e-ESAS: Evolution of a Participatory Design based Solution for Breast Cancer (BC) Patients in Rural Bangladesh

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Abstract Healthcare facility is scarce for rural women in the developing world. The situation is worse for patients who are suffering from diseases that require long term feedback oriented monitoring like breast cancer. Lack of motivation to go to the health centers on patients' side due to socio-cultural barriers, financial restrictions, and transportation hazards result in inadequate data for proper assessment. Fortunately mobile phones have penetrated the masses even in rural communities of the developing countries. In this scenario, a mobile phone based remote symptom monitoring system (RSMS) with inspirational videos can serve the purpose of both patients and doctors. Here, we present the findings of our field study conducted on 39 breast cancer patients in rural Bangladesh. Based on the results of extensive field studies, we have categorized the challenges faced by patients in different phases of the treatment process. As a solution, we have designed, developed and deployed e-ESAS - the first mobile based RSMS in rural context. Along with the detail need assessment of such a system, we describe the evolution of e-ESAS and the deployment results. We have included the unique and useful design lessons that we learned as e-ESAS evolved through participatory design process. The findings show how e-ESAS addresses several challenges faced by patients and doctors, and positively impact their lives.

Keywords Breast cancer . Healthcare . Remote monitoring . Participatory design . User study

1 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. This in turn results in failure to answer common questions like 'how many days you had severe pain since last visit' or 'how many times you felt nausea last week' and so on. All such information is crucial for the physician to diagnose the disease state and prescribe medicines. Moreover, lack of patient information and scarcity of doctors complicate an already challenging situation. In this

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regard a mobile based remote symptom monitoring system can play a potentially revolutionary role.

Fortunately, like most other low-income countries, mobile phones have become ubiquitous in Bangladesh reaching 116.239 million by May '14 (BTRC 2014). Based on our field study, we found that 43 out of 45 rural patients have access to mobile phone. With this in mind, we decided to use mobile phones for remote monitoring of the patients and developed e-ESAS. e-ESAS may notably reduce the necessity of visiting the doctors' facility coupled with the benefit of doctors getting regular patient data.

e-ESAS has been developed based on Edmonton Symptom Assessment System (ESAS; Bruera E, 1991), which is commonly used by the doctors for monitoring and recording symptom levels of terminally ill cancer patients (PALLIATIVE1, PALLIATIVE2). Patients can rate their symptoms on a scale of 0 to 10 and submit the values from the comfort zone of their houses using e-ESAS as shown in Fig. 1. On the other hand, doctors can view the graphical representation of the history of submitted data from mobile phones or desktop computers. Doctors can also change the medication of the patients depending upon the feedback.

Fig. 1 A patient is using e-ESAS from home.

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 system 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.

2 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. CHESS [Gustafson et el. 2005], a complex patient archival system, has been deployed in the USA. 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). Handheld devices (mobile phones, PDA etc.) have also been utilized in domains that require long term monitoring like autism (Hayes et al., 2010; Hirano et al., 2010; Escobedo et al., 2012) and bipolar disorder (Mayora et al., 2013; Mayora et al., 2014; Osmani et al., 2013). 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 Psychlog (Gaggioli et al., 2013), AED SATELLIFE (AED SATELLIFE, 2012) in Mozambique and Uganda, HIV/AIDS program in Angola (Cheng, Ernesto and Truong, 2008), EMR program in India (Anantraman et al., 2002), and household information collection project in Tanzania (Shimira et al, 2007). 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 Asynchronous Remote Medical Consultation (Luk et al., 2008), WiLDNet (Patra et al., 2007), and 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 of a patient-doctor system (Haque et al., 2012a; Haque et al., 2012b; Kawsar et al., 2012). They also mentioned about the improvement of Quality of Life (QoL) in a recent publication (Haque et al., 2014). None of these papers elaborated the challenges faced by patients and doctors in rural context. Also, they did not provide the design details of their system. But in this paper, we have detailed the ethnographic study, challenges, and the evolution of e-ESAS from design and development point of view. We have not found any project that deals with the patients of the developing world, who need long-term regular monitoring like BC.

3 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 to 2010, the total number of patients diagnosed with BC is 1405. Currently they have 67 registered cancer patients.

4 Methodology

We did 5 field trips (Jul '10–Aug '10 (4 weeks), Dec '10–Jan '10 (3 weeks), Jun '11–Aug '11 (12 weeks), Nov '11–Jan '12 (12 weeks) and May '12–Jun '12 (3 weeks)) in several places of Khulna (Khulna, Bagerhat and Rampal) and the 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.

4.1 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. Patients were also encouraged to talk with their family members before making a decision. Finally we set up interview schedule with 39 patients who agreed to take part. Six patients, who did not take part in the field study, mentioned family problems as reason for denial. One researcher and one doctor/health worker (HW) 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. Interviews were audio recorded and

photographed. Fig. 2 shows a doctor preparing a group of patients in Dhaka Medical College and Hospital.

Fig. 2 A doctor preparing the patients for interview

4.1.1 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 especially tried to focus on the following issues.

(1) What types of question doctors frequently ask?
(2) What are the common answers from the patients?

(3) What are the common complaints from the patients?

(4) What are the common symptoms among the patients?

We found doctors to use a paper based symptom monitoring system named ESAS. We then interviewed each patient following the above mentioned procedure.

4.1.2 Hospital Interviews

We interviewed 9 patients in Dhaka Medical College & Hospital (DMCH) and 4 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 state of the disease.

