Barriers for Breast Cancer (BC) Patients in Rural Bangladesh: Design and Deployment of a Mobile based Solution

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Abstract

Here, we present the findings of our field study conducted on 39 breast cancer patients in rural Bangladesh. Lack of motivation to go to health centers on patients' side due to financial, social and transportation hazards result in inadequate data for proper assessment. In this scenario a mobile phone based remote symptom monitoring system (RSMS) with inspirational videos can serve the purpose of both patients and doctors. Based on the results of extensive field studies we have designed, developed and deployed e-ESAS - the first mobile based RSMS for rural context. Along with the detail need assessment of such a system, we describe the evolution of e-ESAS and the deployment results. The findings show how e-ESAS addresses several challenges faced by patients and doctors, and positively impact their lives.

Keywords (Required)

Breast cancer, mobile health, remote monitoring.

Introduction

Healthcare in a developing country such as Bangladesh is scarce. Too few doctors have to attend too many patients thus degrading the quality of care. In Bangladesh, 24.3% of female cancer patients suffer from breast cancer (BC) with only 98 oncologists present in the whole country. 90% of the estimated 30,000 women diagnosed with BC in Bangladesh die (LANTERN 2012); though 1/3 of the mortalities can be avoided through early stage detection, resource availability and appropriate and timely intervention (WHO).

We visited rural Bangladesh to identify the barriers faced by patients and doctors and how and where technology can be used to overcome these problems. From doctors' perspectives, they need constant and accurate data from the patients. On the other hand, visiting the cancer care facility requires time, money and energy from the patients, resulting in long intervals between patient visits. Again, socio-economic factors become decisive in how regularly a female patient can visit the doctor's facility in person. Fortunately, mobile phones have become ubiquitous in Bangladesh reaching 86.6 million by Jan '12 (BTRC 2012). Based on our field study, we found that 43 out of 45 rural patients have access to mobile phone. With this in mind, we have developed a mobile phone based RSMS for patients named e-ESAS based on Edmonton Symptom Assessment System (ESAS), which may notably reduce the necessity of visiting the doctors' facility coupled with the benefit of doctors getting regular patient data.

Figure 1(a). A Patient is Using e-ESAS from Home. 1(b) A Doctor is Checking Pain Graph for a Patient on Her Way to Clinic

The contributions of our paper are following:

- Development of e-ESAS through iterative feedback from rural BC patients. Unlike most other projects, patients are the sole users of e-ESAS system and they themselves are being able to send their symptom levels each day. The overall process is helping in bridging the communication gap between patients and doctors.
- Creation of a positive and encouraging environment for rural BC patients by addressing the socio-cultural challenges through motivational videos.
- Presentation of design and proof of concept evaluation of a health tracking system for low-literacy, rural breast cancer patients.

Related Work

Hayes *et al.* (Hayes et al., 2008) summarized the detailed overview of the cancer treatment process and possible use of pervasive technology in urban settings. The effectiveness of electronic symptom monitoring has been proven in chronic diseases like asthma (Adams et al., 2003), diabetes (Cherry et al., 2002) and cancer (Dubenske et al., 2008). All these projects have been deployed in urban settings of developed world and use web based online monitoring system which is not feasible for illiterate women of rural settings. In rural health care several projects work as 'decision support system' by implementing a guideline set by WHO or other standard organizations in computer or handheld devices (Derenzi et al., 2008; Peters, Kohli and Mascarenhas, 2005; Mitchell et al., 2009). Early Diagnosis and Prevention System (Peters, Kohli and Mascarenhas, 2005), a computer based healthcare management software, registers patient history. e-IMCI (Derenzi et al., 2008) describes a PDA based system for administering the Integrated Management of Childhood Illness (IMCI) protocol. A large number of projects are used for 'data collection/survey' including AED SATELLIFE (AED SATELLIFE, 2012) in Mozambique and Uganda, HIV/AIDS program in Angola (Cheng, Ernesto and Truong, 2008). Our project has two fundamental differences with these projects. Firstly, instead of trained professionals (health workers (HW) or doctors), patients or attendants (who normally stays with the patients) are filling the symptom information by themselves. Secondly, patients are doing this from home and sending data by using the data network of mobile carriers. In all the aforementioned projects, either the patient has to come to the health center or HWs need to go to remote houses of the patients to collect such information. Several Projects like WiLDNet (Patra et al., 2007), iPath (Brauchli et al., 2005) fall under 'telemedicine' category aiming to connect physicians with patients residing in rural areas. But the prerequisite of network infrastructure capable of performing real time media connections in a cheaper way makes these solutions infeasible for rural scenarios of Bangladesh. Importance of motivational videos has also been shown by Ramachandran et al. (Ramachandran et al., 2010) but in a different setting for HWs only. Haque *et al.* reported the short term findings (2 months of deployment) of a patient-doctor system (Haque et al., 2012), but they did not provide the design details of their system. We have not found any project that deals with the patients of the developing world, who need long-term regular monitoring like BC.

