e-ESAS: Improving Quality of Life for Breast Cancer Patients in Developing Countries

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ABSTRACT
In this paper, we present e-ESAS, a mobile phone based remote monitoring tool for patients with palliative care need, carefully designed for developing countries. Most of the current remote monitoring systems are complex, obtrusive and expensive resulting in a system unsuitable to deploy in low-income countries. We here describe evolution and performance of e-ESAS within the contexts of breast cancer patients as these patients require management of pain and other symptoms. Edmonton Symptom Assessment Scale (ESAS) was developed to capture the important parameters where patients themselves report their level of ten symptoms. Our e-ESAS improves the current system by reducing visits by patients to clinics, providing more flexibility to both doctors and patients, improving the quality of data, accommodating doctors to fine tune interventions, and providing a convenient representation of data to doctors. User interface was designed according to feedback from users resulting in a UI with better performance. The system is intended to provide a platform for future research as large amount of real data is being accumulated from the deployment. The system demonstrates the feasibility of accessing quality health care through cell phones by rural, poor patients in developing countries. By ensuring less time to view patient information, the system enables doctors to serve more patients.

Categories and Subject Descriptors
H.5.m. Information Interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms
Measurement, Design, Performance.

Keywords
Breast cancer, mobile computing, remote monitoring.

1. INTRODUCTION
There is tremendous growth of mobile technology worldwide especially in developing countries. Most of the recent growth in cell phone subscribers is centered in these regions. The pervasiveness of cell phones equipped with ever-increasing processing power and storage capacity is opening the door of ideas that were once considered wild.

There has always been a divide between rich and poor when it comes to healthcare service. Healthcare is expensive and poor people simply cannot afford it. Mobile technology has the potential to revolutionize health care in developing countries by reducing this division. So far mobile phones have been used for education and awareness, collection of remote data, and remote monitoring.

Our goal was to identify the problems in the treatment of rural women with breast cancer and come up with a sustainable inexpensive solution that will improve the quality of life of patients, doctors and healthcare personnel and thus improve the healthcare infrastructure as a whole. With this goal in mind, we visited Bangladesh in four phases and worked with Amader Gram. Our system helps in the communication between doctors and patients by creating a cell-phone based channel. In a similar work [1] by Mitchell et al., a PDA-based application was developed to determine if AIDS patients can safely continue their current treatment or require consultation by a physician. In Rwanda TRACNet [2] was developed and deployed to collect data from participating clinics. Luk and her colleagues [4] built a computer-mediated communication system to bridge the gap between doctors. Researchers in [3] gave ASHAs cell phones with videos persuading pregnant women to avail health care facilities. Our system is unique as patients themselves provide data as direct users of the system.

We present background and methods of the study in Section 2 and 3 respectively. In section 4, we present our observations from our visit to Bangladesh. In section 5 we propose and describe a system, e-ESAS. We present the results from our demonstration and feedback to the users of e-ESAS in section 6. Section 7 discusses some of those results. Section 8 discusses future work and conclusion.

2. BACKGROUND
2.1 Statistics
Cancer has become the number one killer of women in childbearing age in Bangladesh, according to Maternal Mortality Survey in 2010. While looking for causes of death of women in childbearing age [5], this shocking finding was noticed. It showed cancer accounts for 21 percent of women's deaths between 15 and 49 years of age. Sixteen percent of the total cancer affected women in the country are victim to breast cancer, says a World

MobileHealth'12, June 11, 2012, Hilton Head, South Carolina, USA.

Health Organization (WHO) study [12]. WHO also ranked Bangladesh 2nd in terms of mortality rate of women in the country from breast cancer [12]. Similar scenarios prevail in other developing countries as 70% of all cancer deaths occurred in low or mid-income countries in 2008.