4.1.3 Home Interviews

The patients feel more comfortable to talk and discuss in their home environment. Since most of the patients visit the health care centers with companions (husband, mother, or neighbor) they could not share stories about how they are being treated by members of the family or neighbors. Along with this issue, 5 patients fail to show up for different reasons including cold, severity of the disease etc. To account all these facts, we visited houses of five patients in Khulna. All of them were within 30 miles distance of AGBCC, Khulna.

4.2 Participant Information

As per requirement analysis we talked with 39 patients, 12 doctors and 5 health workers in Dhaka and Khulna division of Bangladesh. We provide detail description of the participants in the following subsections.

4.2.1 Patients

The patients were quite diverse in terms of level of education, expertise with mobile phones whereas there were striking similarity considering occupation and household income. Patients' age ranges from 21 to 45 years. Patients' education varied from illiterate to high school. We found only one patient who studied up to grade 12. No one has gone beyond that. Table 1 provides a high level view of the demographic information.

Table 1 Summary of patient information

Features	Categories	Percent	Features	Categories	Percent
Familiarity (Breast Cancer)	Yes	7.7	Occupation	Housewife	87
	No	92.3		Employed	13
Education level	Illiterate	34.9	Duration of the disease	< 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	Only receive	26.1	Access to mobile	Personal	47.8
	Call and receive	61		Family	47.8
	Call, receive, and SMS	12.9		neighbor	4.4

These patients came from strikingly similar level of economy class. 87.1% of the patients came from a family with monthly income less than 84.5 dollars. Occupations of their husbands' include farmer, small trader, fisherman, daily laborer, and rickshaw puller. Only 2 of them had comparatively higher family income ($140). All the patients complained that they cannot save enough money to even come to the health center, which costs $5 on an average based on our survey on 39 patients, on a monthly basis. Twenty nine patients were having breast cancer for the first time and 10 having for the second time. They were under different types of treatment including radiotherapy, chemotherapy, and surgery. We met patients who came to the doctor for the first time to patients who have been receiving treatment for 4 years. Finally it would be interesting to note that almost 96% patients said that they have access to cell phone which belongs to themselves or to some members of the family.

4.2.2 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:

— What are the problems you face during diagnosis?

— Why do patients miss appointments?

— How frequently the patients come?

— Average time to assess each patient.

— How mobile phones can be helpful in your work?

These sessions revealed the following critical 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. Though all the doctors reported the fact of exaggeration of pain, they are bound to take the pain score verbally told by the patients as the true value since patients' self-report is the *gold standard for assessment* [PAIN TOOL].

— Two main reasons for missed appointments are financial crisis and transportation problems.

— Frequently, doctors just need regular information and patients do not actually need to come to the health center.

— 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.

5 Challenges

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. Based on the results of our field studies, we have grouped the challenges in the following domains.

5.1 Identification and Disclosure Issues

Women suffering from breast cancer prefer to keep this issue a secret due to several reasons including social, cultural, family etc. A proverb in Bengali language says 'buk phate to mukh fotena' which means that their (women) heart will be shattered but they will not express their sorrows in words. Sometimes health workers go to their houses and meet them personally to encourage them to come to the health centers.

5.1.1 Shyness

Women in rural Bangladesh are generally very shy. In many cases women are dependent on their father, husband, or son and ashamed to talk about breast lumps or cervical discomfort. They keep the problem to themselves till it is too late. All the HWs mentioned this issue as one of barriers for identification of BC patients.

5.1.2 Lack of Familiarity

Many women in rural area are familiar with the term 'cancer' but not with the breast cancer issue. In most of the cases they take it lightly and fail to understand the severity of the issue. They do not pay attention to any lump or tumor developed in the breast as long as it does not pain. They simply ignore the issue with a common belief that it would be subdued automatically. Out of 39 patients we interviewed, only 3 patients (7.7%) said they had some kind of idea about breast cancer.

5.1.3 Fear

Women are afraid of how they will be treated socially and especially within their family. They have a common fear that their husband might leave them for this problem. As a result they try to keep this hidden. We have found 16 patients who were either divorced or their husbands just do not keep relation with them and refused to bear the medical expense. 4 patients said their husbands started sleeping in separate room. Sometimes people believe that when one of the family members has this problem, other female members will gradually have this problem. As a result other people do not want to make matrimonial relationship with this family. One of the patients (P8) described,

> "*..neighbors in the village have told that if you go to hospital they will remove your breast and ultimately you will die. They also told that if you take kimo (actually chemotherapy) all your hairs will be gone and your husband will not let you in the house*."

5.1.4 Undermining Women Problems

Rural women generally take care of the whole family and put themselves as the last in the list of priority. They try to avoid and suppress their own problems. Sometimes their counterparts simply undermine their health issues. As a result in many cases the issue remains hidden till the very last moment. In a rural Bangladeshi society where women eat whatever left after husband, children, and other family members have finished taking

their meals, it is natural for them to put their health treatment in the lowest of the priority list. According to one of the patients (P3):

> "*I am having this type of problem for 10 years when my daughter was 4 years old. First I thought that I am having pain since I carry buckets of water from the tubewell. When I told to my husband that I have a chaka (tumor) in my breast he just did not pay any attention to this. Days went by and finally my daughter (who is 14 now) looked at it. She was aware of breast cancer and forced me to visit doctors.*"

5.2 Treatment achieving issues

After the disease has been diagnosed patients suffer a whole new era of difficulties. Many times they need to wait for getting permission from their husbands and society. Many times, they go to the nearest health centre that has neither appropriate equipments nor female doctors. Long communication delay adds salt to the bitter experience.

5.2.1 Scarcity of doctors

The scarcity of doctors is a big issue especially female doctors and cancer specialists. The availability of doctors is only 0.26 per 1000 people [Nationmaster]. 11 of the patients had previous experience of returning back from health centers without meeting the doctors due to long line.