Local Partner Information

Amader Gram (literally 'Our Village') is an initiative of Bangladesh Friendship Education Society (BFES). In 2006 Amader Gram partnered with International Breast Cancer Research Foundation (IBCRF) to open

Amader Gram Breast Care Center (AGBCC). The mission for AGBCC is to reduce morbidity and mortality from BC and other breast diseases. A trained female doctor and medical assistant attend each center, examining and keeping records of patients. From 2006 till 2010, the total number of patients diagnosed with BC is 1405. Currently they have 67 registered cancer patients.

Methodology

We did 5 field trips (Jul '10–Aug '10 (4 weeks), Dec '10–Jan '11 (3 weeks), Jun '11–Aug '11 (12 weeks), Nov '11–Jan '12 (12 weeks), May '12-Jun '12 (3 weeks)) in several places of Khulna (Khulna, Bagerhat and Rampal) and Dhaka division of Bangladesh. We focused on identifying the needs and challenges faced by patients and doctors in the first 2 field trips. Deployment of e-ESAS and analyzing the results of deployment were done in the last 3 field trips.

Study Procedures

During the first 2 field trips, we talked with BC patients in the AGBCCs, hospitals and their home environment. The doctors involved with AGBCC explained patient participation, project goal, duration and Bengali consent form to the patients registered with AGBCC. Finally we set up interview schedule with 39 patients who agreed to take part. One researcher and one doctor/health worker participated in all interviews. The interview session was divided into two 30 minutes sections. In the first part, we asked the patients and attendants about their familiarity with mobile phones. This included sending and receiving a call, use of SMS and knowledge about the numeric keypad. The second part was to fill out a questionnaire and have an open discussion with the patients regarding the barriers they face as BC patients. We also collected information about average time in transportation, average waiting time to visit doctors and average number of visits per month.

Clinic Observation

We first observed 22 patient-doctor interactions in AGBCCs (11 in Khulna, 10 in Bagerhat and 1 in Rampal) to get better understanding of the current procedures and practices. We found doctors to use a paper based symptom monitoring system named ESAS. We then interviewed each patient following the above mentioned procedure.

Hospital Interviews

We interviewed 9 patients in Dhaka Medical College & Hospital (DMCH) and 3 more in Khulna Medical College & Hospital (KMCH). These patients were admitted in the hospital for either chemotherapy or surgery. The main goal of talking with these patients was to observe how they use mobile phones in advanced stages of the disease.

Home Interviews

Generally patients feel more comfortable to talk and discuss in their home environment. Also, 5 patients failed to show up due to the severity of their diseases. To account all these facts, we visited the houses of these patients in Khulna.

Participant Information

As per requirement analysis we talked with 39 patients, 12 doctors, and 6 HWs in Dhaka, Khulna, and Bagerhat region of Bangladesh.

Patients

The patients were quite diverse in terms of level of education, expertise with mobile phones whereas there was striking similarity considering occupation and household income. Their ages range from 21 to 45 years. Patients' education varied from illiterate to high school. The average family income of the patients we met is BDT 4500 ($63) per month. 29 patients were having BC for the first time and 10 for the second

time. They were under different types of treatment including radiotherapy, chemotherapy and surgery. 96% of the patients have access to mobile phone. Table 1 provides a high level view.

