Requirements and Design Issues of Ubiquitous Community Care Systems for Low-Income Pediatric Asthma Patients

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Abstract. The social support in self-management has shown positive results in chronic condition treatment. In this paper, for low-income children with asthma, we propose ubiquitous community care system, and introduce requirements and some design issues for the system. We elicit sixteen requirements from analyzing interview with seven low-income families and six providers. Based on the requirements, we introduce design issues for the system: being ubiquitous, community care, regimen specific support, easiness of system usage, and privacy concerns. We also propose a centralized architecture for our ubiquitous community care system. We contend that our requirements and design issues for pediatric asthma management can be utilized in building the systems. Furthermore, our work can be applied to other chronic condition management system with minor modification.

Keywords: Chronic Illness, Asthma, Self-management, Social Support System, Requirements, Design Issues.

1 Introduction

Asthma is one of serious illness because of its high morbidity and mortality. The worse thing is that it is a prevalent chronic illness among children in the United States [1]. Chronic illness such as asthma requires long-term treatment and self-management. Self-management includes "understanding of one's disease, effective management of symptoms using a plan of action, medication, and appropriate psychological coping skills" [2]. However, in nature, pediatric asthma patients have difficulties in managing asthma by themselves because 1) they are too young to know how to manage it, 2) they cannot control their desire (for example, playing with their friends) even though they have asthma exacerbation symptoms, and 3) sometimes asthma attack happens so fast that they require the emergency treatment. Therefore they require the support from their family and sometimes community members such as schoolteachers, school nurses, and even neighbors. The support includes "helping the children to avoid asthma triggers", "helping them to medicate regularly", "helping them to manage symptoms properly", and "handling emergency situations".

T.-h. Kim et al. (Eds.): MulGraB/BSBT/IUrC 2012, CCIS 353, pp. 326–333, 2012.

After analyzing interview data [3], we found out the necessity of the systems that are ubiquitous and community-based for caring of pediatric asthma patients [4,5]. In this paper, we introduce the requirements for the ubiquitous community care systems and some design issues for the system implementation. We elicited the thirteen functional requirements and three nonfunctional requirements from the interviews. From the all requirements, the most important functional requirements are that the system should be 1) ubiquitous, 2) community-based, 3) able to support communication, and 4) able to be used for analyzing the symptom trends. The most important nonfunctional requirement is cost, because the system is for low-income families. Based on the requirements, we propose SMS-based, social network service communication system, called Asthma411. Cell phone is almost ubiquitous because people always carry with it. Based on cell phone, we design a small community social network service in which the main subjects are related to asthma and the children with asthma. In the cell-phone based social network, they can communicate each other for help the children to manage themselves with the help from others such as family and schoolteachers.

This paper consists of five sections. In section 2, we summarize the related works and compare our work with them. In section 3, we describe our findings and requirements that are elicited from the interview. In section 4, we discuss the design issues for asthma management system. After that, we show a centralized architecture for Asthma411 in section 5. Finally, we reveal our conclusions in section 6.

2 Related Work

There have been various research topics on pediatric asthma patients. This paper is related to the research on self-management programs for pediatric asthma (with social support or not) and ICT-based systems for asthma management.

There have been researches on asthma self-management and self-management program. Arvind Kumar [2] suggests general guideline for asthma self-management: 1) knowledge about asthma, 2) accepting the disease, 3) skill of taking medication, 4) keeping a daily routine (such as taking prescription medication), 5) monitoring symptoms, 6) adjusting medication, 7) avoiding triggers, 8) knowing when/how to contact hospital, 9) accessing social support mechanisms, and 10) coping mechanism with psychological sequelae. J M Ignacio-Garcia and P Gonzalez-Santos [6] show that asthma self-management improves morbidity parameters (days lost from work, asthma attacks, and emergency room visits).

There have been researches on ICT-based self-management programs. Victor van der Meer and his colleagues [7] argue that internet-based asthma self-management can utilize electronic monitoring, accessibility to information, e-mail, and an electronic action plan. Victor van der Meer's another work [8] shows that Internet based asthma self-management improves asthma control and lung function, but not exacerbations.

Compared to the existing researches, our work has some uniqueness. First, there has been no try on asthma self-management with ubiquitous technology, even though

it does not require high technology. Second, there have been some arguments for community support for asthma self-management, but there has been no ICT-based system for the arguments. As far as we know, our system is the first try in this field. Third, our proposed system can support closed social networks for caring the children with asthma. This is also new try in building a social network with SMS.

3 Requirements for Asthma Care

In order to understand pediatric asthma and their management, we interviewed seven low-income families suffering from pediatric asthma (seven parents and eight children with asthma) and six providers (a pediatric pulmonologist, an allergist, a nurse, a respiratory therapist, a physician assistant, and a certified asthma educator who was a school nurse) in our previous study [3]. By analyzing the interview data, we got some findings and requirements for asthma management systems.