5.2.2 Gender discrimination

In the male dominant rural society women are the last point of attention. Almost everyone, including the husband, children and in laws, get priority over the mother. The male members of the family get the higher consideration since in almost all cases they are the earning source of the family. Rural women are mostly house wives without any personal source of income. If the husband gets sick the whole family starves. So he is taken care of but when the mother gets sick it is kept as it is with the thought that she would be fine with time. As P13 said:

> "*When I got sick, first local doctor told my husband to feed me well like egg, milk etc. But my husband did not have enough money to feed the whole family even. But one day I had the chance to eat an egg and my mother-in-law started scolding me and my husband as if I had eaten everything. When my husband finally agreed to go to the doctor (for this disease) my mother-in-law said him not to waste money on a woman coming from other family.*"

5.2.3 Transportation hazards

Hazards of transportation and distance to health centers play a big role for patients not to go to the health centers. Public transport system is not available in the village area. In rural context the most common form of transportation is rickshaw/van which is not that available during the rainy season due to muddy village roads. Very often the patients need to walk several kilometers to reach a point from where 'rickshaw' can ply. According to our study, on an average 3 changes of vehicles were made by the patients to reach AGBCC. P6 described her experience as:

> "*I live in a distant village of Rajshahi division. First I took a van to come to the boat stand. Then I crossed the river by boat. Then I shared another van to reach the bus stand. It took 12 hours for the bus to reach Dhaka. Finally I hired a taxi and then rickshaw to reach here.*"

This is a very discouraging scenario for a patient who is already suffering from pain.

5.2.4 Common belief and practices

Women in rural villages are biased with traditional practices, suggestions made by the seniors and local practitioners. In case of problems they go to kabiraj (herbalist) first. Most of the time they treat with some paste made of unknown substances. Sometimes they also use spiritual healing and incantation. Though with the spreading of education

people are becoming aware of cheating treatments, we still received 5 patients who were initially treated by kabiraj. The next common thing is to go to homeopathic doctors. This treatment is very popular in rural areas due to the availability of homeopathic doctors and cheaper price. Almost 95% of the patients we met said that they visited homeopathic doctors for 3 to 6 months. History of P22, who was admitted in Dhaka Medical College & Hospital for chemotherapy, summarizes this whole picture. According to her,

> "*I live in a very remote village of Rajshahi division. My husband works in the paddy field of other people during seasons. When I first had this problem (lump in the left breast) I did not pay much attention. Then it started to cause pain. So I told this to my husband. He first went to the imam (leader) of the local mosque and brought holy water and oil for me. It was free of cost but it did not work. Then weeks later he went to a kabiraj and brought some paste. Kabiraj took BDT 10 ($0.014). After I have used that paste in the infectious breast it started to pain more. Then my husband took me to the homeopathic doctor. I took medicine from him for 3 months. When it failed, my husband decided to come here.*"

When discussing about their biasness to kabiraj or homeopathic doctors and reluctance to go to the qualified physicians, commonly known as MBBS doctors, they used terms like 'out of reach', 'way too expensive', 'not available' etc. One patient added, "*They (local kabiraj or homeopathic doctors) are readily available. You can also call them any time.*" Another patient said, "*I do not feel like going that far to visit a MBBS doctor in this physical condition.*"

5.3 Treatment monitoring issues

Once diagnosed, the breast cancer patients need to be under regular checkups. According to our experience in Bangladesh patients are advised to revisit on weekly, biweekly, or monthly basis based on the severity and complexity of the disease. Irregularity in making the appointments becomes an issue to be noted.

5.3.1 Long term monitoring

BC patients require continuous long term monitoring. We met patients, who came to the doctor for the first time to patients receiving treatment for 4 years. Most of these patients have experience of going to doctors once or twice in their life due to severe diseases. They cannot think of a disease for which they have to visit the doctors on a regular basis and tend to lose interest. One of the patients (P9) said:

> "*I am having medicine for long 4 years. I do not feel like living. It seems that I am having medicine throughout my life. I wish not to go to doctor or hospital or anywhere.*"

5.3.2 Lack of consistency

This issue has been found as the weakest link of the treatment chain. Patients visit the doctors infrequently and with unusually long intervals and regularly fail to show up for their appointments. When we asked about this the most common answer was monetary problems. Sometimes when they are advised to meet biweekly they automatically assume that it would be fine if they come once in a month. P17 described her reasons as:

> "*First time I missed the appointment since my husband was out of the town and I failed to manage any other companion. Then my son was having his final examination. There was no one else who can look after him. Then I waited for the crop to be sold so that my husband can save some money for my appointment and medicine.*"

5.3.3 Fading out

When women are to take care of this issue for an extended period of time it gradually seems to lose its weight. They become more and more accustomed with the fact. They

start neglecting the issues and become fatalist. When we went through the history records of AGBCC center, we found that patients are pretty consistent for the first three months. Later they start missing appointments and in some cases they simply stop coming. Health workers in AGBCC center try to keep track of all the patients by calling them.

5.3.4 Managing companion

Rural women generally take some female relatives or husband along with them when they come to visit the doctors. Majority (78%) of the patients we interviewed had companions with them. They consider taking a companion for various reasons. Thirteen patients said they think that they will not understand what the doctors will be saying and 18 patients mentioned about mental weakness and fear about the disease as the main reason for having companions. It is sometimes hard to manage someone to accompany the patient for the same purpose again and again. Again when a woman leaves home, she needs to arrange someone to manage the household activities including looking after her children, cooking for the family etc.

5.4 Environmental and infrastructural issues

We have faced the following environmental issues.

