MOBILE BASED SYMPTOM MANAGEMENT FOR PALLIATIVE CARE

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by

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ABSTRACT

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The goal of palliative care is to improve the quality of life of terminally ill patients through the management of pain and other symptoms. Though the term 'palliative care' is well known in the developed world, it is relatively a new term in the developing world. According to WHO, each year 4.8 million people suffering from severe pain caused by cancer, fail to receive treatment due to lack of resources and other barriers.

In this thesis we have elaborated on the challenges faced by the rural breast cancer (BC) patients of Bangladesh and a solution for their palliative care treatment. Although breast cancer is commonly thought of as a disease of the developed world, the WHO statistics show that 69% of all BC deaths occur in developing countries. Unlike western countries where 89% of the women have a survival rate of more than 5 years, most BC patients in Bangladesh die because the majority of cases are diagnosed in late stages. These patients need palliative care which is almost absent in rural Bangladesh. These issues show the desperate need of a low cost palliative care system solution for the terminally ill patients of the developing world.

Based on detailed field studies, we have developed and deployed a mobile based remote symptom monitoring and management system named e-ESAS. Design of e-ESAS has evolved through continuous feedback from both the patients and doctors. e-ESAS is being used by 10 breast cancer patients to submit symptom values from their home for the last 10 months (Nov'11-Sep '12). Our results show how e-ESAS with motivational videos not only helped the patients to have a 'dignified' life but also helped the doctors to achieve the goals of palliative care. Also the analyzed results are shown in 4 categories to appropriately measure the contribution of e-ESAS in improving the QoL.

This thesis also focuses on developing a mobile based pain intensity detection tool which is a first step in replacing the manual paper based scale for measuring pain. The tool also might play a big role in assessing the pain level of verbally impaired patients.

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And finally I would like to thank my sister and parents for their continuous support in pursuing this highest degree. They always tried their best to arrange the best possible education for me. I will finish this abstract with a little story of mine. During my PhD studies at Purdue University, my mother was diagnosed with cancer. I left Purdue to be at her side. She died after a

month. Amma (mother), you were the inspiration for me to continue my PhD at Marquette university in the area of palliative care. There is not a single day that passes by when I do not think of you. I dedicate this achievement to you.

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LIST OF ABBREVIATIONS AND ELABORATIONS

TERM	ELABORATION
AGBCC	Amader Gram Breast Care Center
BDT	Bangladeshi Taka
BC	Breast Cancer
DMCH	Dhaka Medical College and Hospital
ECOG	Eastern Cooperative Oncology Group
ESAS	Edmonton Symptom Assessment System
HRQOL	Health Related Quality of Life
HW	Health Worker
IMEI	International Mobile Equipment Identity
KMCH	Khulna Medical College and Hospital
MO	Mobile Owner
QoL	Quality of Life
QoS	Quality of System
QoT	Quality of Treatment
QoD	Quality of Data
RSMS	Remote Symptom Monitoring System
TF	Time Frame
WHO	World Health Organization

Chapter 1:   Introduction

Breast cancer (BC) patients need traditional treatment as well as long term monitoring through an adaptive feedback-oriented treatment mechanism. Lack of motivation to go to health centers on the 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 this purpose for 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 a rural context where patients are the prime users rather than just the source of data collection at some point of time. Along with the detailed assessment of such a system we describe the evolution of e-ESAS and the deployment results. We have also shown how 'motivation' and 'automation' have been integrated in e-ESAS and created a unique motivation-persuasion-motivation cycle where the motivated patients become proactive change agents by persuading others. The findings show how e-ESAS addresses several challenges faced by patients and doctors and positively impacts their lives. e-ESAS demonstrates the potential to positively impact the cancer care by (1) helping the doctors with graphical charts of long symptom history (automation), (2) facilitating timely interventions through alert generation (automation) and (3) improving three way communications (doctor-patient-attendant) for a better decision making process (motivation) and thereby improving the quality of life of BC patients.

1.1. Dissertation Focus

In this dissertation, we first focus on understanding the challenges faced by poor rural breast cancer patients who need long term monitoring and treatment. We then focus on the design and development of a mobile based remote symptom management system that can solve the challenges faced by both patients and their associated doctors. The goal of the mobile based system named e-ESAS is to help doctors in managing pain and other symptoms in a better way and ultimately improve the quality of life of these terminally ill patients. Later the dissertation

focuses on identifying the pain intensity level of patients by analyzing the facial features using a mobile phone. The main contributions of the dissertation are as follows:

- 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 able to send their symptom levels each day. The overall process helps in bridging the 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.

- Development of a mobile based automatic pain intensity detection tool.

1.2. Major Contributions

In this section we briefly summarize the contributions of this dissertation.

1.2.1. Design, development and deployment of e-ESAS: Many women in Bangladesh either never seek treatment or arrive at hospitals with late-stage cancer. Our field study shows numerous social, economic, traditional and health-system related issues factor into these circumstances. In this scenario, women need motivation to overcome barriers in order to access medication. Patients are also reluctant to visit health centers regularly due to factors including financial, poor transportation and physical status. Key issues of BC like early detection and long term monitoring are rare events here. Lack of patient information and scarcity of doctors complicate an already challenging situation. In this regard a mobile based remote symptom monitoring system (RSMS) can play a potentially revolutionary role. Hence, we have designed e-ESAS, the first mobile

based RSMS, developed for rural breast cancer patients. Findings of e-ESAS demonstrate its role in improving the cancer care facilities.

1.2.2. Quantifying Quality of Life (QoL) in rural health care context: QoL is a much talked about topic in medical science, behavioral science and psychology. However, measuring a system's contribution in improving QoL is an almost unexplored topic. It is a question that CHI (Human Computer Interaction) community researchers often face and find it difficult to measure. In an effort to handle this issue, we have categorized QoL in 4 domains and mapped our analysis results to inherit the features of these domains. This is the first attempt of its kind that tried to formulate a generic framework that can be used by health care researchers to evaluate the contribution of a system in measuring the improvement of QoL.

1.2.3. Automatic detection of pain intensity from facial images: We are also working on finalizing a mobile tool that captures pain images from patients and find one of the six (0, 2, 4, 6, 8, 10) pain intensity levels. Currently the existence and intensity of pain is determined by the self-reported measure of the patient himself. Developing a mobile based pain assessment tool from facial images may greatly reduce the workload in a hospital scenario as well as increase the quality of life of patients who fail to adequately communicate their pain levels. We have first developed a mathematical model based on the Eigenface method to determine the co-relationship between facial features of patients and their pain level. Then we have developed a mobile phone based prototype based on the mathematical model that will automatically determine a pain intensity level from 0 to 10.

1.3. Dissertation Organization

The rest of this dissertation is organized as follows:

- In chapter 2, we present a brief description of the field study procedures and methodologies we followed. We first discuss the current state of art of existing mobile based health care solutions. Next, we discuss the interview methods, questionnaires and participants' information.

- In chapter 3, we elaborate on the challenges found based on our field studies. We have classified the challenges in appropriate domains and these challenges also show the motivation for devising a mobile based solution.

- In chapter 4, we introduce the desired characteristics of a mobile based symptom management system. Then we discuss the development and deployment of our proposed system - e-ESAS. We conclude with the design issues we learned through the passage of development of e-ESAS.

- In chapter 5, we detail the deployment results of e-ESAS. Later we analyzed the findings to show how e-ESAS system is helping both patients and doctors to overcome the challenges mentioned in chapter 2. The rest of the chapter briefly presents a thoughtful discussion and possible pitfalls.

- In chapter 6, we introduce the notion of health related quality of life (QoL). First, QoL is classified into 4 domains. Then the rest of the chapter presents how these domains can be evaluated to find the contribution of a system in improving QoL. The chapter concludes with the lessons learned and directions on future work.

- In chapter 7, we present a mobile based system to automatically measure pain intensity level from candid facial images. We first describe the motivation and current state of art. The rest of the chapter briefly presents the details of our proposed mobile based system.

- In chapter 8, we have concluded the dissertation with the summary of achievements and future research directions.

1.4. Publications

1.4.1. Publication on e-ESAS

- **Munirul M Haque,** Ferdaus Kawsar, Md. Adibuzzaman, Sheikh I. Ahamed, Richard Love, Rumana Dowla, David Roe, Syed Mozammel Hossain, and Reza Selim, "Findings of e-ESAS: A Mobile Based Symptom Monitoring System for Breast Cancer Patients in Rural Bangladesh,**"** In Proceedings of CHI 2012, 899-908. (**Best Paper Honorable Mention Award**)

- **Munirul M Haque,** Ferdaus Kawsar, Md. Adibuzzaman, Sheikh I. Ahamed, Richard Love, Rumana Dowla, David Roe, and Reza Selim, "Mobile Based health Care Solution for Breast Cancer Patients,**"** In Proceedings of Mobile for Development (M4D), 23-35, 2012. (**Nominated for Best Paper Award**)

- Ferdaus Kawsar, **Munirul M Haque,** Md. Adibuzzaman, Sheikh I. Ahamed, and Md Miftah Uddin, "e-ESAS: Improving Quality of Life for Breast Cancer Patients in Developing Countries," In Proceedings of MobileHealth, 2nd ACM MobiHoc Workshop on Pervasive Wireless Healthcare In Conjunction With MobiHoc 2012 Conference, South Carolina, USA, June 11-14, 9-14, 2012.

Work Under Review:

- **Munirul M Haque**, Ferdaus Kawsar, Md. Adibuzzaman, Miftah Uddin, Sheikh I. Ahamed, Richard Love, Rumana Dowla, Tahmina Ferdousy, and Reza Selim, "Barriers for Breast Cancer Patients in Rural Bangladesh: Design and Deployment of a Mobile based Solution," Submitted In Proceedings of CHI 2013.

- **Munirul M Haque**, Ferdaus Kawsar, Md. Adibuzzaman, Md Miftah Uddin, Sheikh I. Ahamed, Richard Love, Rumana Dowla, Tahmina Ferdousy, and Reza Selim, "Findings

of Mobile based Palliative Care System: Towards Formulating a Generic Framework for Measuring QoL," Submitted In Proceedings of CHI 2013.

- **Munirul M Haque**, Ferdaus Kawsar, Md. Adibuzzaman, Md Miftah Uddin, Sheikh I. Ahamed, Richard Love, Rumana Dowla, Reza Selim**,** Tahmina Ferdousy, and David Roe, "Design, Development and Deployment of a Mobile based Remote Symptom Assessment System (e-ESAS): Lessons and Findings in Rural Bangladesh," Submitted In ACM CHI Journal.

1.4.2. Publication on facial image analysis

- **Munirul M. Haque**, Md. Adibuzzaman, David Polyak, Niharika Jain, Sheikh I. Ahamed, and Lin Liu, "IRENE: Context aware mood sharing for social network," In IEEE International Conference on Service-Oriented Computing and Applications, SOCA, pp.1-8, 2011.

Chapter 2:   Study Procedure and Methodology

The goal of this chapter is to discuss the current economic and treatment status of rural breast cancer patients. We will also elaborate the state of the art and study procedures we followed during our field studies.

2.1. Current State of BC Patients

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. According to Bangladesh Bureau of Statistics, cancer is the sixth leading cause of morbidity and mortality in Bangladesh [BBS]. In Bangladesh, 24.3% of female cancer patients suffer from breast cancer (BC) with only 98 oncologists present in the whole country. National Institute of Cancer Research and other hospitals in Bangladesh can provide treatment to only 2% of all cancer patients per year (20,000 out of 1 million) [Ohmynews]. The Government of Bangladesh devised the 'National Non Communicable Diseases Strategy and Plan of Action' with technical support from WHO in 2007. Even in this scenario, more than 22,000 new BC patients being added each year and 70% of them die due to lack of treatment [Peopledaily] though it is possible to prevent at least one-third of the cancers based on early detection, availability of resources, and effective treatment [WHO].

Many women in Bangladesh either never seek treatment or arrive at hospitals with late-stage cancer. Apart from the sufferings caused by the diseases, patients have to go through a painful ordeal of managing a companion, procure money and make a long commute consisting of various transports only to end up at the tail of long queue at health centers. Our field study shows numerous social, economic, traditional and health-system related issues factor into these circumstances. In this scenario, women need motivation to overcome the barriers to reach the door of medication. Patients are also reluctant to visit the health centers regularly due to factors including financial, poor transportation and physical status. Key issues of BC like early detection and long term monitoring are rare events here. Lack of patient information and scarcity of doctors

complicate an already challenging situation. In this regard a mobile based RSMS can play a potentially revolutionary role.

Fortunately, in Bangladesh, like many other low-income countries, cell phones have become ubiquitous. According to Bangladesh Telecommunication Regulatory Commission, the number of cell phone users in Bangladesh has reached 86.6 million by Jan 2012 [BTRC]. Based on our field study we found 43 out of 45 rural BC patients have access to cell phones. With this in mind, we decided to use cell phones for remote monitoring of the patients, which may notably reduce the necessity of visiting the doctors' facility coupled with the benefit doctors will have by getting regular patient data.