2.2 Infrastructure

With this background in mind, we visited Bangladesh first in the summer of 2010. Our goal of first visit was to identify the problems in obtaining treatment and design a sustainable system for rural breast cancer patients that will improve the quality of life people by improving the processes of healthcare. We demonstrated our system and received feedback about it in our next visit on January 2011. After redesigning and redeveloping according to feedback received, we visited Bangladesh in the summer of 2011 for third time. Our goal of third visit was to deploy the system and collect data about the performance of the system. We eventually deployed the system between 3rd and 4th visit.

We partnered with Amader Gram (AG) (literally means 'Our Village') which is a local organization dedicated to offer breast cancer treatment in rural Bangladesh. Amader Gram partnered with International Breast Cancer Foundation and built AGBCC in 2006. In AGBCC, a trained female doctor and a medical assistant attend each clinic that treat and keep records of patient information. AGBCC also has Community Health Workers (CHW) in rural areas that visit different homes in villages and work as primary screener. They identify the women with breast problems and encourage them to seek help in AGBC centers.

3. METHODS

In our first visit to Bangladesh in summer 2010, we tried to understand the current practice so that we can propose a system which will improve the current system. With this goal in mind, we interviewed people with different roles in the system. We interviewed patients, doctors, medical assistants and field workers. We were interested about their level of familiarity with cell phones, especially in case of rural women. We observed patient-doctor interactions in clinical setting, interviewed patients in 2 hospitals and several patients in their homes. We were especially interested in identifying barriers both from the perspectives of patients in obtaining treatment, and of doctors in providing treatment. Instead of targeting all the barriers, the goal was to identify a subset of problems that our proposed system will be able to solve. We asked patients about their education, environment, family, disease, economic condition and knowledge about cell phone use.

We designed and proposed a system which addresses some of the barriers of the current system. The system was demonstrated to the doctors, patients and health care workers and their feedback was collected. We addressed some of these feedback and incorporated some changes and deployed the modified system in our 3rd and 4th visit to Bangladesh. During deployment, 10 Nokia X6 phones were given to 10 patients for this study. We collected feedback from this second version and deployment and the results we present in this paper are based on data collected from demonstrations, deployment and feedback. We are still collecting data from this pilot deployment.

4. OBSERVATIONS

From our visits to Bangladesh, interviews with doctors, patients, attendants, medical assistants and field workers, we have made several interesting observations. Statistics of the country's health care system also gave us some insight.

4.1 Lack of Resources

Developing country like Bangladesh lacks the resources required for a good healthcare system. Resources for cancer care are even more insufficient than the facilities available for other diseases. One reason is cancer care is very expensive compared to treatment of other diseases. According to a report by 'National Cancer Control Strategy and Plan of Action 2009-2015', there are about 500 hospital beds dedicated for cancer patients throughout different hospitals in the country. This number is very small compared to what is needed for a population of 150 million. According to government, there are about 250 doctors for 1.2 million cancer patients. Every year 200000 more cancer patients are added and about 150000 die of cancer related causes [6]. There are only 18 radiotherapy centers in the country where about 300 are required. Only one of them is situated in the rural areas. Only 11 of these are modern Linear Accelerators [7]. The idea of palliative care for relieving the sufferings of patients is almost non-existent in Bangladesh.

4.2 Doctors use ESAS

We found the doctors use a paper-based tool, Edmonton Symptom Assessment System [10], commonly known as ESAS, to record patient data. This tool was designed to assist in the assessment of ten symptoms common in cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath and other problems.

4.3 Lack of Ethnic Cancer Data

According to [9], Compared to African American women, white women are slightly more likely to develop breast cancer, but less likely to die of it in USA. One possible reason is that African American women tend to have more aggressive tumors. There is lack of such ethnic data in Bangladesh. It is true that population is mostly homogeneous in the country but it has a large population and the possibility of any pattern among the population cannot be ignored and thus demands attention from the researchers. Lack of such database prevents the discovery of such demographic pattern.