Features	Category	Percent	Features	Category	Percent
Familiarity (breast cancer)	Yes	7.7	Occupation	Housewife	87
	No	92.3		Employed	13
Education level	Illiterate	34.9	Duration	< 1 year	47.8
	Up to Grade 5	26.1		1-3 years	43.5
	Grade 6 - 10	34.7		>3 years	8.7
	>Grade 10	4.3			
Average family income (per month)	<$42	61	Number of children	0-2	69.5
	$42-$84.5	26.1		3-4	26.1
	>$84.5	12.9		>4	4.4
Experience with mobile	Receive	26.1	Access to mobile	Personal	47.8
	Call, Receive	61		Family	47.8
	Call,Receive,SMS	12.9		Neighbor	4.4

Table 1. Summary of Patient Information

Doctors

We had focus group sessions with 8 doctors in AGBCC of Khulna and 4 in DMCH. 4 of the doctors have post graduate degrees in their fields and others are resident doctors. 3 of them have more than 10 years of experience dealing with BC patients. We discussed mainly on the following issues:

1. What are the problems you face during diagnosis?
2. Why do patients miss appointments?
3. How frequently the patients come?
4. Average time to assess each patient.
5. How mobile phones can be helpful in your work?

These sessions revealed the following issues:

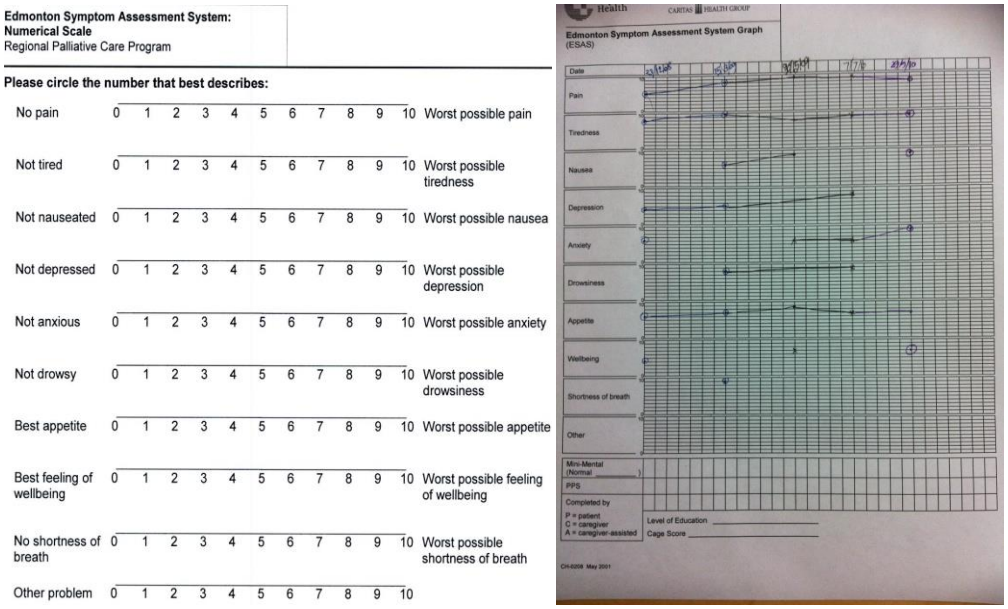
- Lack of regular information about the patients is the biggest drawback. Also, all the doctors mentioned about the exaggeration of symptom values especially pain. Our clinic observation has found all 22 patients to report having maximum pain level.
- All the doctors complained that, they do not like the manual task of drawing graphs in paper-based ESAS and this consumes major part of the patient visit time. This fact shows the necessity of a tool that can automatically generate longitudinal graph based on patient's symptoms.

Problem Identification

The problems identified can be classified in two broad categories; socio-cultural barriers and technical barriers.

Rural women suffering from breast cancer face lots of challenges in different stages starting from identifying the disease, managing money, reaching appropriate health center, meeting doctors and finally continuing treatment. They are generally very shy and stigmatized to discuss such personal issues with anyone. They hardly have the idea of the primary and secondary symptoms. Commonly they assume that the problem will be cured with time and do not go to the health centers until the pain becomes

unbearable. They also keep the problem secret since they are afraid of being a social outcast. These patients come to the health centers with long delays and leave the doctors with hardly any information regarding their symptoms to accurately diagnose their disease condition. Socio-economic condition and cultural-religious stigmas complicate the overall scenario.