Therefore, we have developed a mobile based RSMS named e-ESAS based on Edmonton Symptom Assessment System (ESAS) [ESAS], which is used by the doctors for the assessment of symptoms of cancer patients. e-ESAS has been developed considering the literacy level, familiarity with mobile technology and capability of the rural patients. This system has been deployed in Bangladesh as a pilot project for data collection. Patients can submit values for different symptoms from their home and doctors can view the graphical representation of that data using a cell phone. Accordingly, doctors could change the medication of the patients depending upon the feedback.

The contribution of the work can be documented in broad scale as: *(1) the first mobile based RSMS for rural patients suffering from chronic disease like BC, (2) the first system where patients have become the sole user from home, (3) improvement on awareness of primary and secondary symptoms of BC, which is crucial for early detection, (4) creation of a positive environment through motivating videos, and (5) improvement of quality of life of rural BC patients*.

2.2. Related Work

We have divided the literature using mobile technology and hand held devices for bridging the information gaps in health-care management in two categories- urban and rural settings.

Hayes et al. 2008 summarized the detailed overview of the cancer treatment process and possible use of pervasive technology in urban settings. Skeels et al. [Skeels10] tried to utilize the power of social network to improve the quality of life for cancer patients which is impractical in our scenario. CHESS [Gustafson05], 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 [Adams03], diabetes [Cherry02] and cancer [Dubenske08]. 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.

The low cost availability of mobile devices has greatly enhanced the prospect of mobile based applications being used in rural healthcare. These applications intend to focus on one of the following four areas:

2.2.1. Decision Support System

Several projects work based on implementing a guideline set by WHO or other standard organizations in computer or handheld devices [DeRenzi08, Peters05, Mitchell09]. Early Diagnosis and Prevention System [Peters05], a computer based healthcare management software has been deployed in rural area of Tamil Nadu, India. The software registers patient history and uses this information to develop a screening method. Mitchell et al. [Mitchell09] implemented a HIV screening algorithm in PDA and tested the performance in two AIDS treatment centers in South Africa. They used this to collect data and to provide help in decision support to health workers. e-IMCI [DeRenzi08] describes a PDA based system for administering the Integrated Management of Childhood Illness (IMCI) protocol for treating children in Tanzania. This system

helped doctors to follow the simple IMCI guidelines with reduced deviations and played a major role to combat child mortality. All these projects just check the answers of the interview questions and suggest doctors what to do based on predefined set of rules. But our project feeds doctors with continuous, regular data and presents them in longitudinal fashion to help them in decision making in a better and efficient way.

2.2.2. *Data Collection/Survey*

The feasibility of mobile applications for collecting health data or survey information has been proven in many developing countries including India [Anantraman02], Tanzania [Shimira07], Mozambique and Uganda [AED Satellife]. A modular questionnaire has been designed in PDA to survey 21,600 scattered households in Mtwara, Tanzania [Shimira07]. SATELLIFE PDA [AED Satellife] demonstrated the viability of PDAs by successfully addressing the digital divide among healthcare workers and professionals in Ghana. PDAs have also been used in replacing paper based questionnaire in the context of HIV/AIDS programs in Angola [Cheng08]. Our project has two fundamental differences with these projects. Firstly, instead of health workers or trained professionals, patients or their attendants are filling the information by themselves in our project. Secondly, patients are doing this from home and sending data by using the data network of mobile carriers. In all other projects either patient has to come to the health center or health workers need to go to remote houses of the patients to collect such information.

2.2.3. *Electronic Medical Record (EMR)*

Cash project [Anantraman02] operated in India showed the effectiveness of creating EMR using PDAs. The system was utilized by paramedical health workers to develop a database of 70,000 patients. OpenMRS [OpenMRS] and CommCare [CommCare] are two other patient record systems aimed to solve the EMR problem for low-income countries. In our case, we are

building a patient database by automatically collecting values of 13 parameters regarding breast cancer patients on regular basis. Since we are using mobile technology our system is having the luxury of mobility unlike computer based web service technology.

2.2.4. Telemedicine

Several projects like WiLDNet [Patra07], Asynchronous Remote Medical Consultation [Luk08], iPath [Brauchli05] aim to connect physicians from urban areas or foreign countries to 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.

Current literature review concludes that mobile applications intended to help long term monitoring of patients suffering from chronic diseases like BC of developing world is yet to be implemented. Along with that our paper is fundamentally different from the abovementioned projects in several ways. We have performed a thorough field study and derived the possible issues that can be solved using mobile technology from both patient and doctor point of view where as all other projects focus on one module. The outcome of filed study has been analyzed minutely to accrue primary elements of interface design. In contrast to other projects the primary user of e-ESAS is the patients. Finally, our project handles the issue of '*motivation'* as part of the implementation.

2.3. Local Partner Information

Amader Gram (literally, 'Our Villages') is an Information and Communication Technologies for Development (ICT4D) initiative of Bangladesh Friendship Education Society (BFES). In 2006 Amader Gram partnered with the International Breast Cancer Research Foundation (www.ibcrf.org) to open Amader Gram Breast Care Center (AGBCC) and became one of 9 countries to participate in a clinical trial for breast cancer patients. The mission for

AGBCC is to reduce morbidity and mortality from breast cancer and other breast diseases in the women. At the same time it promotes women to break the silence with local education, addresses cultural issues with performance art, and empowers primary health workers to find and assist affected women. A trained female doctor and medical assistant attend each center, examining and keeping records of each woman who comes to the clinic. Women are provided advice and supportive care; those with more serious issues are referred to an affiliated doctor at Khulna Medical College & Hospital. Patients need to pay a onetime registration fee of BDT 100 ($1.5). Furthermore, 1,405 patients have been registered with BC and 239 of them have been referred for further care from 2006 to 2010. Since then 21 patients have died. Amader Gram also works for the rural ICT (Information, Communication and Technology) efforts which make the NGO an ideal choice for our pilot study.

2.4. Need Assessment

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), 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.

2.4.1. 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. 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 recorded and photographed.

2.4.1.1. 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.

2.4.1.2. 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 advance states of the disease.

2.4.1.3. Home Interviews

The patients feel more comfortable to talk and discuss in their home environment. 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.

2.4.2. Participants

As per requirement analysis we talked with all related personals involving breast cancer. The following table 2.1 summarizes the information.

Table 2.1 Participant list

People\ Places	Khulna	Bagerhat	Rampal	Dhaka
Patient	19	10	1	9
Health Worker	2	2	2	0
Doctors	8	0	0	4

We provide detail description of the participants in the following subsections.

2.4.2.1. Patients

The patients were quite diverse in terms of level of education, expertise with mobile phones where as there were striking similarity considering occupation and household income. We have asked them the following questions for better understanding of the current procedures and practices. We especially tried to focus on the following issues.

        (1)   Education level

        (2)   Occupation

        (3)   Occupation of husband

        (4)   Average monthly income of the family

        (5)   Amount of land

(6)   Number of children

(7)   Experience with mobile

— Can call & receive

— SMS

— Can run some kind of application

(8)   What type of mobile

(9)   Do you or your family members own a mobile?

(10)   Do you have access to that mobile?

(11)   How long your husband or family member who owns the mobile remains

at home (status of availability)?

(12)   What is your husband's reaction about this (cancer) issue?

(13)   What type of social problems you face for going to doctor?

(14)   Do you face any religious issues?

(15)   How is the communication to the nearest health centre? What is the

average cost and time to reach there?

(16)   The average cost to meet an appointment (going to doctor, cost for tests,

cost for the companion etc.)

(17)   What are the reasons for missed appointments?

(18)   Discuss about the following issues:

(a)   Lack of familiarity regarding breast cancer

(b)   Religious and social stigma

(c)   Communication problem

(d)   Any other issue patients want to share

Patients' age ranges from 21 to 45 years. Patients' education varied from illiterate to high school. We found only 1 patient who studied up to grade 12. No one has gone beyond that. 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). 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. Table 2.2 provides a high level view.

Table 2.2 Summary of patient information

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

2.4.2.2. 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 complained about exaggeration of symptom values especially pain. Our clinic observation has found all 22 patients to report having maximum pain level.

- 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.

- A tool that can show patient's medication and other symptoms in longitudinal graphs can be of great help.

2.4.2.3. Health Workers

We talked with 5 health workers in different cities of Khulna. These health workers do the initial steps like checking blood pressure, weight, and primary screening before the patients

go to the doctor's chamber. Sometimes health workers even go to the houses of patients. As a result they have an emotional bonding with patients and patients share inside stories of their life with them. For example, during our visit, a doctor asked one patient to visit after 15 days and later the patient was asking the health worker if it is fine to come after a month since she comes from a distant village. We tried to find out the inside thoughts of the patients that they normally hide from others by discussing with the health workers We also asked their thoughts about the issues that are hindering patients from coming to the center. They added a new point regarding missed appointments. During specific time period of the year like harvesting time or rainy season patients miss appointments at higher rate. This is because they either take part in the work or it is hard to get any companion since everyone is busy. It is to be noted that these health workers are employees of the AGBCC center and they only go to patients' house in extreme emergency. It is not also feasible for health workers to visit each of the patients home, which are distant apart, every day.

Chapter 3:   Challenge Identification

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. The biggest problem for BC patients is the lack of knowledge and motivation for treatment. Due to lack of familiarity, most women identify BC really late. They are very shy and sometimes are afraid to talk with anyone regarding breast problems. Most of the time they think this will be automatically cured as time goes by. Long standing superstitions and social and religious beliefs also stand against visiting and receiving treatment. In many rural families, the husband and mother-in-law believe spending money on women is a complete waste, whereas the male members of the family are treated differently. Long traffic jams, poor road conditions and long distances to health centers complicate the already challenging situation. Due to the lengthy nature of treatment, BC patients become habituated with the disease and start neglecting treatment (fading out issue). Patients also mentioned the problems of finding a companion who will accompany them to health centers. Typically, patients visit doctors with long delay between appointments and miss appointments on a regular basis. Based on the results of our field studies, we have grouped the challenges in the different domains and generated the following barrier tree shown in figure 3.1.
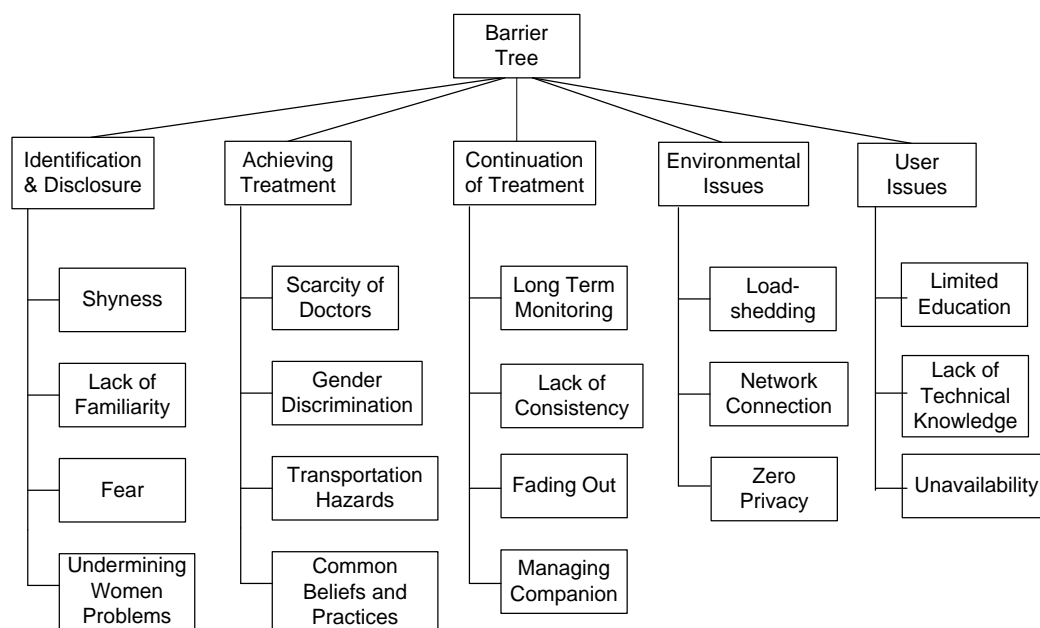
Figure 3.1 Barrier tree for rural BC patients

3.1. Identification & 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.

3.1.1. 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.

3.1.2. 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.

3.1.3. 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*."

3.1.4. 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."*

3.2. 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.

3.2.1. Scarcity of Doctors

The scarcity of doctors is a big issue especially female doctors and cancer specialistsin Bangladesh. 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.

3.2.2. Gender Discrimination

In the male dominant rural society women are the last point of attention. The husband, children, in laws all 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."

3.2.3. 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.

3.2.4. Common Belief & 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% patients we met said

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.*"

3.3. 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, quarterly, or monthly basis based on the severity and complexity of the disease. Irregularity in making the appointments becomes an issue to be noted.

3.3.1. 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."*

3.3.2. 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."*

3.3.3. 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.