4.4 Palliative Care for Cancer Care

Very often cancer is not curable and in those cases goal of treatment changes from curing the disease to improving the quality of life by relieving the sufferings of the patients. In these cases, patients need palliative care along with regular treatment. Patients often complain about pain, nausea, depression and lack of appetite as a side effect of cancer treatment, like chemotherapy, surgery or radiotherapy. That is why doctors try to manage these symptoms by keeping track of them and providing intervention accordingly.

4.5 Pain Management is Important

As cancer progresses, pain management becomes a significant part of treatment. From our sessions with doctor and patients it was evident that pain is a very important symptom as it controls the quality of life of patients significantly. Doctors need regular updated information for improved pain management. The level of pain, trend of pain, current medicine and their doses are some of the parameters that doctors need to be updated of regularly. Doctors have to find the right regimen from the feedback of patients.

4.6 Underdeveloped Transport System

Like many other developing countries, Bangladesh suffers from a not-so-well transport system. There are not enough vehicles and roads to support such a large population. Most people use rickshaws to travel short distance and cars are way out of means for most people. To travel from one city to another, people mostly uses buses, trains or launches which are uncomfortable partly due to bad conditions of the road and partly due to overcrowding. Travelling to and from Dhaka, the capital of the country and moving in the city is a painful experience due to its notorious traffic jam.

4.7 Urban-Centric

The whole country is very much centralized. As a result all the growth and development is centered on Dhaka. There is shortage of doctors, clinics even in small towns, let alone rural areas. As people in rural areas are poorer, there are not many good doctors in those areas. Especially, oncologists are rare even in Dhaka. As a result people often have to travel to the capital or other big cities through a poor transport system to get treatment for complex diseases.

4.8 Irregular Follow-ups

Patients in Bangladesh, especially in rural areas, are not very consistent in their subsequent visits to doctors. Reasons are manifold behind this. Traditionally patients visit doctors with a family member or a friend. All the patients we interviewed came with a relative or a friend. Failure to manage a companion can prevent them from visiting doctors. In case of women, they are mostly responsible for household work, like cooking and taking care of children, especially in rural areas. Rural women have to travel a significant distance in case the doctor is in another city and they have to find a substitute for their household works. The long commute to doctors is another deterrent for patients to visit doctors regularly.

4.9 Growth of Cell Phone Subscribers

There is a steep growth of cell phone subscribers since 2005 and as of December 2011 total cell phone subscribers has reached 85.455 million, according to Bangladesh Telecommunication Regulatory Commission [8]. It has actually tripled since 27.72 million in June, 2007. Unlike other facilities, we observed that cell phones have reached even in rural areas. Almost 96% of patients we interviewed have access to cell phones either by owning a phone personally or having a family member who owns a cell phone.

4.10 Cheap Cell Phone Services

Interestingly cell phone plans are cheaper than lot of developed countries due to intense price competition and high density of population. Also poor families own one cell phone instead of every member in the family. Even a patient, who lives in a mud hut in a remote village of Rampal, a small sub-district of a small southern town, uses a Samsung phone. We found from [11] that 1 MB data cost less than 30 cent and some packages sell 15 MB for 45 cents.

4.11 Smart Representation

Medical data are often poorly represented as not enough attention is given to representation of data. Representing data in a smarter way so that trend and pattern is clearly visible will be helpful to discover hidden information for doctors.

5. E-ESAS

5.1 System Architecture

The system basically consists of two parts: A server and a client. The architecture of e-ESAS is shown in Figure1. The client has two modules; patient's module and doctor's module. Same client software is installed for both modules. So, the same phone can be used by both doctors and patients.