Edmonton Symptom Assessment System:
Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain
Not tired	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness
Not nauseated	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea
Not depressed	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression
Not anxious	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety
Not drowsy	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness
Best appetite	0 1 2 3 4 5 6 7 8 9 10	Worst possible appetite
Best feeling of wellbeing	0 1 2 3 4 5 6 7 8 9 10	Worst possible feeling of wellbeing
No shortness of breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness of breath
Other problem	0 1 2 3 4 5 6 7 8 9 10	

Figure 2(a). Sample ESAS Form 2(b). Sample ESAS Graph

Manual paper based ESAS constitutes the technical barrier domain. This form has 10 symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well being, shortness of breath and others), each having an associated scale from 0 to 10. The ESAS form, though supposed to be filled out by patients, was always filled out by doctors since patients take much longer time to complete. Later the scores given by the patients are graphed for visual representation. From the clinic observation, we found that it takes almost 8 minutes for the doctors to complete a single ESAS form. Example of ESAS form and graph has been shown in Figure 2.

Design & Development of e-ESAS

Based on the findings of the need assessment, we have decided to approach the overall solution from two different perspectives – motivation and automation. From the clinic observation, it was obvious that it is not feasible for doctors to complete the paper-based ESAS considering the timing restriction due to high patient load. Also, a better tool is needed to obtain patient data on a regular basis. Therefore, we developed a mobile based ESAS named e-ESAS for Nokia X6. On the server side of the application, we used Tomcat 6.0 as the server and MySQL as the database. The client side has three modules: patient, doctor and video. The patient and doctor module replace the paper based ESAS data collection system through a mobile based data collection and representation system. The video module inspires the patients, family members and society in order to create a better environment for rural BC patients.

Patient Module Features

IMEI (Internaitonal Mobile Equipment Identity) Based Login

Initially we had conventional username-password based login system (Figure 3(a)). Though we provided a one letter name and password, patients were reluctant of this procedure. As P23 said, "*I like the sliding bar part but I really don't like to enter text at the beginning (login). I actually wait for my son to do that.*" But the user login is necessary to relate the submitted data with a specific user. To serve both the

purposes, we introduced IMEI based login (Figure 3(b)). Here, when the patient enters the e-ESAS application, the system collects the IMEI number using Nokia API and matches the corresponding patient ID from the server. All 10 MOs and their attendants expressed their preference for IMEI based login. 5 of the MOs also said that they have started submitting data by themselves without the help of attendants as a result of this change.

Figure 3(a). Username-Password based Login. 3(b) IMEI based Login

Submission of Symptom Values

A patient is provided with a page containing 10 sliding bars corresponding to 10 symptoms mentioned in ESAS after login (Figure 4(a)). Later 3 more symptoms (maximum, minimum and average pain in last 24 hours) have been added based on doctors' suggestions. Patients can drag the sliding bar to left or right and set the value anywhere between 0 and 10. When the user presses the 'submit' button, it will send all the sliding bar values set by the patient to the database server as a string. In the first version, all the sliding bars were on the same page. The idea was to ensure reduced amount of time. But this design proved to be error prone since the users were repeatedly touching the wrong sliding bars which were placed close together. Based on the findings, we later put 2 sliding bars per page which ensured enough free space for the patient (Figure 4(b)).