3.3.4. Managing Companion

Rural women generally take some female relatives or husband along with them when they come to visit the doctors. They consider taking a companion for various reasons. Often they think they will not understand what the doctors will be saying since they do not know how to read and write. In many cases they are mentally weak and afraid about the disease. 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 manage someone to manage household activities including looking after her children, cooking for her husband etc.

3.4. Environmental & Infrastructure Issues

We have faced the following environmental issues.

3.4.1. 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. But conditions are still enough to charge mobiles to keep them active.

3.4.2. Network Connection

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.

3.4.3. Zero Privacy

The concept of privacy is completely absent in rural Bangladesh. It is even hard to make someone understand about the privacy of health care data. All 39 patients said it is quite common for them to look at other's prescriptions.

3.5. User Issues

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

3.5.1. Limited Education

The rate of education is quite low in rural women as shown in table 2.2. 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, 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.

3.5.2. Lack of 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).

3.5.3. 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.

3.6. 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.

3.6.1. 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. Example of ESAS form and ESAS graph has been shown in Figure 3.2 and 3.3.

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 3.2 ESAS symptoms form
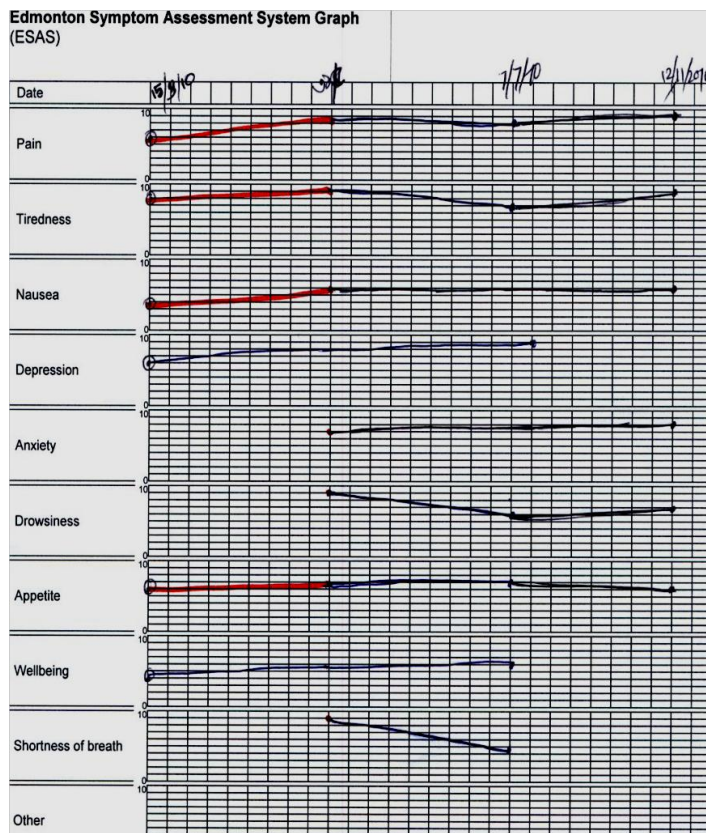
Figure 3.3 ESAS graph showing incomplete symptom charts

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 the following reasons:

- They do not get enough time to fill all the charts.

- The patients could not give them appropriate information.

- They primarily treat the patients based on pain level and are not much concerned about less important symptoms.

- They listen to the patient history and put the symptom values altogether instead of asking them separately.

3.6.2. 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 Figure 3.3, doctors have recorded only 4 visits and corresponding symptom levels in an 8 month period.

3.6.3. 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).

3.6.4. Missing Information

Due to communication gaps and lack of knowledge, BC patients miss reporting crucial information. Loss of prescription is also quite common. We have found 7 patients without prescriptions during our clinic observation.

3.6.5. 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.

Chapter 4:   Design and 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.

4.1. Design Characteristics

As a result of the meeting outcomes we have received several important issues and a guideline about the possible desired characteristics of an automated system.

4.1.1. User friendliness

The user interface should be designed considering the background of the target people. Their familiarity with certain technology, education level, physical condition etc. should be considered during the design of the system.

4.1.2. Mobility

One key characteristic of the system is to maintain the mobility of the patients and doctors. Doctors are expected to view patient data using their mobile phones from anywhere anytime, even when they are travelling. Patients also should be able to transfer data from anywhere, even from remote places.

4.1.3. Continuous data collection

One of the problems doctor regularly face is that patients do not follow up regularly and the information about patients is irregular. Collecting the patient data should be continuous and regular. Once the system is deployed, it should be able to add new users (patients and doctors) and collect and store the data in the server regularly.

4.1.4. Quality over quantity

Data collected in a health center can be biased by different factors. For example, when a patient travels a long distance in various modes of transport and wait in doctor's chamber for her turn, the feedback she gives to the doctor may be distorted by her experience. The patient's response is influenced by her current situation. So the quality of the feedback doctors receive in this kind of setting is not the best. Another way to increase the quality of the data is to record the data when it matters most. For example, recording pain level when pain is very high or very low should also increase the quality of data as the drastic change is being recorded.

4.1.5. Local dialect

Instead of using English, local dialect should be used in the user interface as much as possible.

4.1.6. Configurable data representation

Viewing the data in right format is important for doctors. The pattern that is obvious from the graph may not be so obvious from a table. The system should provide the opportunity to doctors to view the data in different format.

4.1.7. Smooth & comfortable

The system should be designed in such a way that users are comfortable with it and it causes little or no obstruction to the daily activities of the patient. Accessing the data by the doctors should not hamper their normal interaction process with the patients.

4.1.8. Extensible

The system should be designed in such a way that some other useful services can be incorporated into the system later, i.e. the system should be extensible. Also it should be easy to incorporate suggestions from users in the later versions of the system.

4.2. Motivation

Motivation is needed to overcome most of the barriers faced by patients. We have developed 2 different videos named 'Motivating Video for Women (MVW)' and 'Motivating Video for Society (MVS)' for this issue. One patient took part in the MVW and local influential persons took part in the MVS. The statements of the MVW and MVS were carefully chosen to cover different areas of motivation. In MVW, the patient talks about her experience, symptoms of BC, and motivates other women to visit doctors. At the end of the MVW, doctors made some important comments. The MVS video is directed towards the family heads (husbands) and addresses the social and cultural challenges to create a better environment for BC patients. At the same time, both the videos convey important information regarding BC. At the end of the 1st month of deployment, we replaced the MVW with a new patient statement to continue the viewers' interest. Below are the excerpts of a patient and doctor from the MVW:

> *"When I first found a **lump** in my breast I took homeopathy treatment… It was also **paining, irritating** and I found **discharge from the nipple**… then I visited AGBCC and visited a **foreign doctor**…Later I went through an operation. I'm going there **every month** and taking medicines regularly. Now I am better than earlier. Whoever has this problem, don't feel **shy** or **don't get afraid** and get treatment **as soon as possible**." (patient)*

> *"We should give importance to all the **lumps** whether it is a cancer or not. We should check it **regularly** by expert doctor at least **once a year**… We the doctor and health workers of AGBCC are always beside you." (doctor)*

The statement of MVS is as follows:

> *"Breast cancer is a **curable disease**. It is **not infectious** and it is also not true that if someone has breast cancer then other members of the family will also have it. Mothers and sisters please be conscious...I will request the male members of*

the house not to neglect the health issues of the women...We are lucky that AGBCC is located close by where doctors are ready to give you all necessary treatments."

The following figure 4.1 shows some snapshots of patients using e-ESAS.

Figure 4.1 a) Patient and family members enjoying the video b) Patient showing e-ESAS to others in AGBCC

4.3. 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, we have used Tomcat 6.0 as the server and MySQL as database. The client in turn has two modules. We call these modules as patient module and doctor module.

4.3.1. Patient Module Features

This module has the following features.

- ***IMEI (International Mobile Equipment Identity) based Login***

Initially we had conventional username-password based login system (Figure 4.2(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 mechanism (Figure 4.2(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. Finally when the patient submits the e-ESAS data the matched ID is padded in the packet and sent to the server.

Figure 4.2 a) Username-password based login b) IMEI based login

- *Submit Symptom Values*

A patient is provided with a page containing 10 sliding bars corresponding to 10 symptoms mentioned in ESAS after login (figure 4.3(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 4.3(b)).
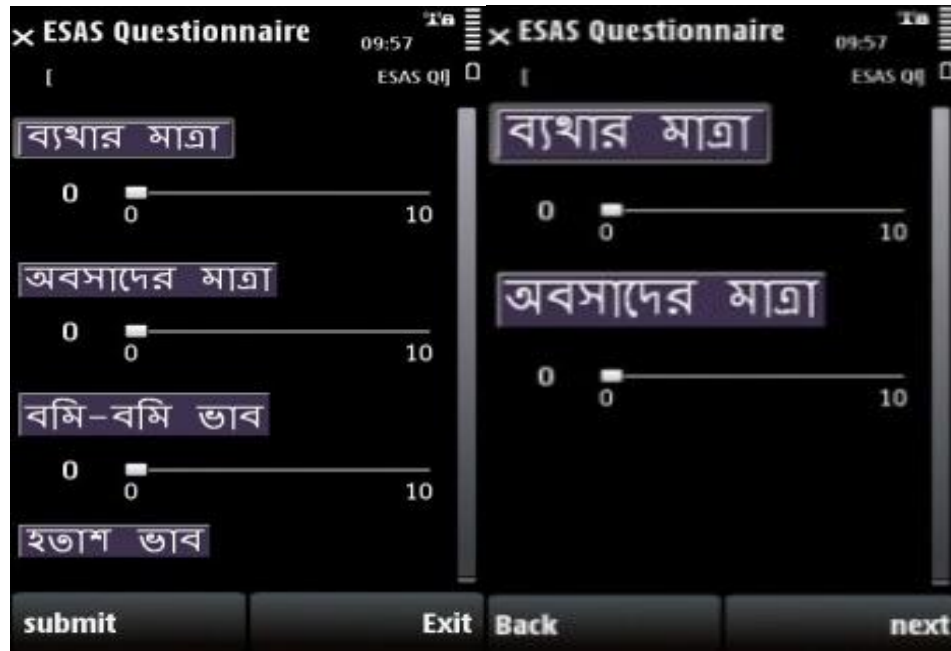
Figure 4.3 a) e-ESAS 1st version b) e-ESAS 2nd version

- *Voice Instruction*

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 the sliding bar.

- *View Prescription (Intervention)*

Patients can view their prescriptions by clicking the 'Prescription' button.

4.3.2. Doctor Module Features

We have developed the following features for doctors' module in mobile phone and desktop.

- ***Single Graph Single Patient Single Symptom***

For example, a graph of patient A for any chosen symptom, like pain against selected time period.

- ***Single Graph Single Patient Multiple Symptom***

For example, a graph of patient A for the symptoms pain, depression, and anxiety against selected time period.
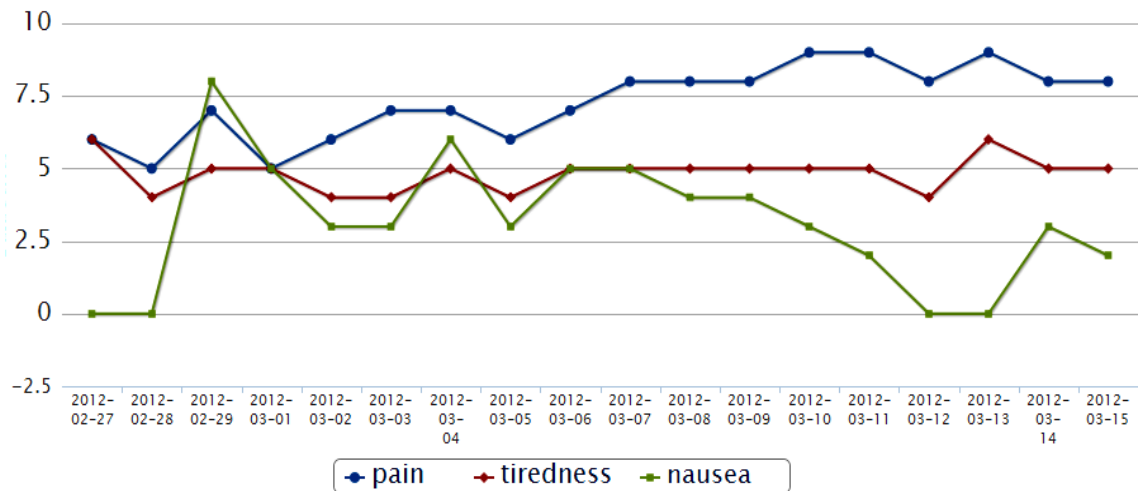
Figure 4.4 Graph of patient X for the symptoms pain, tiredness and nausea

- ***Single Graph Multiple Patient Single Symptom***

For example, a graph of patient A, B, and C for the symptom pain against selected time period.
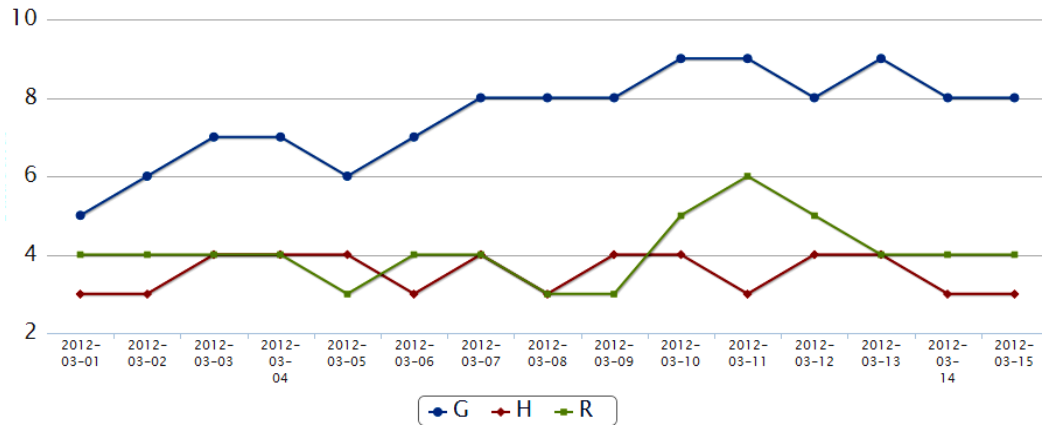
Figure 4.5 Graph of patient G, H and R for the symptom pain

- *Alert Generation*

For timely intervention, a notification will be generated if a certain symptom level of any patient exceeds a predefined threshold value. For example, e-ESAS automatically sends the following alert message (Figure 4.7) to designated doctors when the pain level of any patient is more than 6.