5.4.1 Load-shedding

Load-shedding (temporarily switching off distribution of energy to different geographical areas) is a very common phenomenon in rural and urban Bangladesh. Some people in urban area use Uninterrupted Power Supply (UPS) to generate electricity during load-shedding which is completely absent in rural areas. During our visit to Khulna we have faced around 8 hours of load shedding per day. In the rural areas a separate electric company 'Palli Biddyut' (Rural Power) is responsible for distributing electricity and the situation is worse compared to that of the city. But conditions are still enough to charge mobiles to keep them active. Two of the patients said they do not have electricity line but they can charge their mobiles from neighbors' house.

5.4.2 Network connectivity

As a matter of surprise the mobile and data network connection is quite good throughout all the remote places we visited. One of the reasons is the high density of population everywhere. We were able to browse and check email in all the patient premises without notable difficulty.

5.4.3 Data security

Since all the medical records are maintained manually in paper format, it is hard for the doctors to ensure security and privacy of patient data. We have seen record books containing confidential information of breast cancer patients, left unattended as shown in Fig. 3. Also other staffs of the AGBCC have access to the doctor's room where the records are stored.

Fig. 3 Open unattended document of patient records

5.4.4 Zero privacy

The concept of privacy is almost absent in rural Bangladesh. It is even hard to make someone understand about the privacy of health care data. It is quite common to use others' mobile or see personal stuff like medical records. Eleven of the patients, who have their own mobile, said that their mobiles are used by other family members and sometimes by neighbors. All 39 patients said that they regularly look at others' prescriptions.

5.4.5 Mobile theft

Mobile theft is quite a common experience in Bangladesh. And normally people do not take the backup service provided by the operators due to the cost involved. When we asked about mobile theft, 3 patients said that they have this experience. 13 patients said this happened to at least one of the members of their family.

5.5 User issues

Other than the aforementioned issues, women suffer from several other problems. These issues also play roles in hindering getting better treatment.

5.5.1 Limited education

The rate of education is quite low in rural women as shown in table 1. But we found 2 interesting things to note. Firstly, out of 12 illiterate patients we interviewed, all but 2 can count and read numbers. This is possibly because they need it for calculating household expenditure and grocery. Secondly, though 35% of the patients are illiterate, all of them said they have close family members in the house (husband, children, brother-in-law etc.) who can read and familiar with mobile applications. Fig. 4 depicts one of the patients in her natural home settings. This picture actually gives a general idea about the socio-economic status of the patients interviewed.

Fig. 4 A study patient in front of her house in rural part of Khulna division

5.5.2 Limited technical knowledge

Many women have just used mobile phones to call someone. Most of them do not have any idea about other mobile applications like Short Message Service (SMS).

5.5.3 Unavailability

The concept of a personal mobile is not that common. Most of the time the family has a single mobile phone which belongs to the family head (husband). When he is not at home the mobile is not available. And generally men spend a good amount of time outside for earning purpose.

5.6 Current system issues

Manual paper-based medication process forms this problem domain. Based on our clinic observation, we found that doctors use a paper-based symptom monitoring system named ESAS. This form mentions 10 symptoms, namely pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath and others. Each of them has an associated scale from 0 to 10. Doctors talk with the patients and ask the value they want to assign against each symptom. The following issues are noted in the current treatment process.

5.6.1 Paper-based ESAS

The ESAS form, though supposed to be filled out by patients, was always filled out by doctors since patients take a much longer time to complete. Later the values given by the patients are put in paper-based ESAS graph for visual representation.

Unfortunately we have not found any ESAS graphs where all 10 symptoms have been graphed. In all the ESAS graphs, we have found the pain graph indicating that this is the most important symptom to be considered by doctors. All the ESAS graphs missed the graphs of 3 to 6 symptoms. Here the doctors pointed out the following reasons:

(1) They do not get enough time to fill all the charts.
(2) The patients could not give them appropriate information.
(3) They primarily treat the patients based on pain level and are not much concerned about less important symptoms.
(4) Instead of asking all 10 symptom values one by one, they listen to the patient history and put the perceived symptom values at the end of their interaction with the patients.

Example of ESAS form and ESAS graph has been shown in Fig. 5(a) and 5(b).