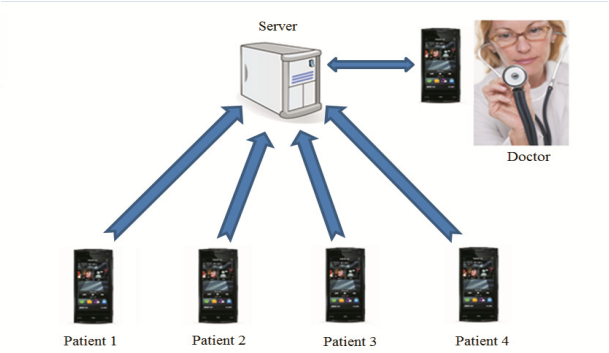

Figure 1. Architecture of e-ESAS

5.2 Technologies

On the server side, we used Apache Tomcat 6.0.26 as server and MYSQL as database. We created 5 tables in the database. These are: 'patient', 'doctor', 'record', 'medicine_record' and 'videolog'. The 'patient' table stores patient information. We added a new field in the table for IMEI number as we moved to IMEI-based authentication. The 'Doctor' table contains doctor information. The 'record' table stores all records of 13 symptoms (integer number), their date and patient id in 15 fields. The 'medicine_record' table stores prescription, patient ID, doctor ID and time. A new table called 'videolog' was added to keep track of frequency of video viewing by patients. It logs 'video_ID', patient name and timestamp. Another client was PHP based client website. Ajax with PHP was used for developing the website. For Web Service, JSP and SOAP were used. The application was developed for Nokia X6 phones. We used s60 5th edition SDK v1.0 emulator for developing the system. The data is actually transmitted over internet using the data plan of cell phone operators or Wi-Fi service. When a command is executed in client, a web service is called in sever which executes corresponding operations on the data in the database, insertion, deletion or update in database, for instance.

5.3 ESAS to e-ESAS

For cancer patients, palliative care is very important as quality of life drastically decreases due to pain, tiredness, and depression as a side effect of chemotherapy, radio-therapy or surgery. ESAS works as a tool for doctors, especially palliative care specialists to assess the symptoms and provide interventions accordingly. Patients usually complete a paper-based ESAS questionnaire when they come to the clinics. This form gives only an instantaneous view of the symptoms to the doctors.

In the case of e-ESAS, a screen (Figure 2(a)) with several buttons with Bangla text appears after it is started in the cell phone. The page has the option to log in as a doctor. Initially the patient too had to log in using username and password. Now the IMEI number is used for automatic authentication as the IMEI number of each patient's mobile phone is already in the database. After pressing the yellow button, patient is directed to ESAS page. The page has 13 questions. Each item consists of a button followed by

a sliding bar. The button-texts are in Bengali which is translations of pain, tiredness (and other symptoms). If the button is pressed, it plays a voice in Bangla language instructing how to use the corresponding sliding bar. The patient uses the sliding bar and set a value from 0 to 10 as per the intensity of the symptom.

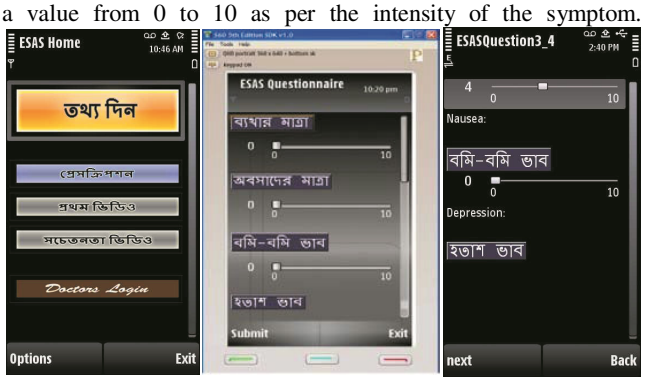

Figure 2. a) First screen b) First version of ESAS page c) ESAS page after modification

The default value is 0 for each symptom. After setting values for all the symptoms, a submit button below is pressed which transmits the data to the server and stores it in a table (patient table) in the database. Date, time and patient ID are also recorded in each submission in the table. Figure 2(b) is a screen shot of first version of ESAS page where all 10 questions are in same page. Figure 2(c) is one of six pages of second version where each page has only 2 questions.