SI	Username	Patient Name	Phone	Pain	Highest Pain	Lowest Pain	Average Pain
1	J			8	8	8	8
2	R			7	7	6	6

Figure 4.7 Alert generated by e-ESAS

- *Editing of prescription*

Doctors can view previous prescriptions and opt for editing the previous one as shown in Figure 4.6.
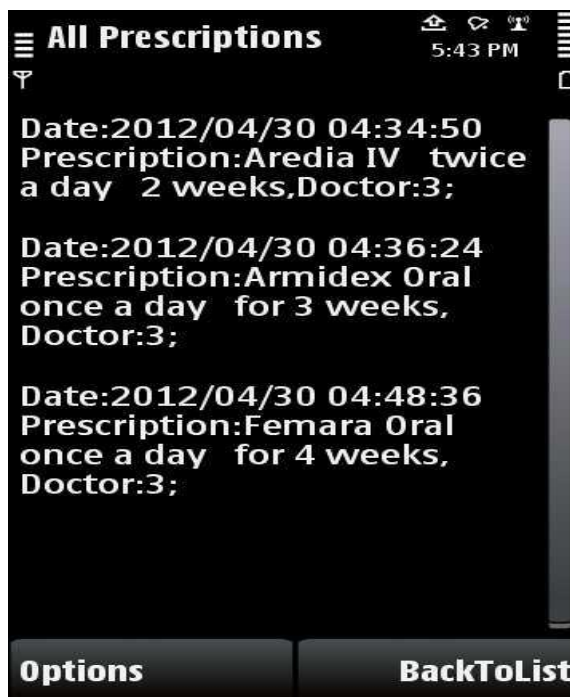
Figure 4.6 Prescription send through e-ESAS

- *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.

- *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 Figure 4.8.
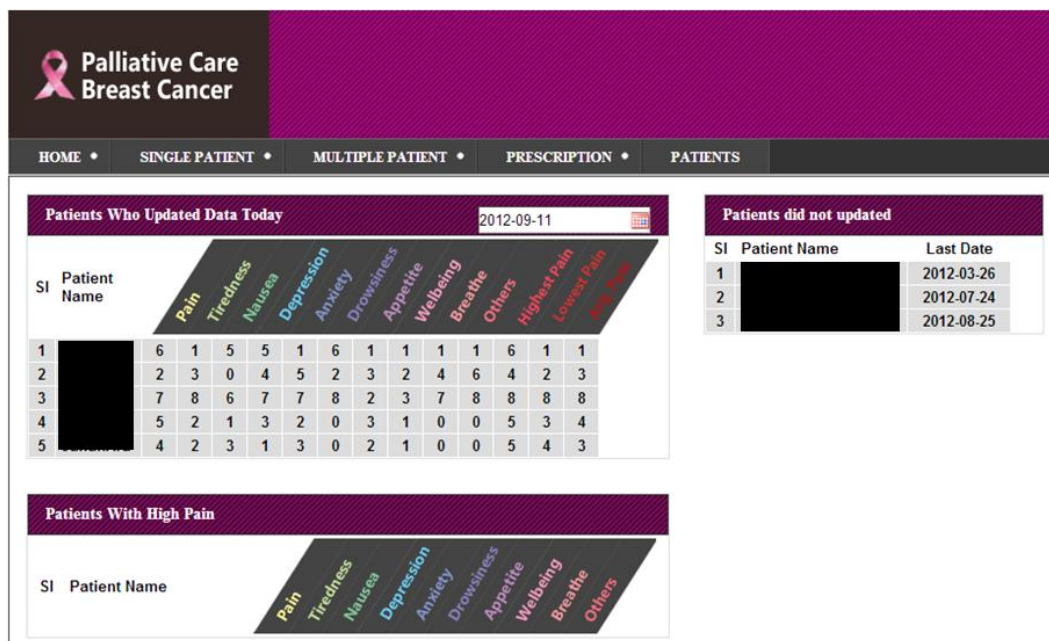
Figure 4.8 Web interface for doctors

4.4. Deployment Methodology

We conducted our 3rd field trip in June '11 for deploying the final version of e-ESAS and collecting data. But due to delayed BMRC (Bangladesh Medical Research Council) approval we have been prohibited to use the data collected in the 3rd field trip. So we have analysed the data collected in 4th and 5th field trip after receiving the approval. The following figure 4.9 shows patients using e-ESAS in different environments.

Figure 4.9 a) A patient is using e-ESAS from home b) Patient using e-ESAS from hospital

The following figure 4.10 shows the timeline of deployment.
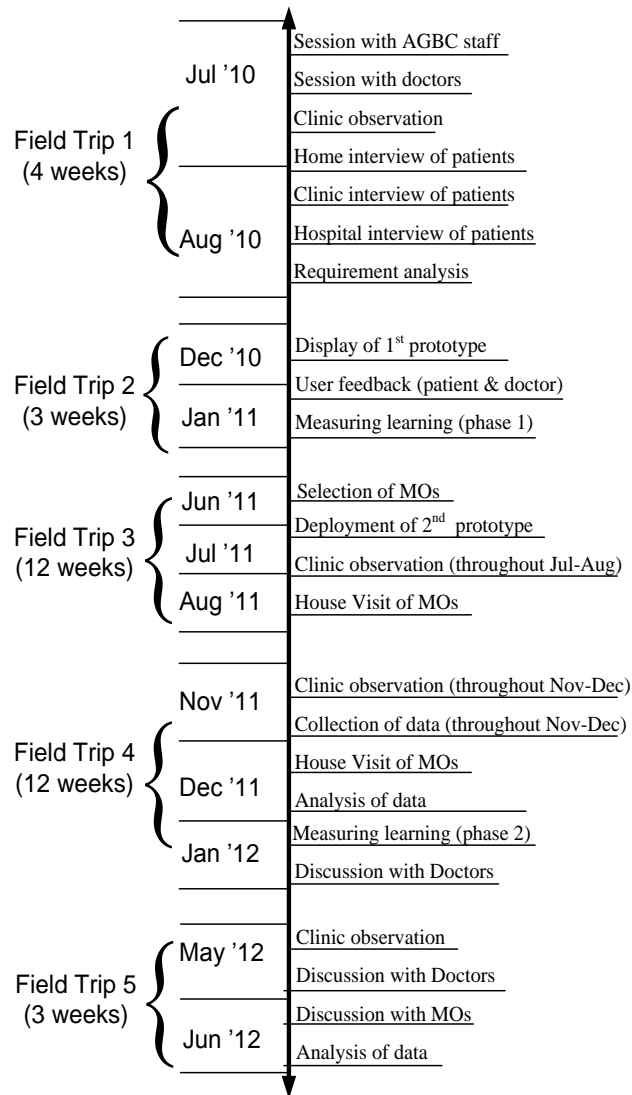
Figure 4.10 Timeline of design and deployment of e-ESAS

We have deployed e-ESAS in 12 Nokia X6 phones. Two of them will be used by doctors in different AGBCCs. The rest will be used by 10 BC patients for six months.

4.4.1. Selection of e-ESAS User

Patients were selected based on the following criteria.

(1) Chronic pain score, usual level, on ESAS 0-10 scale reported to be less than or equal to 5.

(2) Life expectancy, greater than 6 months.

(3) Normal mental status.

(4) Performance status 0, 1, or 2 based on ECOG scale [ECOG].

(5) Able to understand and cooperate with study protocol.

(6) Patient has two people living with her (attendant).

(7) Patient lives less than one hour commuting distance from either AGBCC or DMCH.

We refer to these 10 patients as Mobile Owners (MOs) in the rest of the paper. MOs have been provided with the cell phone and a prepaid internet card worth BDT 100 ($1.30) to send the e-ESAS data once daily to the server.

4.4.2. Training of MOs

We arranged a small ceremony where all MOs were present with at least one attendant and received the phone. One researcher showed each of the MOs and attendants how to use e-ESAS. Then both MOs and attendants used e-ESAS for 15 minutes under the supervision of the researcher. Later MOs and attendants were handed a piece of paper with 13 random values and asked to set these values sequentially using e-ESAS. We followed this procedure 3 times with each of them.

4.4.3. House Visit

A team of one researcher and one HW visited the houses of the MOs after 1 month of deployment. The purpose was twofold. We first replaced the old MVW with the new one. We then had open discussion with the MOs and attendants regarding their experience with using e-ESAS.

4.4.4. Group Session with Doctors

We arranged a group discussion with all doctors (8) and researchers in AGBCC Khulna in Jan '12. Doctors shared their experience with patient interaction using e-ESAS. We also discussed future plans regarding e-ESAS.

4.4.5. Clinic Observation

In order to assess the quality of the patient visits, we observed 77 patient-doctor interactions during 4th field trip. A research team member acted as passive observer during these interviews.

4.5. Discussion & Design Issues

As our design evolved through the field study and real life patient feedback we learned the following lessons.

4.5.1. Interaction Delay Confusion

Patients expect the data to be submitted immediately as they click the submit button. But due to slow data network it takes time to complete. Meanwhile patients think they have not pressed the button properly and press it repeatedly. We have found patients clicking the submit button from 3 to 5 times at a stretch. 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.

4.5.2. 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.

4.5.3. 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:

• They forgot that they had already submitted data. (Multiple Submissions)

• Sometimes their family members accidentally submitted data. (Multiple Submissions)

• 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.

4.5.4. 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' (figure 4.3(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.

Chapter 5:   Findings from the Deployment of e-ESAS

We have collected a huge amount of data during the long deployment phases from doctors, patients and family members of the patients. Though we first deployed e-ESAS in mid June '11, here we publish result starting from Nov '11 due to delayed BMRC clearance.

5.1. 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.

(1) Firstly, patients are shown how to use the sliding bar.

(2) Patients practice e-ESAS by themselves for 5 minutes.

(3) Each patient is given 10 random numbers from 0 to 10 to set these values using the sliding bars sequentially.

(4) Record the time required by each patient to set the values.