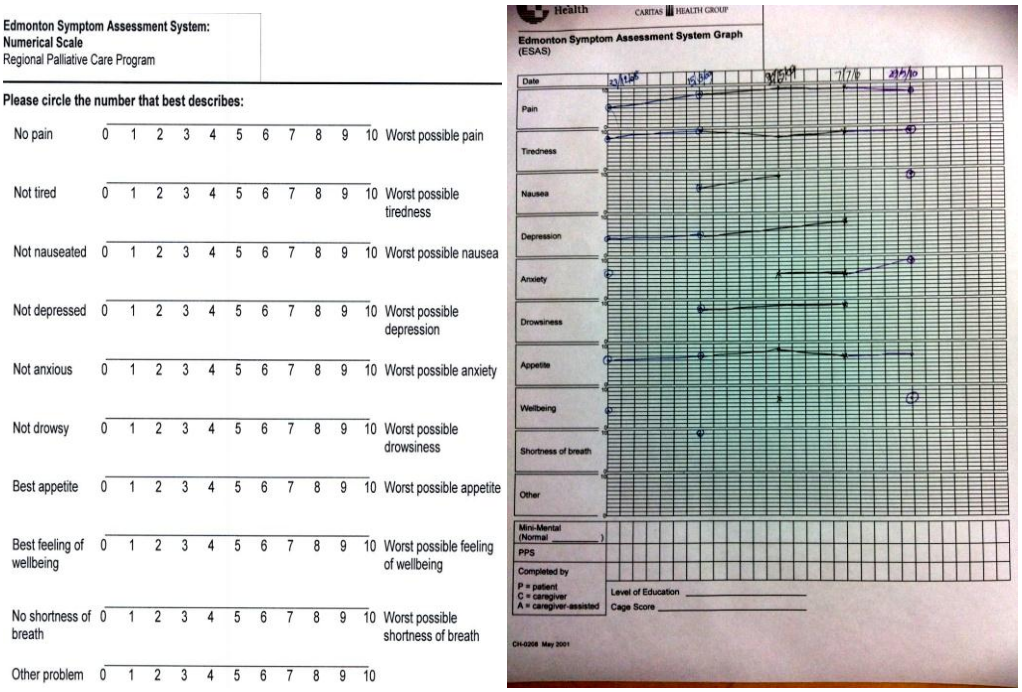

Fig. 5 a) ESAS form b) ESAS graph showing incomplete symptom charts

5.6.2 Lack of information

According to the ESAS graph patient data was supposed to be collected once every day which is impossible in rural context. Several times doctors find it difficult even prescribing a patient since they have very little symptom history available. As D3 said:

> *"..this patient X came to me around 3 months ago and now she came. I do not know how the last prescription worked for her. The patient cannot tell you how the symptoms varied over such a long time."*

For the graph in Fig. 5(b), doctors have recorded only 5 visits and corresponding symptom levels over a period of 24 months.

5.6.3 Limited patient visit time

All the health centers including AGBCC suffer from high patient-doctor ratio. During our interview in DMCH and KMCH, we have seen long lines of patients. Doctors are always in a hurry completing the paper based ESAS and at the same time listening to patients. It takes 8 minutes to complete the ESAS graph (based on 35 observations).

5.6.5 Biased data

The quality of the patient feedback to doctors in AGBCC is biased by different factors. Hazards of transportation, heat, long waiting time, attempts to gain more attention from the doctors all factor in exaggerating symptom values that they endure normally. Recording data in a natural setting (patients' home) should increase the quality of the data.

6 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 –automation and motivation. 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, for the automation part, 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. For the motivation part, we have integrated a video module with two motivational videos to inspire the patients, family members and society in order to create a better environment for rural BC patients.

6.1 Patient module features

6.1.1 IMEI (Internaitonal Mobile Equipment Identity) based login

Initially we had conventional username-password based login system (Fig. 6(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 (Fig. 6(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 patients finally selected for using e-ESAS on regular basis and their attendants expressed their preference for IMEI based login. 5 of these patients also said that they have started submitting data by themselves without the help of attendants as a result of this change.

Fig. 6 (a) Username-password based login. (b) IMEI based login

6.1.2 Submission of symptom values

A patient is provided with a page containing 10 sliding bars corresponding to 10 symptoms mentioned in ESAS after login (Fig. 7(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 (Fig. 7(b)).

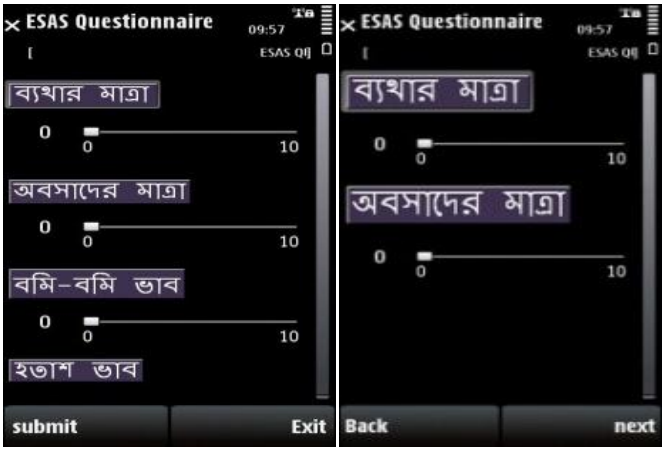

Fig. 7 (a) e-ESAS 1st version. (b) e-ESAS 2nd version

6.1.3 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.

6.2 Doctor module features

6.2.1 Single graph single patient single or multiple symptom

Doctors can choose any number of symptom levels for a specific patient against selected time period. Fig. 8 shows the symptom levels of pain, tiredness, and nausea for some patient X.

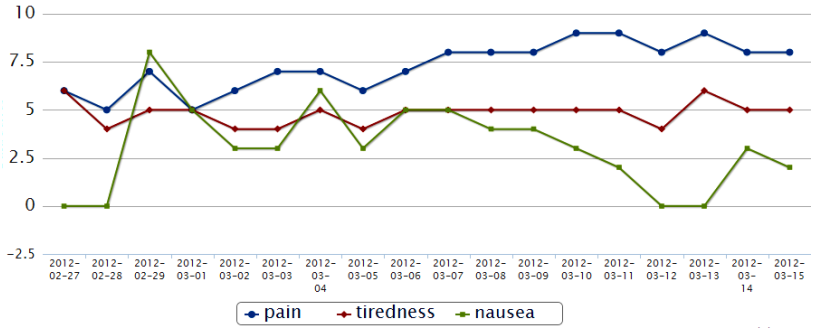

Fig. 8 Graph of patient x for the symptoms pain, tiredness and nausea against selected time period

6.2.2 Single graph multiple patient single symptom

Sometimes doctors need to compare a specific symptom of multiple patients who are under similar medication. Fig. 9 shows the pain curve for multiple patients.