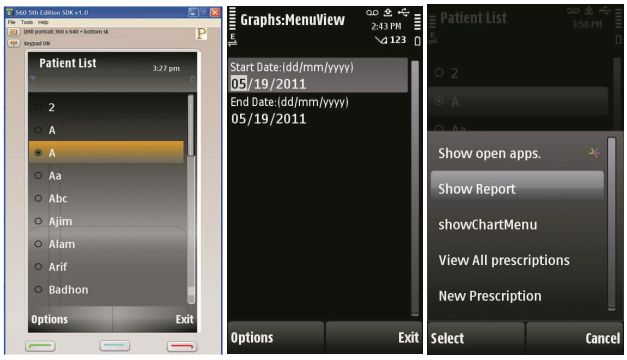

Figure 3. a) Patient list b) Prompt to enter date c) Options for doctors

When a person logs in as a doctor, a page with list of all the patients appears. Figure 3(a) shows screen shot of a list of the patients. Doctor can select a patient by selecting the text by finger. After selecting the patient, a doctor has several options as in Figure 3(c). She can view all previous prescriptions, create a new prescription, and view patient symptom data in graphic form or in simple text form. These actions can also be done from a website. Doctors have the option to access the same patient data from both cell phones or from a website.

If a doctor selects to view the graphs of a patient, a page appears and is prompted for a start date and end date as in Figure 3(b). The doctors had to type dates in the cell phone.

After selecting the 'options' menu date page, a doctor can select several operations from menu bar. There are menu items for each of the symptoms and the doctors can view the graph by selecting his intended symptom. In our first version, we had 10 menu items for 10 symptoms which we increased to 13 items as 3 more pain questions were added. The label below the graph explains what the graph is about along with the time range and the patient name.

Another change we made for the doctor's module was segmentation of the graph. Instead of squeezing all the data points in a single page, at most 7 data were shown in each page as in figure 4(b). Figure 4(c) is graph of 3 parameters in webpage.

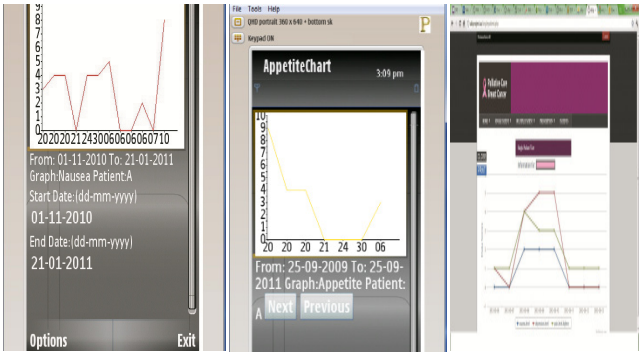

Figure 4. a) Graph of nausea (All data points in one page) b) Graph of Nausea: 7 data points per page c) Graph of 3 parameters of a patient (in web)

6. RESULTS

After our field study in the summer of 2010, we built our first version of the system and demonstrated it to patients, doctors and healthcare workers in our second visit to Bangladesh. We demonstrated the patient module to 37 patients at different AGBC centers and hospitals and 2 patients at their homes. Both doctor's module and patient's module were shown to doctors, both at Khulna AGBC center and to several doctors in Dhaka. We also received feedback from pilot deployment.

6.1 Reduced Errors

We asked the patients set some values in their ESAS questionnaire. We found that when the patients scroll down to set values of later symptoms, they unintentionally change the values of previously set values. Also, sometimes they unintentionally touched the exit button and closed the application. As can be seen from table 1, the patients made 1.2 errors on average in completing the form. We changed the UI, and instead of all 10 questions in one page, we made 5 pages, each with 2 questions removing any need to scroll down.

Table 1. Error comparison of two versions of e-ESAS

#Errors / Version	0	1	2	3
First	9	16	11	3
Second	10	1	0	0

We also added one page for 3 new questions related to pain. In our 4th visit, we asked patients to fill out ESAS form and only 1 patient made a single mistake. We also removed the exit button from each page and placed it as a menu item in a menu on the last page. This prevented accidental closing of the application.