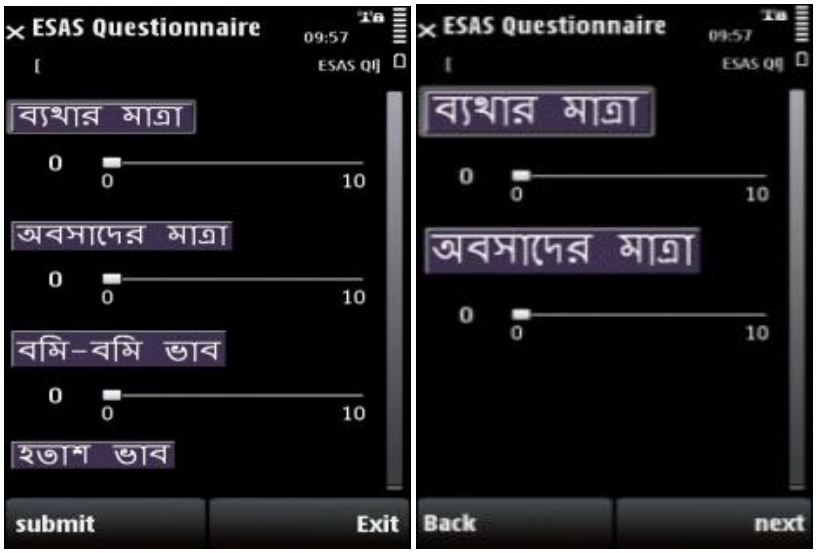


Figure 4(a). e-ESAS 1st Version. 4(b) e-ESAS 2nd Version

Voice Instruction and View Prescription

A button is placed corresponding to each sliding bar containing a Bengali text as a label. If pressed, a voice in local Bengali dialect will be played with instructions on how to use that particular sliding bar. Patients can also view their prescriptions by clicking the 'Prescription' button.

Doctor Module Features

Single Graph Single Patient Single or Multiple Symptom

Doctors can choose any number of symptom levels for a specific patient against selected time period. Figure 5 shows the symptom levels of pain, tiredness, and nausea for some patient X.

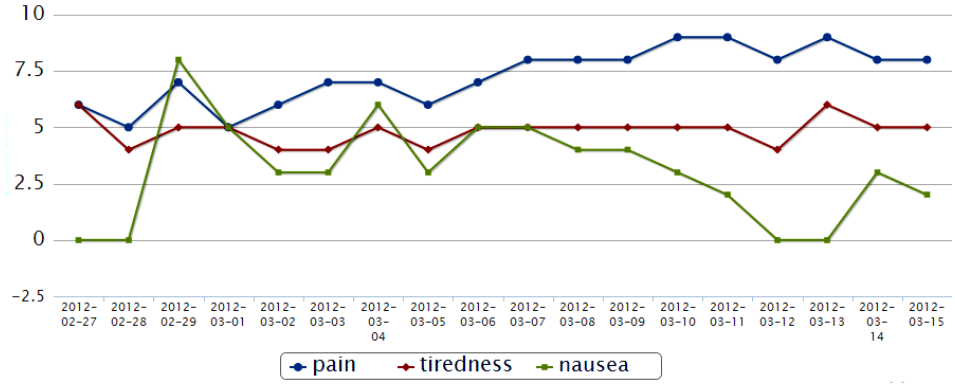


Figure 5. Graph of Patient X for the Symptoms Pain, Tiredness and Nausea against Selected Time Period

Single Graph Multiple Patient Single Symptom

Sometimes doctors need to compare a specific symptom of multiple patients who are under similar medication. Figure 6 shows the pain curve for multiple patients.

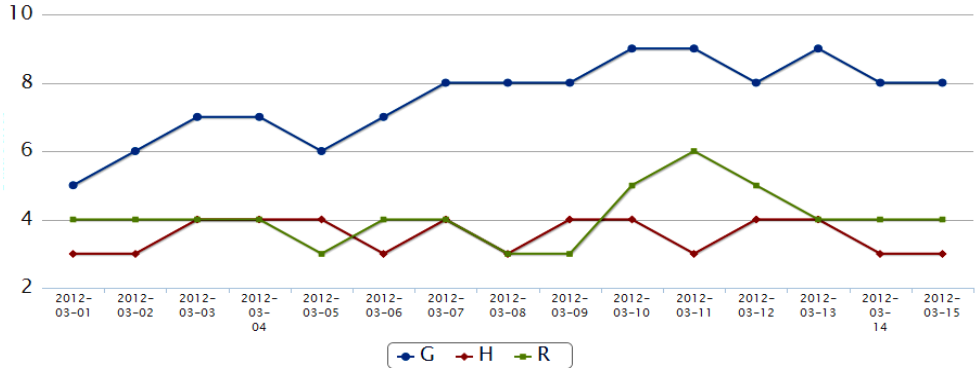


Figure 6. Graph of Patient G, H and R for the Symptom Pain

Alert Generation

For timely intervention, a notification will be generated for the doctors if a certain symptom level of any patient exceeds a predefined threshold value. For example, e-ESAS automatically sends an alert message to designated doctors when the pain level of any patient is more than 6.