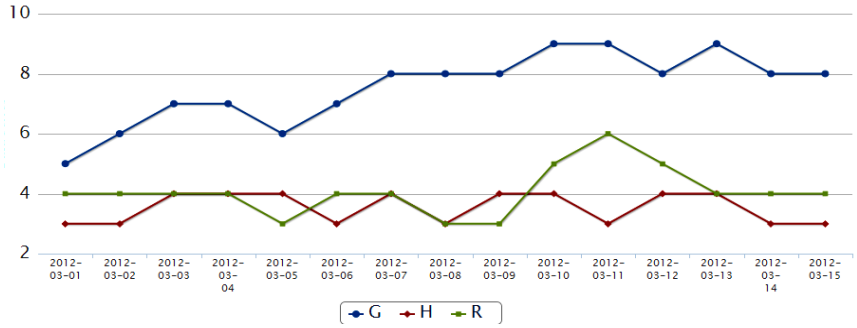

Fig. 9 Graph of patient G, H and R for the symptom pain

6.2.3 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. Fig. 10 shows a sample alert message.

Sl	Username	Patient Name	Phone	Pain	Highest Pain	Lowest Pain	Average Pain
1	J	[redacted]		8	8	8	8
2	R			7	7	6	6

Fig. 10 Alert generated by e-ESAS

6.2.4 Editing of prescription

Doctors can view previous prescriptions and opt for editing the previous ones. Patients receive an alert message when the prescription gets changed.

6.2.5 Time as context

Along with the value of a symptom in the graph doctors also want to see the time when the patient submitted that value. For example they like to see the 'pain value of 7 on date 02/14/12 at 9:00 pm'. This information will be useful for doctors to determine whether patients are suffering from pain (or any other symptoms) at any specific period of day or night.

6.2.6 Web interface

We have found that doctors in AGBCC use a desktop for official purposes. Since desktops offer a bigger screen size, we have developed a web interface for monitoring patient condition. This will also show the list of patients with pain level more than 6 and when did the patients last submitted e-ESAS symptom values. A screenshot of the home page has been shown in Fig. 11.

6.3 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)'.

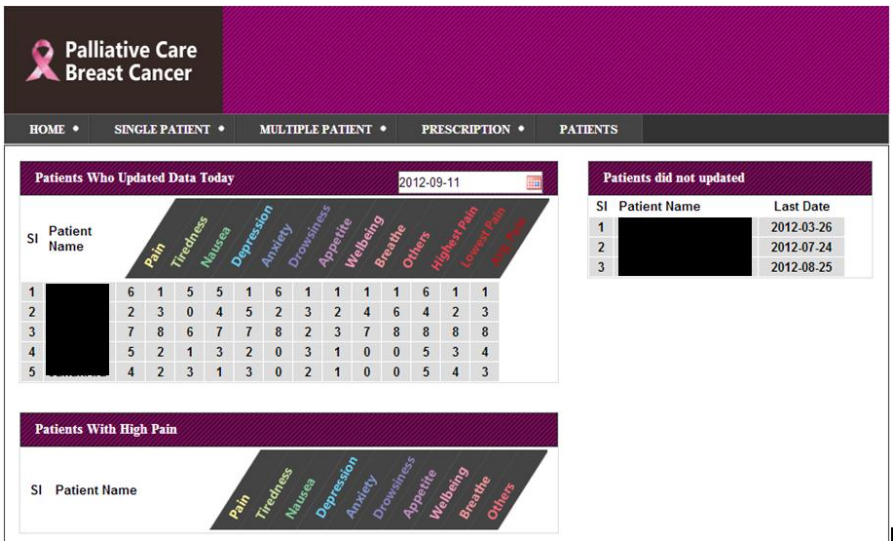

Fig. 11 Web interface for doctors

Both doctors and patients can view the motivational videos. 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. She talks about the primary and secondary symptoms of BC and encourages village women to go to the health centers without feeling shy or being afraid. Influential local persons spoke for the MVS and urged the family members (especially the husband and mother-in-law) to put emphasis on mothers' health. He also conveys 2 important pieces of information regarding BC: i) BC is not infectious and ii) BC is not exactly hereditary.

7 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.

7.1 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 errors)

7.1.1 Timing requirement

The average time required by attendants is 2.25 minutes which is slightly less than that of the patients (2.66 minutes) as shown in Fig. 12. This is expected since in most cases attendants were younger than the patients and more familiar with mobiles phones.

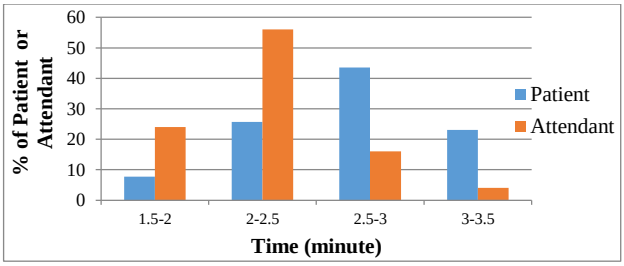

Fig. 12 Timing requirement histogram

7.1.2 Error histogram

Fig. 13 shows the number of errors made by the patients and attendants. 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.

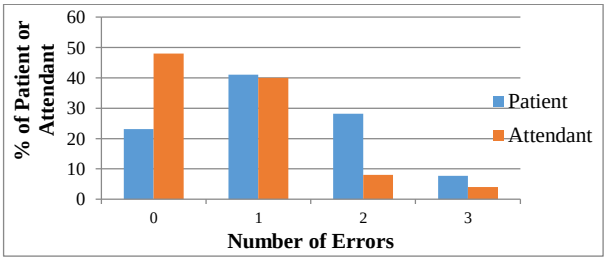

Fig. 13 Error histogram

Based on our observation we learned 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.

7.2 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. Here we will share two experiences of the doctors.