- F1. One important problem in asthma management is that asthma attacks or exacerbations can happen anywhere and at any time. It means that people who are around the child should be able to help him/her. The people can be schoolteachers, school nurses, his/her friend's parents, or even school bus driver. This finding leads two requirements: (R1) being ubiquitous and (R2) ability to get the information required for helping the child.
- F2. Early treatment in time is critical. Asthma exacerbation should be managed in time, or it might cause a serious situation like emergency room or even death. This leads at least two requirements: (R3) knowledge for proper treatment of asthma exacerbation, and (R4) constant monitoring the child with asthma.
- F3. Like many other chronic conditions, the child's asthma condition changes continuously. Therefore, if it is not properly managed, the condition gets worse, and the treatment action called asthma action plan should be changed. This leads this requirement: (R5) keeping updated asthma status information.
- F4. Asthma patients visit clinics to see doctors on the regular basis (every three to four months according to their severity). During the visit, doctors ask patients about their asthma symptom since the last visit, but the answer is not so accurate. This leads two requirements: (R6) recording asthma symptoms and (R7) summarizing the symptoms information for doctors.
- F5. Caregivers (parents, schoolteachers, doctors and nurses, and CHWs) communicate each other with various purpose and various media including face-to-face, phone calls, emails, text messages, sticky notes, and even fax. Phone call is very easy to talk, but sometimes it is hard to connect to the caregivers. (R8) For implementation, the communication media should be limited to a couple of media.
- F6. For asthma management, it is important to keep daily routines including taking medicine every day, and checking lung capacity. Sometimes, family members cooperate to help their child keep the daily routines. This finding leads two requirements: (R9) a mechanism to cooperate each other to keep daily routines, and (R10) reminder mechanism not to miss the daily routines.

- F7. Asthma patients should avoid asthma triggers. Asthma triggers are various, but the well-known triggers include smoking, dust, high or low temperature, high humidity, and pollen. This finding leads to the requirement: (R11) sensing asthma triggers and (R12) providing weather information.
- F8. Parents want to get educated about asthma management. Therefore, (R13) the system should have a mechanism that community members give parents medical information for asthma management.

In addition to findings from interview data, we can also elicit other requirements from general information. These requirements are not related to system's function, but these are also very important. Requirement from 14th through 16th are those non-functional requirements.

- (R14) Cost is a very important feature because it is for low-income families. If the system is expensive, they will not be able to utilize the system.
- (R15) The system should be easy to use. If it is hard to use, they will not use the system, and they cannot help the children with asthma.
- (R16) In medical information, privacy and security are very important issues. Somehow, this requirement is contrast to the requirement R2.

We have sixteen requirements, but some of them are non-functional requirements and some functional requirements are combined into a couple of functions.

4 Design Issues for Ubiquitous Community Care System

4.1 System Usage Scenario

The following usage scenario will reveal how our system works. This is a scenario of monitoring and helping the child with asthma at school:

At school, John (child with asthma) has a bad cough, so his homeroom teacher requests his asthma action plan from the Blackboard and checks his status. According to his asthma action plan, he has to take a specific medication, so she takes him to the school nurse and leaves a message about his status on the system for other caregivers: his parents and his after school basketball coach. And the school nurse gives him the medication, and she also leaves a message to his parents, "Make sure he brings his medication to school tomorrow", because his medication almost runs out.

In this scenario, the schoolteacher is the caregiver. She senses his bad cough, checks his asthma action plan, and cares him by taking him to the school nurse. If she does not sense or does not check his status, she might ignore his cough, and it might cause an emergency situation.

4.2 System Model

From the requirements, we made system model in our previous work: being ubiquitous, blackboard communication, and community care [4,5]. In this section, we will describe the model from the perspective of system design. It is closely related to our system platform and core technology for the system.

Being Ubiquitous
From the requirement R1, the system should be ubiquitous, and it also should be able to monitor the children (R4) and to provide proper information (R2). For being ubiquitous, there are two possible approaches. First approach is for the children to carry a device to everywhere all the time. The device can be a cellphone or other special device such as Smart Asthma Box [9], which is suggested because most of asthma patients keep their asthma box when they go out. Cellphone have been used as an assistant technology for helping the children with asthma [10]. The second approach is to implant sensors everywhere the children go. There have been researches on embedding sensors in home [11] for asthma patients. From the two approaches, we choose the first approach, because the second approach cannot cover all places where the children go.

Blackboard Communication and Community Care
The Blackboard Communication meets many requirements. First, Blackboard Communication is combined with cellphone SMS or data communication such as smartphone app or desktop web. The unified data communication (R8) allows all the data transferred to be processed and stored. The unified communication allows all care givers to communicate more conveniently and more effectively (R9). Second, Blackboard Communication plus an information processing component meet the information processing related requirements: R10 and R12. Blackboard Communication plus information retrieval function can help care givers (including doctors) to care the children with proper information (R3 and R7). They can get the information via cellphones and desktop computers. Blackboard Communication plus storing function meet the requirements R5 and R6. Any care givers can record the children's asthma symptoms and their current status using SMS. The stored data are very helpful when care givers treat emergency situation and when doctors determine the children's asthma severity.