Video Module

In order to address the socio-cultural challenges we have developed 2 motivational videos. They are termed as 'Motivating Video for Women (MVW)' and 'Motivating Video for Society (MVS)'. One BC patient took part in the MVW and conveyed important information regarding BC along with motivating others to overcome the challenges based on her personal experience. Influential local persons spoke for the MVS and urged the family members to put emphasis on mothers' health.

Findings of the Deployment of e-ESAS

During our 3rd field trip, we installed e-ESAS in 12 Nokia X6 mobiles. 10 of the mobiles will be used by the patients and 2 by the doctors. Doctors selected 10 patients for our study, termed as Mobile Owners (MOs). Chronic pain level <=5 on ESAS scale, life expectancy >6 months and able to understand and cooperate with the study procedure were the main selection criteria. MOs have been given a mobile and prepaid internet card of BDT 100 ($1.30) each month for submitting e-ESAS symptom values once on daily basis. They have not been given any other type of monetary assistance since we did not want financial assistance to be a motivating factor for using e-ESAS. Though we visited to deploy e-ESAS during our 3rd field trip, we started analyzing data starting from Nov '11 (4th field trip) due to delayed BMRC (Bangladesh Medical Research Council) approval. During the 4th and 5th field trip we (a team of one researcher and HW) visited the houses of the MOs to openly discuss the issues and impacts of using e-ESAS and the motivating videos. A focus group session with 8 doctors was arranged in Khulna where they shared their pre and post e-ESAS experience. We also observed a total of 77 patient-doctor interactions for MOs and other BC patients (registered with AGBCC but not in our pilot study) to compare the results with the observations we made during our 1st field trip. Here we present our findings.

Usability Findings

One of our biggest concerns was whether MOs will be able to use the system correctly from home by themselves. To measure this issue we have shown the 1st version of e-ESAS (10 questions in one page) to 39 patients and 25 attendants and collected their feedback at the end of Dec '10. One of the research team members conducted the following steps.

- Firstly, patients are shown how to use the sliding bar.
- Patients practice e-ESAS by themselves for 5 minutes.
- Each patient is given 10 random numbers from 0 to 10 to set these values using the sliding bars sequentially.
- Record the time required by each patient to set the values.
- Count the number of errors (difference between the given vs. recorded values are considered as error)

The average time required by the attendants to set the given e-ESAS values is 2.25 min which is slightly less than that of the patients (2.66). This is expected since in most cases, attendants were younger than the patients and more familiar with mobiles phones. It was a bit discouraging that on an average, each patient and attendant made 1.2 and 0.68 errors respectively. The errors occurred mainly due to accidental touch of the previously set sliding bar value. Based on our observation, we decided the following:

- Font size needs to be increased. (poor eyesight issue)
- More space is needed between 2 sliding bars. (shaking hands issue)

In the 2nd version of e-ESAS we have put 2 sliding bars in each page to accommodate bigger font size and appropriate spacing between 2 sliding bars. At the end of Dec '11, we performed the same usability test on 10 MOs and 10 attendants on the 2nd version of e-ESAS. In this case, the average time required by attendants and MOs was 2.4 and 2.8 minutes respectively. Though it seems that the timing requirement has increased rather than the expected reduction, it should be remembered that this version has 13 questions distributed over multiple pages. The similar error analysis resulted in only 1 error made by one of the MOs and none by the attendants. We also wanted to make sure that the patients in vulnerable conditions are also able to use e-ESAS. To evaluate this, we asked all 10 MOs to perform the same usability test (submitting 13 given e-ESAS values) one day after they have received chemotherapy in hospital settings. In this scenario, the average time required by the MOs was 3.4 minutes and the average number of errors was 0.7. Only one MO failed to complete the task due to severe shaking of hands. These

findings indicate the simplicity and easy-to-use nature of the system required for rural women to be able to use it without any supervision.