Case 1: D2 shared one such incident saying, "*I know a patient whose lung was affected and this was not deteced until too late since we didn't have enough information to predict that. But now when I see high value for 'shortness of breath' for a long period of time, I suggest further investigation predicting she might have lung involvement.*"

Case 2: 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 Fig. 14). As you can see pain level of MO1 has decreased after 03/12/12 whereas 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.*"

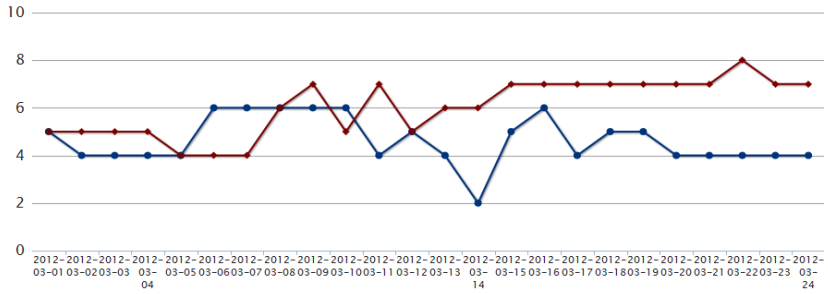

Fig. 14 Comparison of pain graph for MO1 and MO8.

7.3 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 Fig. 15) 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."*

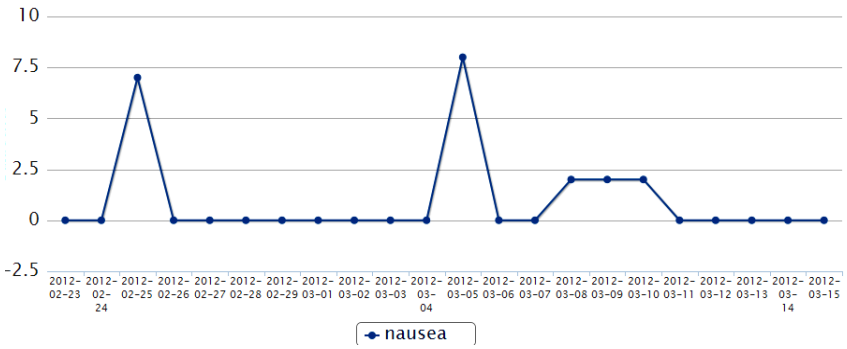

Fig. 15 Nausea graph of MO2

7.4 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.*"

8 Addressing the challenges

'Long term monitoring' is possible now since doctors are getting information of the patients each day. Users of e-ESAS will no longer need to come to the health center just to provide regular updates on symptom values on a weekly or biweekly basis. They now go to the health center only when they feel any problem or the doctors ask them to come based on analyzing the symptom values. This automatically reduces the average number of appointments (1.78 to 1.25 appointments per month) and the associated 'transportation hazards'. Moreover, lesser number of appointments will help to reduce the monetary and 'managing companion' issues. This also motivates the patients to meet the scheduled appointments with more urgency since they know that doctors now call them only when

something unusual is found in the submitted data. This issue helped to reduce the average percentage of missed appointment rate from 48.8% to 39.8% addressing the challenge 'lack of consistency'. Since the patients are virtually interacting with the doctors each day through submitting e-ESAS data on a daily basis, they are less prone to suffer from 'fading out' issue. Doctors are also able to serve more patients since they do not need to spend their time in filling out the paper based ESAS form. Thus e-ESAS helps to solve 'scarcity of doctors'. The symptom values submitted by the patients are being stored in a secure server with restricted access thus overcoming the threats of 'data security'. Also the issue of 'mobile theft' will not compromise patients' privacy since none of the symptom values are stored in patients' mobile phones. Motivational videos have been introduced as part of the e-ESAS system to help in changing the long standing social and cultural practices ('undermining women problem', 'gender discrimination', and 'common belief and practices'), improving knowledge of breast cancer ('lack of familiarity'), and addressing predefined mental blocks ('shyness' and 'fear'). Finally the 'usability findings' section shows that MOs were successful in using e-ESAS even with 'limited education' and 'limited technical knowledge'.

9 Design lessons

Each change in terms of feature of e-ESAS resulted as a direct feedback from the MOs. As our design evolved through the field studies and participatory design process, we learned the following lessons.

9.1 Interaction delay confusion

When the patients click the submit button at the end of e-ESAS, they expect the data to be submitted immediately. But due to slow data network it takes a bit of time to complete the submission process. Initially we thought a 'successfully submitted' message would be fine. But in reality that was not the case. As soon as the patients press the submit button and do not see any message, they think that they have not pressed the button properly. As a result they press the submit button again. We have found patients who are almost continuously pressing the submit button for 3 to 5 times. In order to solve this problem, we introduced a progress bar. As soon as the patients press the submit button it will appear confirming that they have pressed the button correctly. When the data submission is completed, the progress bar and e-ESAS will be closed automatically. Measures are needed to ensure that the right button has been pressed when there is an interaction delay involved.

9.2 Same pattern questions

For all the symptoms in original ESAS, 0 and 10 denoted the best and worst condition respectively. For example, 0 denotes no pain (best condition) and 10 denotes the highest pain (worst condition). Patients simply used to think 0 means no 'X' and 10 means highest level of 'X' where X is simply the name of the symptom. This strategy worked fine for all symptoms but 'appetite' and 'well being'. According to ESAS, 0 denotes 'best appetite' and 10 denotes 'worst possible appetite'. Similarly for 'well being' 0 denotes 'best feeling of well being' and 10 denotes 'worst possible feeling of well being'. This contradicted with the patient strategy. While putting values for appetite they think 0 means no appetite and 10 means highest level of appetite which is actually just the opposite. Same contradiction happened with the symptom well being. In order to solve this issue we simply replaced 'appetite' with 'lack of appetite' and 'well being' with 'level of sickness'. This solved the problem since now patients think 10 means highest level of sickness or lack of appetite. The lesson here is to try to understand how the target audience thinks and set up the questions in such a way so that they can answer all of them by a similar thought pattern.