(5) Count the number of errors (difference between the given vs. recorded values are considered errors)

5.1.1. 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 Figure 5.1. This is expected since in most cases attendants were younger than the patients and more familiar with mobiles phones.
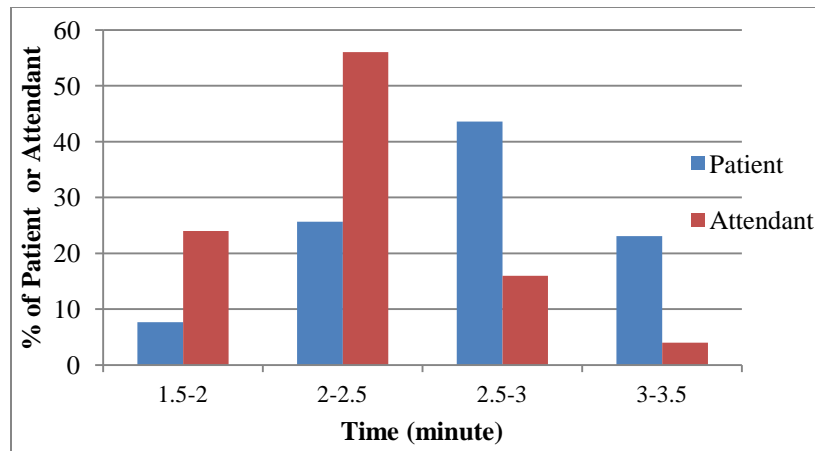
Figure 5.1 Timing requirement histogram

5.1.2 Error Histogram

Figure 5.2 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.
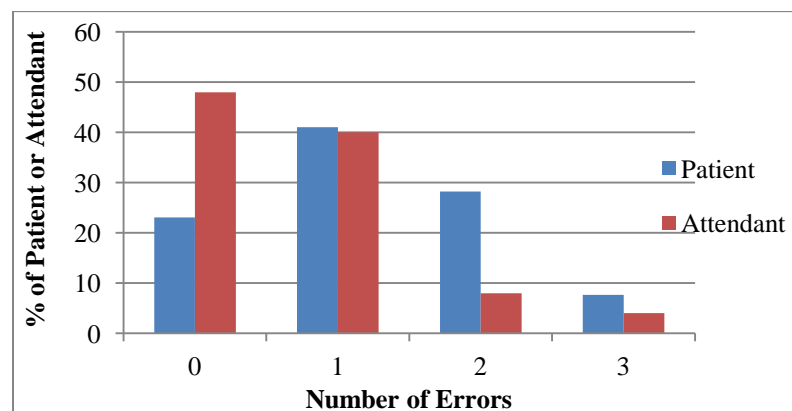
Figure 5.2 Error histogram

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. The following Figure 5.3 shows the timing requirement for MOs and attendants.
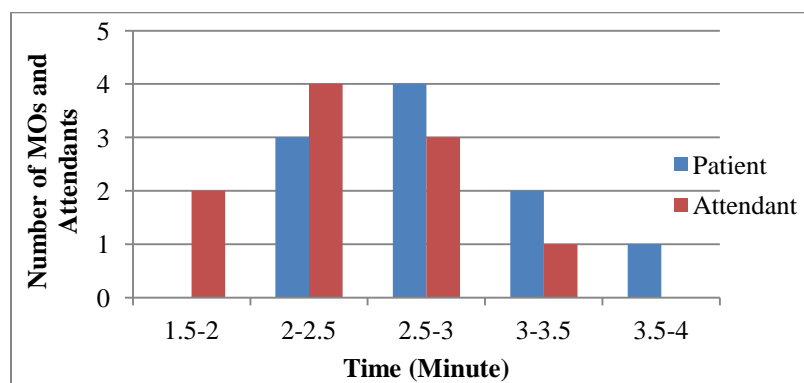
Figure 5.3 Timing requirement histogram

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. 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.

5.2. Increased Familiarity with BC

One of the major goals of e-ESAS was to increase the knowledge and awareness of women regarding BC. During our 2nd visit (Dec '10) in Bangladesh we asked 39 BC patients and 15 other patients the following questions separately.

Q1. Have you heard about Breast cancer before?

Q2. What is the most common sign of breast cancer?

Q3. What are the other signs of breast cancer?

Q4. If someone has breast cancer do you believe her daughter will must have breast cancer?

Q5. Do you think it is infectious?

Q6. Have you heard of mammogram or Breast Self-Exam?

All 39 BC patients were registered with AGBCC and the others came to AGBCC with different breast-related problems. The former class of patients will be termed as BC1 and the later as OP1. Three teams (each consisting of one researcher and one HW) were formed to conduct the interviews. On the first day of interviews, we noted a problem. Every time the patients asked to explain the questions, the HWs were eager to give long explanations that contain partial or full answers. We then stopped the procedure and arranged a focus group session with all 3 teams to ensure congruency in explaining each of the questions to patients in a non-leading way. We followed the same procedure in Jan '12 on 45 BC patients (BC2) and 21 other patients (OP2). In both phases the interview ranged over 3 weeks and took place in different AGBCCs. All the interviews were audio recorded and later transcribed in English. The BC patients, being already diagnosed, naturally have better knowledge than the other patients. This was the reason for making two separate groups while analyzing the data. The measurement of learning has been summarized in the following Figure 5.4.
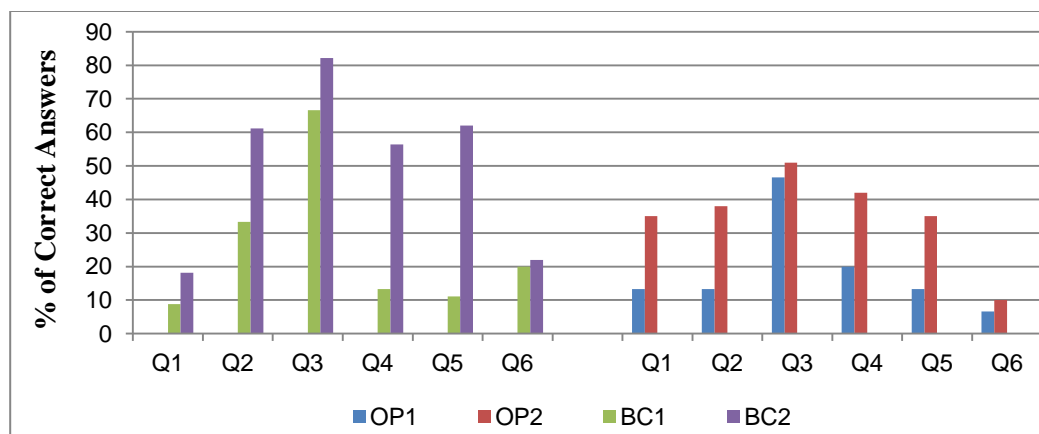
Figure 5.4 Comparison of percentage of correct answers for BC and other patients before and after e-ESAS deployment

In most cases patients provided overlapping answers for questions 2 and 3. The correct answer for question 2 is 'breast lump', while that of question 3 is swelling, pain, discharge from nipple, etc. If a patient mentions a lump and at least one of the other symptoms, we have included their responses as correct answers for questions 2 and 3. The percentage of correct answers for question 3 is significantly higher than that of question 2 since it is easier to mention at least one of the common symptoms.

The graphs show a large increase of correct answers for questions 1, 2, 4 and 5. We have identified 2 sources that contributed to the improvement of learning. First, a big fair was held in Jan '11 where AGBCC had a stall for breast screening and distributed booklets containing important information regarding BC. Second, the motivating videos and e-ESAS created an interest among women. Thirty patients said they have seen the e-ESAS and the motivating videos at least once when they met the MOs in either AGBCC or their houses. We found that when patients wait for their turn to meet the doctors, they flock around the MOs to see the e-ESAS and motivating videos. It should be noted that the MVW contains the answers for questions 2 and 3, where as MVS contains the answers for questions 4 and 5. Question number 6 was covered neither in our pilot study nor in the booklets of AGBCC, and the percentage of correct answers is

pretty much the same in both phases. This also indicates that the motivating videos and booklets are the main contributors in the increased learning for other questions.

5.3. 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. D2 shared one such incident saying:

> *"I know a patient whose lung was affected and this was not detected 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. If e-ESAS was available at that time I would have been able to diagnose this issue in earlier stage and very probably that patient would be able to spend a little more time with her family."*

5.4. Real Time Pain Management

According to doctors, pain management is the single most important feature in treating terminally ill patients. Previously patients used to come in the AGBCC roughly once a month and they would not have any kind of communication with the doctors in between. The common trend is to continue the current medication no matter if it makes their pain management better or worse. On the other hand doctors did not have any way to analyze the effect of the prescribed medication until the patients return for their next visit. But now doctors are receiving 4 pain related symptom

values for each MO every day. They can readily observe the effect of their intervention in a graphical representation. e-ESAS is serving as a real time follow up tool for them. One of the doctors (D1) opened MO8's pain curve as shown in Figure 5.5 and said:

> *"This patient was having high pain for weeks. Then I changed her pain medicine like this...but as you can see it actually did not alleviate her pain. So I discussed the situation with Dr. X (palliative care specialist) and changed her prescription again (9th Feb). Now she is doing better."*
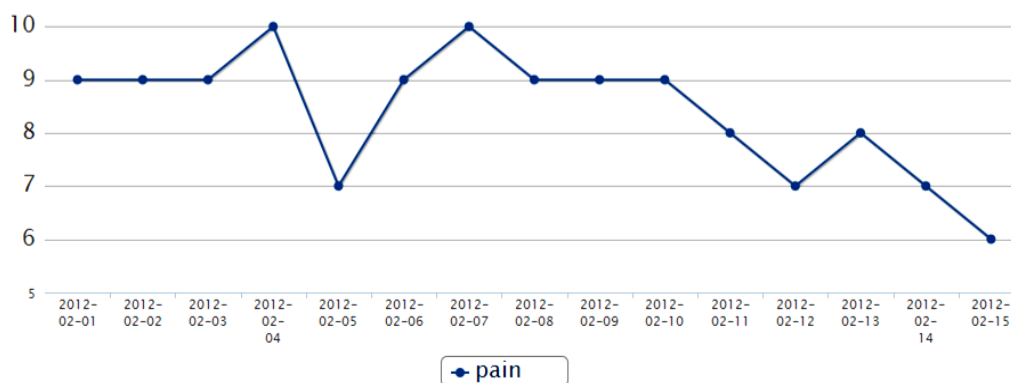
Figure 5.5 Pain graph of MO8

5.5. Improvement on Self-reporting

During our clinic observation in the first field trip, we found that several times doctors get irritated due to the inability of patients in answering their questions. It was very difficult for doctors to get a clear idea about the symptom levels of the patients due to their indefinite and sometimes inappropriate answers. When the doctors ask about the level of nausea during the last week, patients answered the following way:

> *"I think I vomited sometimes but I cannot recall exactly."*

> *"When I was returning to my house from here last month I vomited in the bus."*

> *"I feel like vomiting whenever I go to the restroom."*

The patients also used to fail in remembering and reporting important information about crucial symptoms due to lack of familiarity about the features of BC and long intervals in between visits. Doctors need to derive the actual facts from the commonly exaggerated, vague and sometimes contradictory answers. We provide a sample patient-doctor conversation observed during our 2nd field trip:

Doctor: What is the level of pain?

Patient: *Extreme pain (**common answer by all patients**)*

Doctor: Where do you feel maximum pain?

Patient: *In the whole body..(**lack of clarity**)*

Doctor: When do you feel maximum pain?

Patient: *The whole day…all the time..(**lack of clarity**)*

At this moment doctor pressed her elbow and then abdomen firmly and asked the following:

Doctor: Do you feel pain here?

Patient: *No (**contradictory statement**)*

Doctor: Do you feel vomiting?

Patient: *Yes ..5/6 times everyday…*

Doctor: 5/6 times?

Patient: *May be 2/3 times..(**lack of accuracy**) I can't remember anything now a days…you know what.. (**a long irrelevant story**)*

But during the clinic observation in the 4th visit, we found that the answers of the MOs are overall accurate and concise. Since they were submitting about these symptom levels each day, they became knowledgeable and up to date about their current health conditions. We found

the MOs making additional useful comments when doctors were observing their symptom curves. One of the MOs (MO2) said to the doctor,

"*I vomited 2/3 times for 3 days last week. That is why I have put 10 in the sliding bar of nausea for those 3 days*."

We were interested to measure the effect of the deployment of e-ESAS on the self-reporting ability of the patients. Based on our observation and doctors' suggestions we identified 5 features namely clarity, accuracy, exaggeration, relevancy and contradiction as the basis of evaluation. Later, we asked a group of 4 doctors from KMCH to evaluate the MOs and 10 other BC patients separately against these 5 criteria on a scale of 0 to 10 based on their patient visit experience. To avoid biasness we made sure these doctors are not aware of the identity of the MOs. We explained them the features of evaluation. The evaluation results provided by the doctors are averaged to show in the following Figure 5.6.
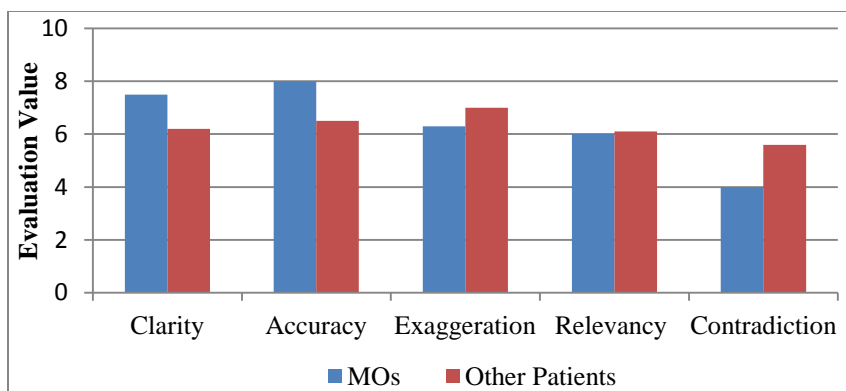
Figure 5.6 Self-reporting evaluation of patients by doctors

We can see that the performance of the MOs is clearly better in terms of clarity, accuracy and contradiction with slight advantage with exaggeration. The evaluated value for relevancy feature is almost same because MOs also like to tell different unrelated stories and incidents. We discussed with the doctors (who actually treat the MOs) about the possible reasons for the improvement.

- MOs feel that they are interacting with the doctors every day unlike other patients who come after long delays and try to gain the attention through exaggerated and sometimes contradictory answers. As explained by D6,

  "*….previously they used to think that I come here after a long time and don't know when I will be back..so doctor will decide my pain medicine based on the single pain value I am going to say. So I must say a high value to get the best medicine….but the MOs don't do that since they are virtually relaying their pain value every day.*"

  When we pointed out that the exaggeration level for the MOs (6.3) is pretty close to that of the other patients (7), D1 said, "*This does not happen with me. I think MOs were trying to gain attention from the new doctors by exaggeration.*" Other doctors supported this statement.

