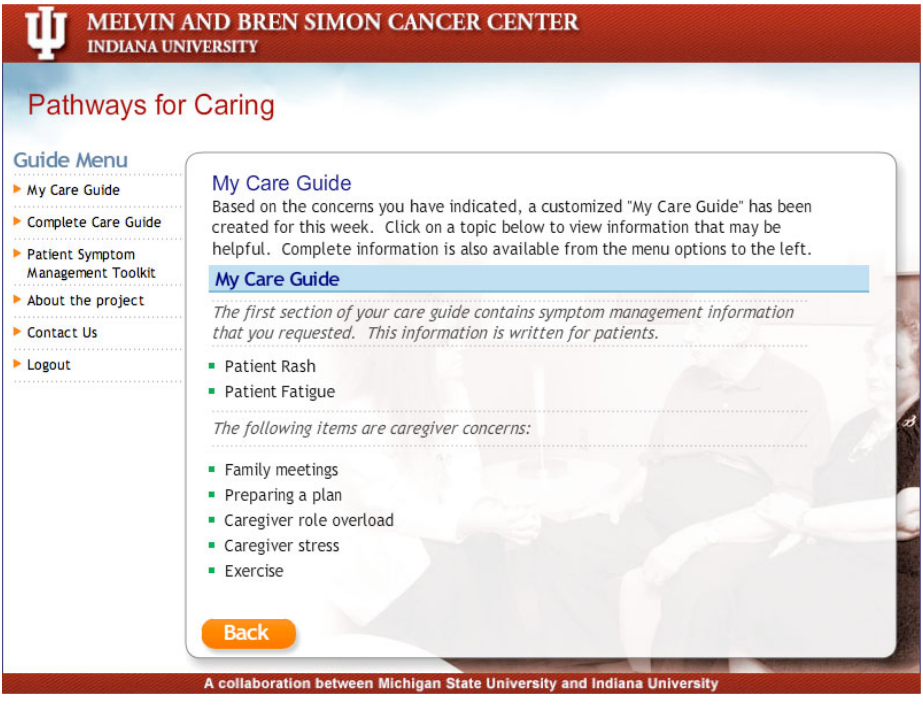

Fig. 3. Custom Guide screen showing links to self-help information about a hypothetical caregiver's concerns

6 Conclusion – Patient-Facing Smart Medical Interfaces

Given the broad demographic and the emotional frailty of those dealing with life limiting illness such as cancer, a well-tested interface is an imperative. This paper has covered the basic methodologies that we have used to develop and test patient-facing medical interfaces that are smart in the sense that they customize themselves based on the needs of the user. In particular, the *Pathways for Caring* project's *Patient-Caregiver Management System* provides an example of the potential for such interfaces to mediate interactions among such healthcare stakeholders as the patient, the caregiver, the provider, and the medical researcher. We would like to encourage further development of this sort of medical application. We also hold that a medical application design methodology such as the one herein described should be used as a general practice in the development of interfaces for health care applications.

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