9.3 Have I submitted data?

The MOs were instructed to submit e-ESAS once every day. But we marked 2 problems. For several MOs the database recorded multiple submissions and no submission problem. When we discussed the issue with MOs they mentioned the following:

(1) They forgot that they had already submitted data. (Multiple Submissions)
(2) Sometimes their family members accidentally submitted data. (Multiple Submissions)
(3) They thought that they had submitted data but actually they did not. (No Submission)

We adopted a simple mechanism to handle both the issues. Once e-ESAS data has been submitted, the 'Enter Data' button will be deactivated which will ensure single submission and also tell the MOs whether or not they have already submitted data for the day.

9.4 Exit button issue

During the usability study of the 1st version of e-ESAS we received 5 complaints of abrupt closing of the application. Then we tested e-ESAS by ourselves but did not find any problem. Later we asked 5 MOs to use e-ESAS arbitrarily in front of us. Then we found that MOs were accidentally touching the 'exit' button while dragging the sliding bar. This 1st version had 2 buttons 'submit' and 'exit' (Fig. 7(a)). Then in the 2nd version we provided the 'next' and 'back' button in all pages except the last page that contains 'back' and 'submit' button. The system automatically exits the application when the user clicks the 'submit' button in the final page. This process fulfills the usual purpose of 'exit' button but the responsibility has been removed from the users thus ensuring no accidental closing of the application. After this, we never heard of this complain.

10 Discussion

10.1 Addressing Motivation

Most of the challenges extracted from patient interview show lack of motivation for patients, family members, and the society. Any health care based IT project needs to address not only the direct solution (mobile/desktop software application) but also the motivation issue to create a smooth participation of the knowledgeable and informed patients. In general we argue for handling motivation in 3 dimensions as follows:

- Motivation for knowledge: Most of the patients come to the AGBCC when they cannot tolerate the breast pain or in other word at incurable state. But if the disease can be detected early, full recovery is possible. It is very important for the village women to learn about the initial symptoms and other common issues regarding BC.

- Motivation for women: Village women need to be motivated to come out of their usual shyness and fear. They need encouragement to consider their health with priority.

- Motivation for society: BC patients and other women need the support of the family heads (usually husband) and society. The society needs to change the customs and long standing practices that are hindering patients from going to the health centers. This motivation is needed to fight against the challenges like gender discrimination or religious beliefs.

10.2 Motivation-ability-trigger

Using a mobile based system like e-ESAS that has never been used by the rural patients and submission of data each day requires a change in behavior. In order to ensure this change we followed Fogg's Behavior Model (FBM) to incorporate 3 parameters: motivation, ability and trigger. Hope of getting better treatment from home without visiting the health center regularly motivated the MOs to use the system. The usability findings in section 7.1 ensure the ability of the MOs to use the system. Sense of being an important member in the family and neighborhood and being considered as part of the decision making process encouraged the MOs to continuously submit data.

10.3 Rural women & technology

The familiarity of patients with mobile technology is encouraging but not enthusiastic. On the positive side we found almost all patients having access to mobile phones but on the other side none of them have ever used any mobile application. During our clinic observation we marked that the young population in Bangladesh have a craze about mobile devices just like any other country. And our field study shows that all the patients live in combined family with other members of the greater family. In most cases these BC patients are bed ridden and the relatively younger family members, who are familiar with mobile applications, play the role of caregivers/attendants. Based on this scenario we argue that time has arrived to extend health care facilities to rural villages through mobile based solutions where patients/caregivers will be the primary user of the system.

10.4 Foreign and local influence

People in rural area are pretty biased to local influential persons and especially to foreigners. We have seen several incidents that support this theory. According to one of the doctors (D4), "*A new patient came to me yesterday with sore in her nipple. I asked her why she did not come early. She replied that one of the BC patients live beside her house and she saw foreign people coming to that house. As foreign doctors are involved here it must be good that is why she came now.*" Doctors and other people from the USA coming to the houses of rural BC patients was big news in the village. During our short stay, we saw neighbors coming to visit these houses and talk with us. A common belief exists among the village people that foreign doctors are much better than the local ones. In general, we can say that the incorporation of foreign doctors promotes the reliability and credibility of any rural health care project in developing countries.

11 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 shown. Since many of the developing countries share similar barriers in terms of socio-cultural and user issues, our categorized representation of 'challenges' and design lessons can be used as a generic framework for such studies. 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.

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 chose Nokia X6 for its built in accelerometer sensor since we also plan to evaluate the physical activities of these patients. Information regarding physical activities including duration of walking, sitting, lying can provide vital clues about the status of the patient. We will use other sensors to collect temperature information and talking time as suggested by the doctors.

We are also working on developing a SMS based e-ESAS system for low end mobiles. For this system client software will be developed and deployed in patients' mobile. The software will ask questions, collect answers, and then send the data as SMS. There will be a SMS server (Server and mobile connected with server) to receive the patients' SMS and parse the SMS to collect necessary data. At least java supported mobile will be required to run this software. We have decided to build the SMS based system in java enabled phone due to extreme penetration of Nokia phones in rural Bangladesh. 32 out of 43 patients who have access to mobile phones, possess a Nokia phone and 46.7% of these phones were java enabled.

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.

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