- MOs find that the doctors are changing prescriptions based on the e-ESAS data they are submitting. As a result they feel more responsible and part of the decision making process. This fact inspires them to provide precise, accurate and non contradictory data.

- According to D3,

  "*For MOs I normally ask about some sharp rise or fall in symptom level curve. For example one of the MOs never had any problem with nausea but I found a high value in her submitted data for 2/3 days last week. So I asked her about this issue during her visit. She was ready with the answer. Since she always put 0 for that symptom it was in her memory why she is putting a higher value there. e-ESAS is acting like a triggering event for them to remember things that we need.*"

5.6. Validity of Data

It was hard to determine whether the commonly reported maximum level of pain and other symptoms by 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.

(1) **Case 1**: 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 5.7) 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."*
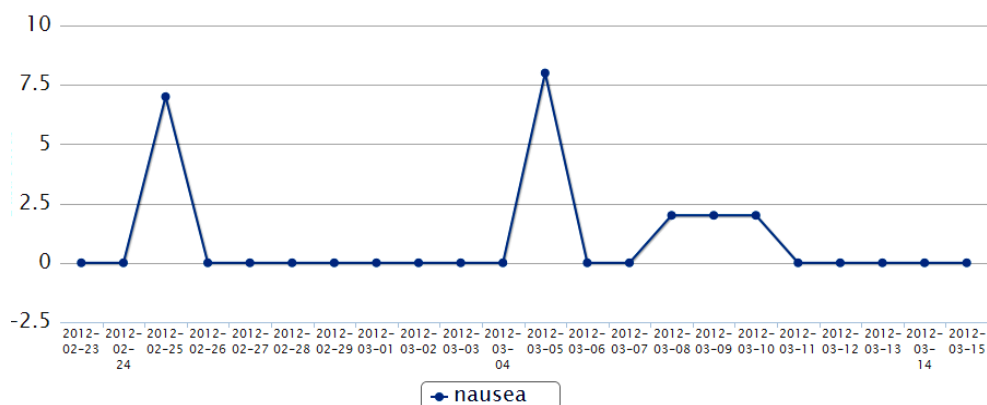
Figure 5.7 Nausea graph of MO2

(2) **Case 2**: Another doctor (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.

5.7. Being Proactive

The deployment of e-ESAS and its advertisement (through MVW, MVS and posters in AGBCC) made a positive impact in encouraging women to come out of the shell and be proactive about their health issues. According to one of the doctors (D2):

> *"In the last 2 weeks I have received 3 patients with minor furuncle in their breasts. It is not usual for patients coming to the center with such minor breast problems. Normally I always see patients coming to the center only when major*

complications occur. Otherwise either they just do nothing or go to local herbalists at best."

Another notable change supports this fact. Doctors reported 6 incidents of non-scheduled visits by current BC patients during the 4th field trip. This is unusual in a setting where AGBCC patients miss roughly half of their scheduled appointments. Moreover, all of these 6 patients had a history of missed appointments, with 3 of them missing appointments at least 3 times. One of these motivated patients explained to the doctor saying:

"I have reported my pain level more than 7 for the last 5 days. So I thought I should come and talk to the doctor."

5.8. Changes in Social Dynamics

BC patients need the support of the family (especially husband) and society. The society needs motivation to change the customs like religious beliefs or gender discrimination. The introduction of e-ESAS by the health advisor (equivalent of a minister) of Bangladesh, new mobile based technology and motivational videos all combined in creating a positive environment for the patients. The research team went to visit the MOs. Other women having higher status also started coming to their houses. All these issues created a symbol of higher status for the patient in that family. The result is similar to that of 'Avaaj Otalo' [Patel10]. MO1 described this change:

"Since the starting of the disease, my mother-in-law was very rude on me. She always used to say to my husband that he should not spend money for my treatment. I have missed several appointments because either she did not permit me or she assigned me some other task. But now when she saw that people are coming to see me and the mobile, she has become pleased with me. Even she said that she wants to go with me to AGBCC next time."

We have found instances where patients' husbands carried mobiles outside to show videos to others. The MVW created a sense of belief and will power in others when they saw one of their neighbors saying how she survived BC by taking appropriate measures. One of the MOs (MO9) shared her experience of social changes 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."

5.9. Reduction in Missed Appointments

The most common complaint we heard from doctors was missed appointment schedules. We were interested to see the effect of the deployment of e-ESAS on this issue. We analyzed the data in two time frames; Dec '10- May '11 (before the deployment of e-ESAS) and Nov '11-Dec '11. We will call these periods time frame 1 (TF1) and time frame 2 (TF2) respectively. We also divided the cancer patients into 2 groups: MOs and the rest. This is because the MOs, having received the mobiles, are naturally expected to be more punctual in their appointments. We show the missing appointments statistics of each of the MOs for TF1 in Figure 5.8. These 10 MOs were scheduled for a total of 107 appointments over the six month period, making an average of 1.78 appointments per patient per month. They missed a total of 40 appointments, thus the average percentage of missed appointments became 37.4. According to the records of AGBCC, only 2 MOs missed one of their appointments each in TF2.
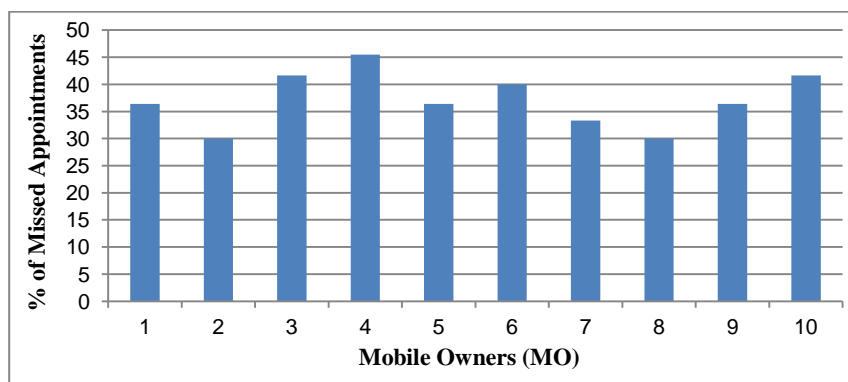
Figure 5.8 Missing appointments data for MOs in TF1

Then, we focused on the appointment history of the other BC patients for TF1 and TF2. The average percentage of missed appointments are 48.8 in TF1 and 39.8 in TF2 as shown by yellow and red solid lines in Figure 5.9.
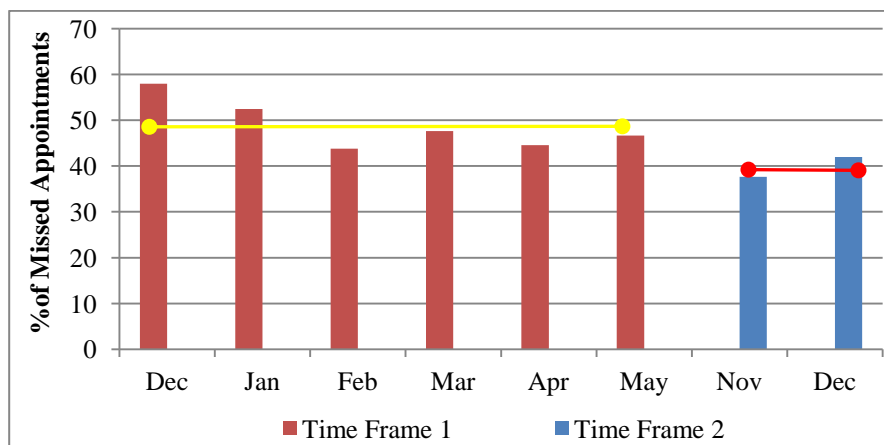
Figure 5.9 Comparison of percentage of missed appointments for BC patients in TF1 and TF2

We can clearly see an average drop of 9%. We identified two possible reasons for this fact.

(1) Deployment of e-ESAS created an environment where women are more encouraged to participate.

(2) Some of the patients said that they think the MOs are selected based on appointment history and are also getting better treatment. They want to reach that level so doctors give more attention to them. However we need more time to make any conclusive remarks on this issue.

It is to be noted that the local doctors have been operating since 2nd week of August when the foreign doctors left. Also November to January is the winter season in Bangladesh and the percentage of missed appointments is much less in Dec '11 (42%) compared to that of Dec '10

(58%). This indicates that the drop in percentage of missed appointments is not just due to external factors like foreign doctors or weather.

5.10. Reduction in Total Number of Appointments

Normally, doctors ask the BC patients to meet weekly or biweekly based on their current health status. But in case of MOs doctors asked them to come monthly. They were also encouraged to come if they feel any problems in between. As a result of this, the number of appointments assigned for MOs has been reduced automatically. According to Figure 5.10, the average number of appointments for each patient per month has been reduced to 1.25 in TF2 compared to that of 1.78 in TF1.
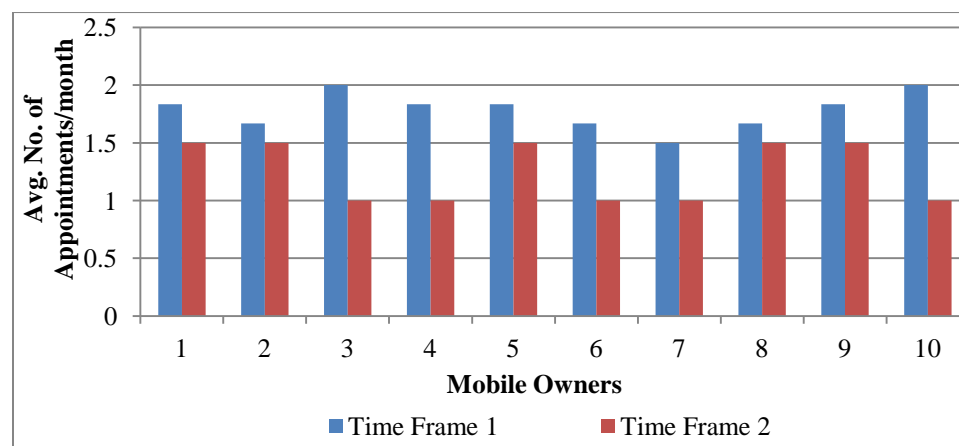
Figure 5.10 Comparison graph of required number of appointments in TF1 and TF2

Along with normal monthly visit, MO1 and MO2 received 1 extra appointment each from doctors due to their unusual pain curves. MO5, MO8 and MO9 made one nonscheduled visit each to discuss their health conditions. Reduction in number of appointments is in turn reducing the cost and transportation hazards of patients.

5.11. Reduction in Visit Time

The effectiveness of doctors can be increased by reducing the visit time required by each patient without compromising the level of care. During TF2 we recorded the duration of clinic visits of MOs and other BC patients through clinic observation. MOs made 12 and 13 appointments in Nov '11 and Dec '11 respectively and that of the other BC patients are 51 and 48. Along with all MO visits we recorded the timing of 23 and 29 visits of other BC patients in Nov '11 and Dec '11 respectively. The average timing requirement of MOs and other BC patients in TF2 is shown in Figure 5.11. The figures are based on averaging the time recorded during those visits. To avoid biasness, doctors were not notified about the timing issue.
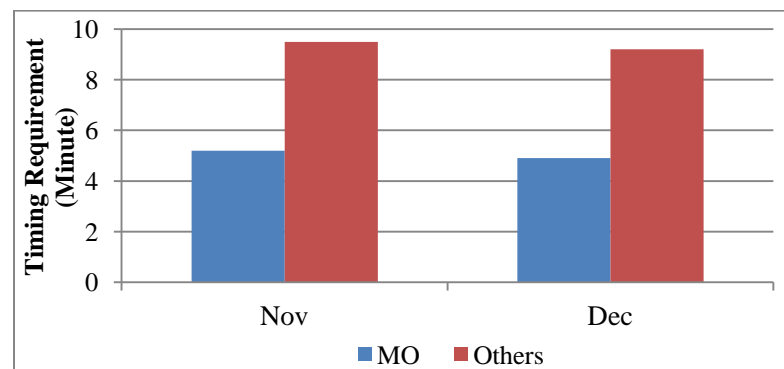
Figure 5.11 Average timing requirements of MOs and others during TF2

The reduced timing requirement by MOs is pretty much anticipated since the doctors do not need to ask them about their symptom values and fill the paper-based ESAS graph.