During the 5th field trip, we asked the MOs to rate the satisfaction with doctors and the treatment process before and after using e-ESAS. We found that MOs have significantly higher satisfaction level with both doctors (t test = 6.3; P < .005) and treatment process (t test = 5.9; P < .005) after using e-ESAS.

Better Assessment

Better assessment of any chronic disease (e.g., cancer, diabetes, blood pressure) requires information about the crucial symptoms over a period of time. Doctors in rural contexts are highly constrained in assessing the progress and criticality of the BC patients due to extremely limited availability of data. Doctors' diagnosis of the disease symptoms and possible prescriptions were reliant on obscure information of the patients who typically come after long delays and many times without previous prescriptions. But now doctors can see the symptom curves for any MOs over any defined period of time. They can also compare a specific symptom level of multiple MOs for analysis. Doctors are now able to diagnose patients in a better way due to the availability of longitudinal history of symptom values created through e-ESAS. D1 stated the usefulness of the feature 'comparing multiple patient against specific symptom value' as, *"..these 2 patients (MO1 and MO8) were under my supervision since the beginning and they have almost identical disease condition. They were under same type of medication and their reported pain scores were also similar. But all on a sudden I found the MO8 is experiencing much higher pain values compared to MO1. Then I talked with her and changed her medication with no effect. Then I compared their pain symptom graph over around 20 days time (as shown in Figure 7). As you can see pain level of MO1 has decreased after X (some date) where as that of MO8 has increased. Later I found that both these patients were scheduled for chemotherapy around that date. MO8 missed her chemo due to family reasons. Later I talked with the doctors in Khulna Medical College Hospital for her chemotherapy."*

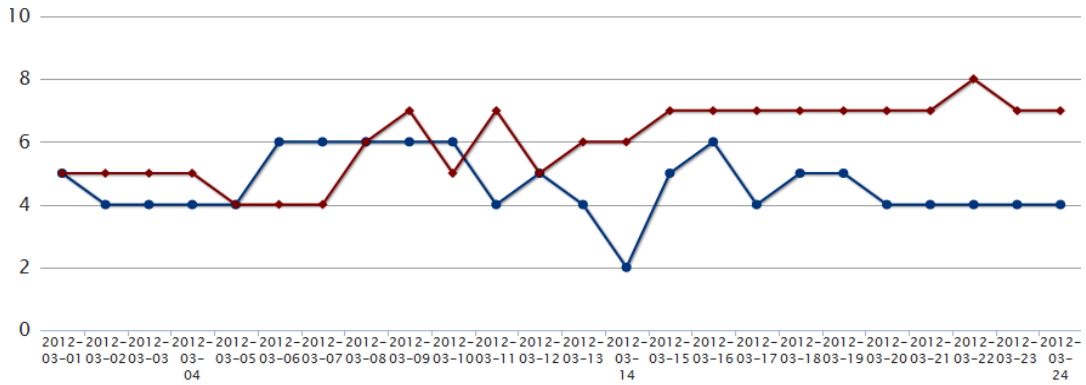


Figure 7. Comparison of pain graph for MO1 and MO8

Validity of Data

It was hard to determine whether the commonly reported maximum level of pain and other symptoms by the patients during visits is due to the severity of the disease or due to the long grueling journey they just commuted. e-ESAS system has cleared this doubt and increased the validity and reliability of data. Also it was easy for the doctors to find the consistency of the data by looking at the continuous graphs. We will share 2 incidents here to support our claim.

Case 1: D2 shared her personal experience saying, "*To be honest I can hardly recall any patient who did not say that she is not going through the highest level of pain. This is true that they feel pain more than usual due to the long travel. Then they fail to distinguish between the high pain of that moment and their*

average pain level. But now I can find her average level of pain throughout a long period of time and decide the appropriate medicine and its dose." This fact was supported by all other doctors.