6.2 Timing Requirement

In our experiment, we also collected timing requirements to fill out the 10 questionnaire of ESAS. For the first version, it was 2.66 minutes on average. For the second version, for 7 patients and attendants, we found that on average it takes 2.8 minutes to fill out the form. The increase in timing requirement is due to two reasons: First, the number of questions has increased from 10 to 13. Second, a small amount of time is required to move to the next

page (five page changes in total). Table II shows time consumption to fill out the form for two versions of e-ESAS.

Table 2. Timing requirement of two versions

Time(mins) / Version	1.5-2.0	2.0-2.5	2.5-3	3-3.5	>3.5
First	3	10	17	9	0
Second	0	3	4	2	1

Though the 2 versions do not differ significantly in time consumption, for both doctors and patients, e-ESAS saves time by saving time for travelling as e-ESAS decreases need for travelling. Saving a travel is a very important benefit for rural women as it saves them a lot of hassle.

6.3 Saves Time for Viewing Patient Data

A doctor can view the patient ESAS data through cell phones or from the website. Viewing from website was added later. The system, e-ESAS represents the information in a line graph and no time is required for this smart representation, unlike the paper version where it would have taken a significant amount of time and human effort to do it manually. Doctors can view all the previous prescriptions and they are sorted by date. We argue that it saves time for doctors as the prescriptions are organized and e-ESAS automatically converts data into graphs. We conducted a survey among other patients and patients with these phones. We found that latter group requires less time (5.05 minutes) than the former group (9.35 minutes).

6.4 Improved Data Quality

Our e-ESAS improves quality of data as data are captured more frequently. Doctors can view data instantaneously so that the information is fresh and relevant. There is no possibility of forgetting to record date, time and patient name as the system automatically records this information which is a possibility in paper-based system. Also the symptoms are recorded in the clinic where they are biased by several factors. It can be that the patient wants to make an impression on the doctor by mentioning a severe pain level to attract more attention. Or she might mention higher tiredness level as a result of travelling a long distance and waiting in the queue at clinic. The e-ESAS captures the true data as data are recorded in 'natural' setting and not influenced by such factors. In case patients forget to bring previous prescriptions, doctors can view all previous prescriptions through e-ESAS from their cell phones or website and still remain informed. Also in paper-based system, converting data to smart representation requires human effort and thus have the risk of errors. For e-ESAS, this is not the case. We argue that e-ESAS thus improves the quality of data.

6.5 Increased Flexibility

The greatest advantage of e-ESAS is its flexibility. Doctors can view at anytime and from any place. They can view patient information from their taxi while struck in a traffic jam or from a train or a bus or rickshaw. Patients can also record symptom data at anytime or from any place. Cell phones have the advantage that people carry them all the time. So, no extra device is being carried.

6.6 Better Representation of Data

Doctor can view the trend of pain and other symptoms as data is represented graphically which makes it easy to recognize any pattern if there is any. Our first version had all the data of a patient in a single page which becomes messy when a lot of information is being viewed. The doctors we demonstrated e-ESAS to, suggested modifications so that at most 7 data is shown in one page. According to feedback from doctors, we introduced option to view data of one symptom (pain or nausea etc.) of multiple patients on a single graph in the website. This allows doctors to compare how an intervention working on different patients. Also, graph of multiple symptoms (pain, tiredness and nausea, for example) of one patient can be viewed in a single graph. Viewing this information in graphic form makes it easier to make critical observations.

6.7 Finer Pain Management

Doctors emphasized on pain as a symptom as it is a common symptom and also because it greatly controls the quality of life for cancer patients. Three new pain related questions were added according to their suggestions. We expect this would increase the accuracy of pain related data. Along with current pain level, highest, lowest and average pain level of last 24 hours were recorded in these three questions. This helps the doctors to be more informed about patients.

6.8 Others

6.8.1 Less Communication Time

The system increases information exchange between patients and doctors by creating a new channel between them which decreases communication overhead.