5.12. Video Download

In order to analyze how many times the motivating videos have been played from each of the specific mobiles we added a log counter in the server. On an average the MVW video has been played for 3 times per day from each mobile where as that of MVS is 2.3. The following Figure 5.12 shows the total number of times (considering all 10 mobiles) the MVW and MVS

videos have been played over TF2. As expected the curve has been gradually decreased with an exception in week 5. At the end of Nov '11 we replaced the old MVW with new one. This is the possible reason for sudden increase in the otherwise declining video played graph shown in Figure 5.12.
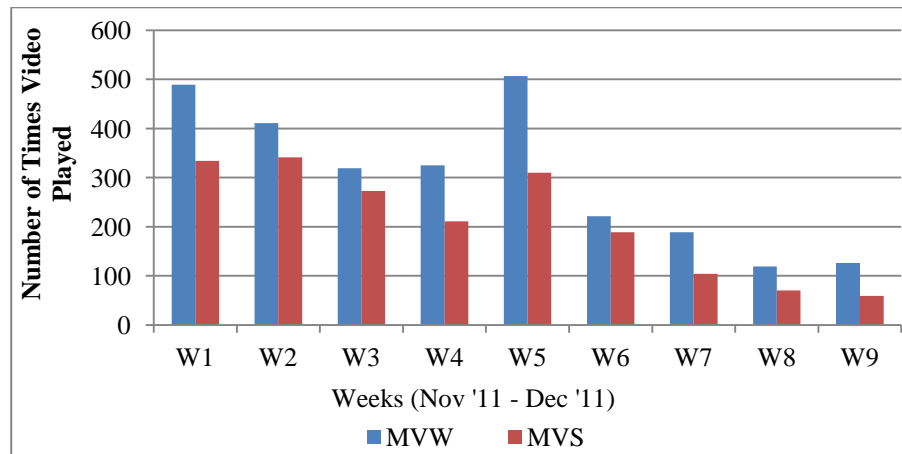
Figure 5.12 Week wise download statistics of MVW and MVS videos (Nov '11-Dec '11)

When analyzed the data patient wise, as shown in Figure 5.13, we found notable discrepancy with 3 MOs.
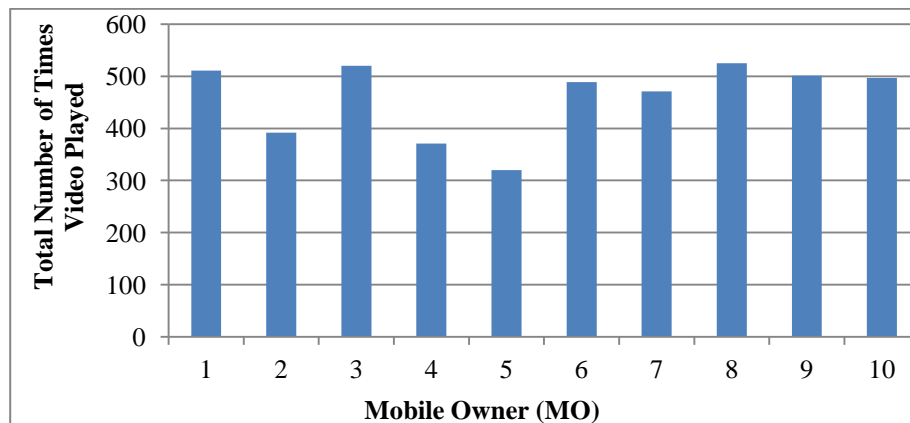
Figure 5.13 Device wise total video played statistics (Nov '11-Dec '11)

While the total number of times videos played of the other MOs ranged from 351 to 391 averaging 372, that of MO2, MO4, and MO5 records 245, 259, and 236 respectively. When we asked the other patients living in the neighborhood of these MOs one patient said:

> *"Husband of MO4 is a powerful person in our village. So she has a very high status and we do not feel that comfortable going to her house and asking her mobile."*

We found that MO2 also has a significant higher status compared to other MOs. But MO5 has a social status just like the rest 7 MOs. Then we discovered that she is the only women in the MO list who has neither husband nor any children. This is the most likely cause for less number of downloads from MO5 since all other MOs said that their children play with the mobile and also watch videos. We also found children taking the mobiles to their friends to show them the videos.

Along with that the log records of MO4 and MO5 indicate that they are the only two who have played MVS more than MVW. When we asked them they said that their husbands have good terms with the local community representatives and several times they take the mobiles to show the MVS video to them.

We also found that women are more interested to watch the MVW video where the participant is a woman where as their counterparts are more interested in the MVS video where the participant is a male. One of the women who was watching the MVW video during our house visit said:

> *"I have watched the MVS video once but I like to see the MVW since I want to hear breast related things from a woman."*

On the other hand the husband of MO2 said:

> *"I took the mobile with me yesterday night when we all had a meeting with the community members. There many people saw the MVS video because they wanted to see what our chairman is saying about this issue."*

5.13. Improvement in Quality of Life

Interaction of the MOs with other patients in the AGBCC and with other women in their village area started to make women more knowledgeable and caring about their health. The motivating videos are also playing their part to change the social customs in patients' favor. Doctors are getting regular data of patients which help them to make better diagnosis. By addressing the following three barriers e-ESAS is encouraging BC patients for a better life.

5.13.1. Enhanced Clinic Visit Experience

e-ESAS helps the doctors to better prepared for the patients in 2 ways. First, they can see the longitudinal symptom curves for a selected period of time which was not possible before. Secondly, since they do not need to fill the ESAS chart anymore during the patient visit, they get more time to listen to the problems and questions of the patients. The following Figure 5.14 shows a doctor using e-ESAS on her way to clinic.
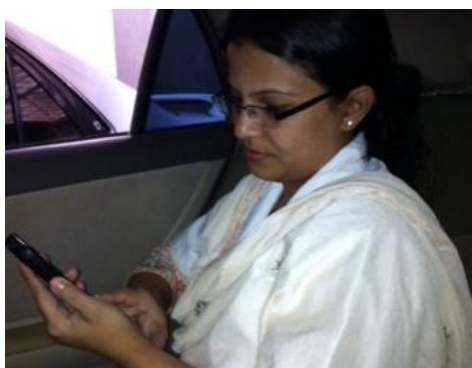
Figure 5.14 A doctor is checking pain graph for a patient

One doctor (D3) shared her experience during open discussion session as:

"I feel much relax now because I have visual representation of the data I need and I feel I have enough time compared to my previous experience."

5.13.2. Facilitating Earlier Intervention

In cancer care early intervention might help to avert a potentially critical situation. From our experience we have seen that patients normally visit the AGBCC once a month. So if there is any change in their pain level or other symptoms meantime, it goes unreported and unattended. Since there is no other way to contact with the doctors other than visiting them personally, in most cases the patients just continue with the same medication given in the previous visit. But now doctors can make timely intervention since e-ESAS automatically generates alert for doctors when any symptom value exceeds its predefined threshold. We have seen 6 cases where the doctors have changed the medication and in 4 cases they asked the MOs to visit them during 4th field trip. When the doctors change the prescription a notification is sent to the mobile of the MO. They can simply take the mobile to the pharmacy and get medicine accordingly.

5.13.3. Enhanced 3 Way Communications

e-ESAS helps to bridge the communication gaps among patients, attendants, and doctors by endowing them to actively participate in the process of cancer care. Previously patients/attendants used to think themselves as passive participants of the medication process but now when they are submitting data each day they feel more responsible and part of the decision making process. This issue helps all to be more co-operative in information sharing thus bridging the communication gap. Similar results are found in [Dubenske08, Bielli04] in urban settings.

5.14. How e-ESAS addresses the challenges

5.14.1. Current System Issues

The patient module is used by patients to submit the symptom values from their home on a daily basis thus developing a sequential symptom database of nonbiased data. Prescriptions will never get lost and patients would not need to worry about storing it and bringing it during visits

with all old prescriptions. These features address the 'lack of information', 'missing information' and 'biased data' problems. Doctors no longer need to fill out the paper based ESAS ensuring they are not restricted by 'limited patient visit time' issue. During our 4th field trip we recorded 25 visits of the MOs and 52 visits of other BC patients through clinic observation. It shows that the required visit time for MOs (5.05 minute) is much less than that of other BC patients (9.35 minute).

5.14.2. Identification and Disclosure Issues

The motivational videos have been introduced to change the traditional beliefs and customs mentioned in 'undermining women problem', 'shyness' and 'fear' sections. The findings section proves the improvement in the 'lack of familiarity' issue.

5.14.3. Treatment Achieving Issues

MOs now only need to go to the AGBCC when doctors ask them to come or they have a problem. The previous requirement of visiting AGBCC in weekly/biweekly fashion on a regular basis is no longer required thus automatically reducing the number of appointments. This in turn reduces the 'communication hazards' and associated cost – the two biggest concerns of patients. The reduced visit time is helping to overcome the 'scarcity of doctors' since now the same number of doctors can serve more patients without compromising the level of care. The motivational videos helped in improving the issues of 'common belief and practices' and 'gender discrimination' sections.

5.14.4. Treatment Monitoring Issues

'Long term monitoring' has become much easier now since patient conditions are being updated each day from the comfort of their home environment. Reduction in number of required appointments automatically reduces the burden of 'managing companion' far too often. This

requirement of lesser number of visits also made patients aware that if they have been called for an appointment it must be something important. This has resulted in solving the 'lack of consistency' problem. As MO7 said:

> *"..that day doctor called me and told me to come to AGBCC. I knew I have put very high pain values for the last couple of days and the appointment must be very important. Also as I don't need to come every week now, I try to be consistent to meet the appointments."*

Uploading e-ESAS data on a daily basis and better interaction with the doctors ensure that patients will consider their health with priority and do not suffer from 'fading out' issue.

5.14.5. Environmental Issues

Though 'load shedding' is a big problem it was never an issue to charge their mobiles. The 'zero privacy' lesson helped us shift to an IMEI based login. We were a bit worried about the 'data network connectivity' issue. During our 4th field trip we asked the patients to send e-ESAS data from their home as a test. For each of the MOs, we measured the amount of data usage available before and after the e-ESAS submission. This gave us the size of the total data being used in sending e-ESAS values. On an average each e-ESAS submission took only 2.3 KB of data. After 5 months in deployment only 6 times MOs said that they received the 'Patient Data Not Successfully Recorded' message which occurred due to connectivity problem.

5.14.6. User Issues

As per our study procedure we selected patients from the poorest and least educated domain of rural Bangladesh. The final timing requirement (2.8 minute for MOs) and error analysis (only 1 error) proves that even a population with limited technical knowledge is ready to accept and operate a mobile based solution. The timing requirement also addresses the 'unavailability' issue since only minutes are required to complete e-ESAS procedure.

5.15. Discussion

Here we discuss the key lessons derived from our study.

5.15.1. Motivation-Persuasion-Motivation Loop

As mentioned in [Ramachandran10], motivation and persuasion go hand by hand for successful ICT projects in developing countries. But they have shown this to be applied on 2 different classes of people- the target audience (persuasion) and those who work for the project termed as change agent (motivation). In our case we have generated an end user scenario where motivation and persuasion have been merged to a single point. The patients get the initial motivation when they see a new approach (automation of ESAS) has been developed for them and feel pride that others are watching their videos. They automatically become very active in persuading others since they are getting respect and a different status in the village. These issues of motivation transform an ordinary village woman from mere patient to change agent. Overall we got better result by creating a cycle where motivated patients are persuading others and the end result of persuasion (praise, higher status, and feeling of being different) giving motivation again to the patients. **Try to create a never ending cycle of motivation and persuasion.**

5.15.2. Continuous Monitoring Loop

One of the biggest problems of rural health care is the missing feedback loop. On one hand doctors do not receive the feedback from the patients on how they are doing with the latest prescription. On the other hand patients simply follow their latest prescription which remains unchanged till the next visit regardless of its effectiveness. So far the only way to complete the feedback loop was to visit in person which is not a feasible solution for financially and physically constrained rural BC patients. e-ESAS provided the complete solution here. Doctors are getting the feedback from the patients regularly and if needed patients are receiving updated prescriptions.

Thus e-ESAS is completing the much needed feedback loop. **Any health care system in rural context needs to make a complete cycle of monitoring based on feedback loop.**

5.15.3. Concept 'Part of the Team'

In current rural settings doctors are single handedly in the position of decision making. As a result patients do not feel themselves as important as it should be. This is a barrier in the effective communication between patients and doctors though several studies have proved the necessity and importance of information sharing [DuBenske10, Celler03]. In our experience as a result of using e-ESAS patients became more active in information sharing. Instead of being passive patients they felt that they are providing the necessary information that doctors are using for medication. This gave the patients and attendants (who are filing e-ESAS on behalf of the patients) a sense of 'part of the team' for decision making. The lesson here is that a successful health care based IT project should **facilitate active participation of individuals' (patients, attendants, and doctors) in care and decision-making**.

5.15.4. Bottom up Approach

Current literature does not show any project where the patients, being the end user, use the system by themselves. We find ICT projects for doctors, nurses or HWs being the user of the desktop or mobile applications. Though the symptom levels stated or inputted by the patients for any disease are considered as 'gold standard', we have not found any health care project for rural village people where the real patients have been given the priority to use the IT application by themselves. At least 2 symptom monitoring systems being studied in USA [Bielli04, DuBenske10] have concluded that active user participation approach resulted in better care. **The patients should be the primary user of any symptom monitoring system and the system should be developed based on analyzing their needs, capabilities, and drawbacks.**

5.15.5. Entertainment and Attention

Any application for patients should have something that serves as their entertainment. By doing a specific task on regular basis patients may feel obligated and loose interest in doing that. At the same time the application might need to have new look and feel which will help to regain the attention of the patients. In our case the videos serve the purpose of entertainment. But as time goes by the number of downloads decreased sharply. Then we changed the subjects of the video with similar type of statement. This increased the number of video downloads again. The lesson is that the **application should be entertaining to patients and changes might be necessary to keep the attention of the target audience**.