Case 2: D3 mentioned about a patient (MO2) as, *"..this patient complained about nausea in each of the last 2 visits. But when I checked her nausea graph (shown in Figure 8) I found that she has put high values for nausea only 2 days including the day she visited us. When I asked her whether she feels sick during journey she said that she has a habit of vomiting during traveling. Then I decided not to prescribe any medicine for nausea. This wouldn't have been possible without such longitudinal history of symptom data."*

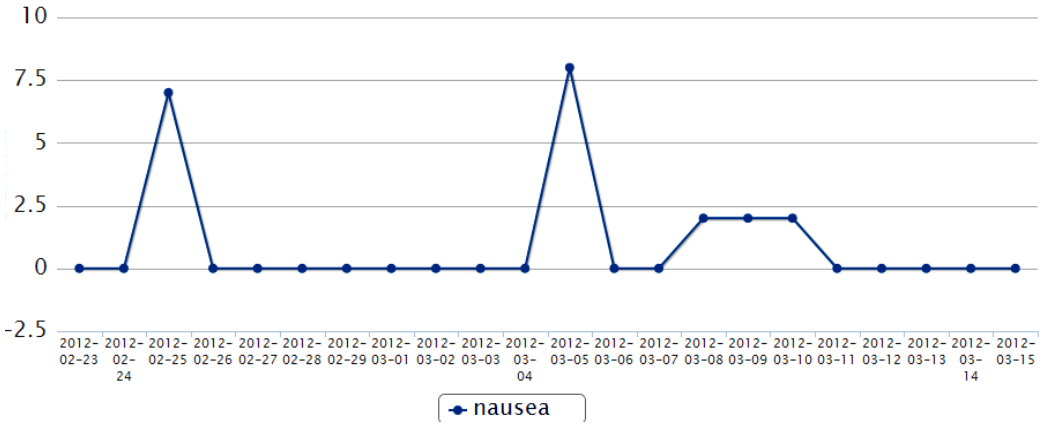


Figure 8. Nausea Graph of MO2

Impact of Video Module

Our 1st field trip showed a pathetic scenario regarding the social life of breast cancer patients. 35 out of 39 BC patients said they do not have social relations with their neighbors. When we asked why, 31 of them said that their neighbors believe they would also be infected by the disease if they come in contact with them. During our house visits in the 4th and 5th field trip we observed a much better social life for the MOs. On 4 occasions we found MOs with neighbors. Motivational videos played a big role here as the MOs successfully used them as a means of social interaction. These MOs find pride in educating the neighbors who are coming for information or just to see the videos. The MOs started acting like local health workers. As one new patient said, "*I am having this small lump in my left breast for couple of months but I did not pay attention. I thought it will be automatically cured. But one day I saw the MVW video from my neighbor who is a MO. And I decided not to neglect it anymore*." In order to measure this role, we logged the number of patients who came to AGBCC with referrals from the MOs for 4 months (Nov '11-Feb '12). On an average, MOs played the videos 85.7 times per month during this time period and referred 81 patients to AGBCC. The videos also helped in creating a positive environment for the patients. One of the MOs (MO9) shared her experience saying, "*My husband was a bit suspicious about my enrollment. But when he saw the MVS where Mr. X (a local influential person) said good things about AGBCC and the importance of proper treatment, he accepted this*."

Conclusion and Future Work

Here we have presented the evolution of e-ESAS through iterative user feedback. The impact of e-ESAS in improving the socio-cultural condition and quality of treatment has been proved. We chose Nokia X6 for its built in accelerometer sensor since we also plan to evaluate the physical activities of these patients. In order to make e-ESAS available for masses we are working on developing a lighter version of e-ESAS that runs in low cost devices like Nokia C2 ($35). Inspired by our initial results, we are in the process of deploying a similar system for American Indian cancer patients in South Dakota, USA. We also plan to analyze the developed symptom database for finding behavioral patterns of terminally ill patients and compare the life expectancy of the MOs with that of other BC patients of similar disease state. Our proposed system can work with any disease that require long term monitoring like asthma, diabetes etc.

We believe our findings will motivate researchers in building new mobile based health care solutions for rural patients of developing countries.

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