6.8.2 Improved Follow up

Patients in Bangladesh in general are inconsistent to follow up with doctors. They only visit doctors when they are in pain. In case of e-ESAS, implicit follow up is continued as doctors can monitor day-to-day ESAS symptoms, even if patients do not show up. For example, if a patient data mentions high value for shortness of breath for several days, a doctor may suspect spread of cancer in the lungs. This is a critical observation which can only be made if frequent relevant data is available and much easier if it can be viewed graphically too.

7. DISCUSSION

One of our design principles was that the solution will have to be viable one. Instead of developing a sophisticated system with good performance which requires expertise from the users or is expensive, we focused on a simple inexpensive system. As our end users were poor women with breast cancer in rural areas who have some experience with cell phones, we expected that instead of introducing a complete new device and training people with that, incorporating our system in the cell phone would keep it simpler.

Discrimination between health services received by rich and poor can be narrowed to some extent by e-ESAS. In an urban-centric country like Bangladesh, the e-ESAS should remove the notion of distance to some extent and narrow the gap between urban and rural areas.

While developing and deploying the system, some problems occurred because of the unique nature of our users. Initially we had a log in screen which the patients were supposed to use to authenticate. But the task of logging in proved difficult for these patients. So we removed the log in screen and used IMEI to authenticate. The trade off is the reduced security. Another change was introducing auto exit. Initially there was an exit button which the patients used to close the application. But before that, patients used to press the submit button repeatedly because they were not

sure if the data had been sent. So we removed the separate exit button and the submit button closes the application after submitting the information. With two questions per page, we increased the gap between two sliding bars as patients were mistakenly touching the wrong sliding bar. Also we added two awareness videos which can be played from the first screen. The goal was to create awareness about breast cancer. In the first video patients describe their experience about breast problems. The second video was a motivational speech from a local influential person. We found that patients did not submit their ESAS information regularly. To track their submissions, we built a panel in our website. Doctors can see which patients have not submitted on a particular day through this panel. After investigation, we found several reasons for irregular submissions. First, some patients are not motivated. Second, the system was not properly deployed in some phones. To motivate them, AGBC people called them to remind them to use e-ESAS to submit information. We changed the phone setting of some patients which solved their problem with submission of ESAS data. We used Nokia X6 which cost about $250 in fall 2010. One cell phone can serve multiple times as patients can return the phone after they do not need it anymore. This should lessen the burden of the cost for a patient. An alternate solution is to visit regularly which not only cost money, but also a burden on the patient who are already beset by the disease. We argue that benefits of the system outweigh the cost of application.

8. CONCLUSIONS

In this paper, we present the analysis, design, development and deployment of e-ESAS. The system, at its present state would especially help palliative doctors in management of pain and other symptoms. Patients in a developing country, where there is shortage of palliative doctors, will be immensely helped by accessing services from remote doctors.

We plan to analyze data from this pilot deployment and study pain management capability by doctors. Based on its performance in this pilot deployment, we plan to deploy the system in urban settings. We plan to collect data from another deployment in a developed country. We will analyze the data and study the performance of the system in these different environments.

As a consequence of our pilot deployment of e-ESAS, a large growing database of quality data is being created. So far, data of only 10 patients is being updated. As more patients register in the system, statistics of cancer will be easily available as there is a lack of statistics of cancer patients in Bangladesh. This growing database can be used by researchers for data mining which may lead to the discovery of interesting patterns or even an early discovery of an epidemic. In the future, we would like to pose questions like: which region has highest breast cancer patients? Or where is it spreading fast? If we observe a particular cancer in a specific area, we may pinpoint the reason. For instance, proximity to a particular industry may be identified as a cause of particular disease from mining the database.

The idea of cell phone questionnaire can be extended to other diseases. Diseases like diabetes and asthma can be monitored using cell phone. This system architecture will work as a generic framework for development of future such systems.

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