4.3 Regimen Specific Features

The systems that support chronic illness self-management should support regimen specific features because it has been known that regimen specific self-management have positive influence. Therefore, our system also should support asthma specific features: avoiding triggers, performing routine tasks, early treatment, and sensitivity to the weather. These asthma specific features are covered by the requirements, so that our system meets the asthma specific requirements.

4.4 Easy to Use

There have been successful efforts using SMS in healthcare [12], and we extend SMS to a social support platform for chronic illness management. The SMS communication should be easy to use (R15). The communication types are categorized into two: sending "write" messages and "read" (request) messages to the system. This covers getting information about patients, leaving messages about the patients, giving educational messages for caregivers, communicating with each other, and time-specific task reminders.

When a user wants to share information, he/she can use the system following a simple text message format: <command, person, message>.

For example,

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R John's action plan
W John had a bad cough at school
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The first message requests (R) John's asthma action plan from Asthma411, and the second one saves John's status to the system (here "W" is writing the John's status).

4.5 Openness and Privacy Issues

Healthcare information is very private and it should be protected (R16). However, in order to get helps from care givers, the access to the information should be open (R2). Therefore, there is contradiction in privacy and openness. In our system, we utilize two approaches. The first one is to build a closed social group consisting of family, schoolteachers, school nurses, coaches, CHWs, and other neighbors. The group members can access the information freely, but others can access only the information for emergency situation. The second approach is to get the grant that allows everyone to access the information at initial stage from the parents. The parents can choose one from the two approaches.

5 System Overview and Architecture

5.1 System Overview

Asthma411 is a system that has four main features: it is asthma-specific, patient-centered, and ubiquitous (accessible from anywhere at any time by anyone) and socially mediated. Its goal is to mitigate asthma symptoms and increase the quality of life for asthma patients and caregivers. This goal will be accomplished by 1) providing communication paths that are available at any time and from anywhere, 2) helping caregivers to send asthma related information on a regular and timely basis.

We classify Asthma411 users into three groups according to their roles: parents and family, schoolteachers and extra-curricular caregivers (for simplicity's sake we will refer to them as "coaches"), and CHWs. Parents are the primary caregivers. They are responsible for monitoring their children's asthma status, making sure their children are taking their medicine and managing communication about the children's

asthma with the other caregivers. Schoolteachers and coaches monitor the students and manage the students' activities while the students are in their care. CHWs help parents and children with asthma get educated on how to take medicines, what to be avoided, and how to manage their houses.

5.2 System Architecture

Every message is transferred to the Asthma411 server, it is processed there, and then it is delivered to a specific caregiver or is open to everyone. It follows the centralized client server architecture as shown in Fig. 1.

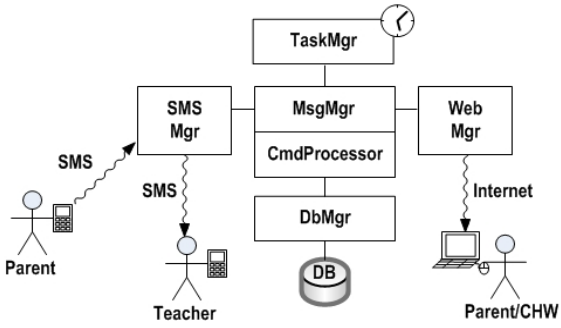

Fig. 1. Asthma411 System Architecture

In Ashtma411, there are two types of clients: web client accessed from desktop and SMS client accessed from cell phones. SmsMgr plays the bridge between cell phones and the information system. It receives SMS and transfers it to MsgMgr, which processes messages according to its meaning. MsgMgr includes CmdProcessor, which interprets commands and process the message. TaskMgr executes time-specific tasks such as reminder jobs. WebMgr makes web pages with accumulated message data for web users.

6 Conclusions

Pediatric asthma is a widely prevalent chronic illness, and it requires management strategies that mediate communication between numbers of care givers. In this paper we proposed a ubiquitous community care system, and introduced sixteen requirements and six design issues for the system. The system requirements were elicited from the interview with seven low-income families suffering from pediatric asthma and six providers. The requirements cover the needs for asthma specific treatment such as sensing asthma triggers and getting weather information. They also cover the needs for general chronic illness management including routine task reminder function.

Based on the requirements, we proposed six design issues: being ubiquitous, blackboard communication, community care, regimen specific support, easiness of system, and privacy concerns. After considering the design issues, we chose SMS-based, centralized system architecture for our ubiquitous community care system.

We contend that our system model can be used to build the ubiquitous community care system. Furthermore, our proposal and design issues can be applied to caring for a variety of populations where communication between varieties of caregivers must be established. This includes the elderly and patients with other chronic illnesses such as diabetes. In the future, we plan to implement Asthma411 system that follows our requirements and our design, and conduct user studies with the system.

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