5.16. Pitfalls

We are concerned about the following issues.

5.16.1. Misconception in Motivation

Distribution of the mobiles and visiting the MOs houses created some misconceptions in the mind of other BC patients that contributed in their motivation and increased participation. Six patients asked the doctors during their visits in TF2 whether they will get the mobile next time if they maintain their appointment schedules properly. Two of them added that they also thought if they follow the medications properly and come to the center regularly foreign doctors would visit their houses in future and they would receive better treatment.

5.16.2. A Glitch in Data Quality

While analyzing the data pattern of the MOs we have found that the values for 'depression' and 'anxiety' are the same (or 1 unit apart) in many cases for at least 2 MOs. During the 4th field trip all the MOs were asked why they have put some specific value for all 13

symptoms to judge their understanding. It was discovered that 3 MOs failed to clearly distinguish between 'depression' and 'anxiety'. One MO said:

> *"When I think of BC I feel sad and tensed and I put the same values for both the symptoms."*

Though the patients' answer is considered as the 'gold standard' for any symptom there is a little glitch in the data quality for the mentioned symptoms.

5.16.3. Login Trade off

Though all the MOs preferred the IMEI based login, this flexibility comes with the trade off that now any one can enter in the e-ESAS application using the MO's mobile. But our field study found that a mobile is considered a precious object in rural Bangladesh and never left unattended. The mobile is mostly shared by children and husband who actually help the MOs submit data and see her prescriptions anyway. So the trade off was a gain despite the privacy concern since MOs thought a major difficulty has been removed and it motivated them to use the system alone.

Chapter 6:   Towards Formulating a Generic Framework for Measuring QoL

When we tried to analyze the long term data (Nov '11-Sep '12) and measure the system's impact in improving the QoL of the BC patients, we faced a unique challenge. Though the existing QoL surveys cover several aspects (physical, social, emotional, functional and sometimes spiritual) of patients' life, they never account for the quality of the system involved or the quality of the data being submitted by the patients. These missing aspects, which are important in measuring the improvement of QoL from a system's point of view, have been covered in this chapter. Along with the mobile owners (MOs) we have interviewed different number of other BC patients (registered with AGBCC) during different field trips. We term this patient group as OPs (Other Patients) in rest of this chapter.

6.1. Related Work

QoL studies mainly focus in i) measuring QoL with different questionnaires like SF-36 [SF36], FACT-B [Bradly97] and Missoula Vitas Quality of Life Index (MVQOLI) [MVQOLI], ii) finding expectations or needs of palliative care patients [Selman11, Tang04] and iii) comparing among different questionnaires including paper based and electronic QoL data collection systems [Velikova99]. Instead, we focus on evaluating the impact of e-ESAS in the improvement of QoL based on analyzing the results from our field studies.

6.2. Quality of Life

According to WHO, The definition of health-related quality of life (HRQOL) has emerged as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' [WHOQOL]. In order to assess a system's impact on HRQOL we have classified it in 4 domains as shown in Figure 6.1.
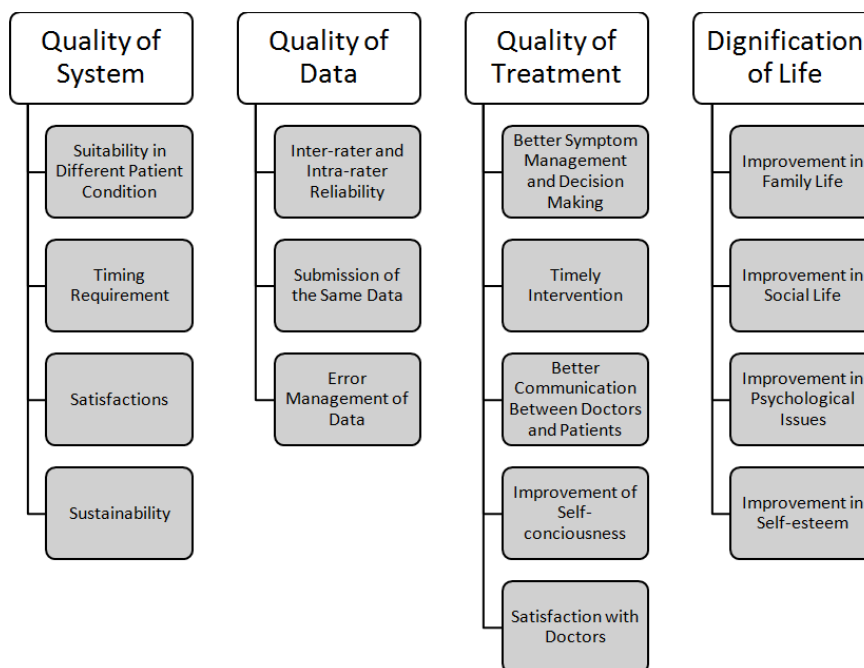
Figure 6.1 Classification of QoL

6.2.1. *Quality of System (QoS)*

Usability tests are needed to verify the ability and satisfaction of the target users in using the system. Many pilot studies fail to continue with same effectiveness due to lack of feasibility and adaptability among the patients when the project ends. That's why the quality of the system needs to be determined from 2 domains: usability (effectiveness, efficiency, satisfaction) and sustainability.

6.2.2. *Quality of Data (QoD)*

In cases where data are being collected from patients and decisions are being made based on these data, qualities of the submitted data need to be verified. This is very important since quality of submitted data is often directly related to the quality of symptom management. We adopted statistical measures like inter-rater reliability and intra-rater reliability to ensure QoD.

6.2.3. Quality of Treatment (QoT)

Any health application system aims to improve the quality of the existing treatment process by some means. Here the researchers need to identify the features related to their system that are helping the stake holders (doctors, patients, health workers and so on) to create a better treatment environment. As a proof that the system really improves the quality of treatment, researchers need to evaluate the satisfaction level of the stake holders before and after the deployment of the system. As an ultimate proof of improved quality of treatment, a long term data analysis should be done to find any change in life expectancy.

6.2.4. Dignification of Life

The term 'dignification' came up during one of our meetings with the health advisor (equivalent to minister) of Bangladesh. According to him,

> *"..these rural patients are dying in the corner of their room without any kind of treatment screaming in pain. That can be the death scenario for an animal and complete disgrace to human lives. Let's try to do something that dignifies their life as human being."*

Here we tried to evaluate the system's impact on the family, society and self-esteem of the patient.

6.3. Findings

We have grouped our findings in the abovementioned domains.

6.3.1. Quality of System (QoS)

6.3.1.1. Satisfaction

In order to find the level of satisfaction of the users about e-ESAS, we asked the MOs and 5 doctors to rate their corresponding e-ESAS module against 5 features (easiness to use, easiness to learn, interactivity, helpfulness and overall satisfaction) in a scale of 0 to 10 during 5th

field trip. Figure 6.2, shows the average results. Both patients and doctors find the system very satisfactory in terms of 'helpfulness'. Being more educated and familiar with mobile phones, doctors found e-ESAS more usable than the MOs in terms of rest of the features.
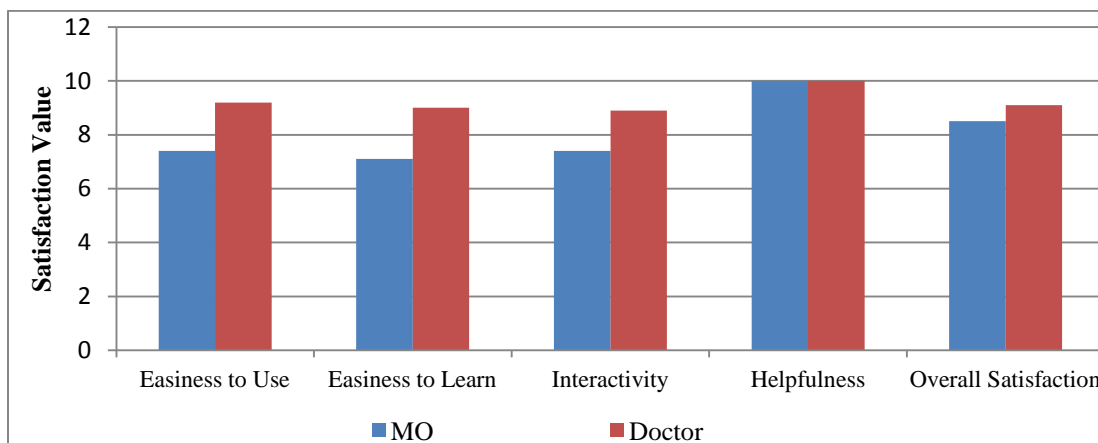
Figure 6.2 Usability results of e-ESAS

6.3.1.2. Suitability in Different Patient Condition (Effectiveness)

A recent study [Das11] showed that cancer patients failed to complete several features of health applications in certain disease state. In order to ensure system's usability we need to verify how the target subjects are performing under most vulnerable conditions. To test this issue we asked the MOs to perform the following tasks in normal time (not due for chemo) and vulnerable time (1 day after chemo).

- T1: 13 random values from 0 to 10 are given to each of the MOs and asked to put these values sequentially to 13 symptom levels and then submit the values. If any of the 13 submitted values is different from the corresponding given value then we consider it as an error.

- T2: MOs are asked to login and see their prescriptions.

- T3: MOs are asked to play the motivational videos.

The following table 6.1 summarizes the results.

Table 6.1 Ability measurement result for MOs

	Normal Time	Vulnerable Time
Avg. time to complete T1	2.8 min	3.4 min
Avg. no. of errors/MO in T1	0	0.7
% of MOs who have successfully completed T1	100	90
% of MOs who have successfully completed T2	100	90
% of MOs who have successfully completed T3	100	100

This result shows that e-ESAS is simple enough to be used by the MOs even when they are in critical disease condition.

6.3.1.3. Timing Requirement (Efficiency)

Any mobile based system should take as less time as possible to make sure patients will be interested to use the system on regular basis without hampering their daily lives. The average time required by the MOs starting from login to finally submitting all the symptom values is only 2.8 minutes. During 10 months of submission period (Nov '11 – Aug '12), MOs missed to submit data 3.5 days/month on an average. Figure 6.3 shows the average number of missing data per month.
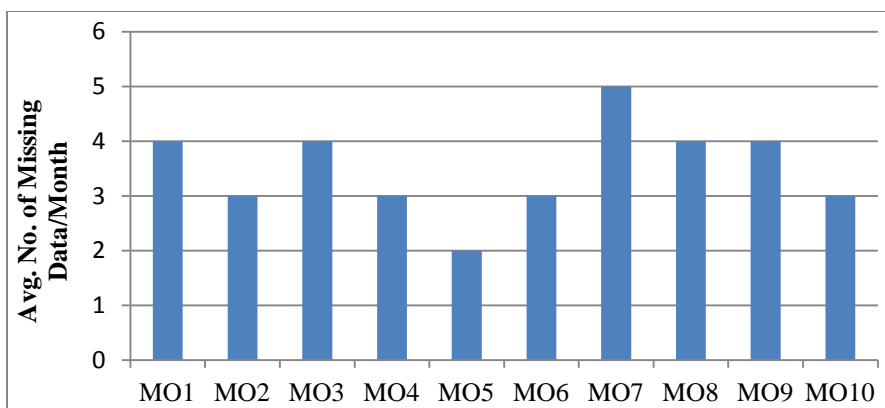
Figure 6.3 Average no. of missing data/month (MO wise)

From doctors' point of view they expect any new system would be more useful in analyzing data and take less time and complexity compared to the existing system. On an average, the paper based ESAS graph that doctors used to fill prior to the deployment of e-ESAS, takes 8 minutes. But now doctors do not need to spend any time on filling it out since the patients are submitting the symptom values from their home every day. During patient visit they simply need to select the patient's name and the time interval for which they would like to see the submitted data and e-ESAS would represent the data in graphs.

6.3.1.4. Sustainability

We wanted to study the sustainability of our study when the project ends. We prepared the following Table 6.2 to show the cost analysis of e-ESAS.

Table 6.2 Cost Analysis (with and without e-ESAS)

	Avg. no. of appointments	Avg. transportation cost/appointment	Avg. time in transportation	Total cost/month	Total time/month in transportation
Without e-ESAS	1.84	380.45	5.19	700.03	9.55
With e-ESAS	1.25	380.45	5.19	475.5	6.5

Then we classified the patients in 3 groups: a) patients with high end mobile phones where e-ESAS application can be deployed, b) patients with Java enabled mobile phones, and c) patients with non Java enabled mobile phones. On an average BDT 1.02 is needed to submit e-ESAS information each time. So each patient of the 1st group needs only BDT 31 ($0.41) each month to submit e-ESAS once a day. The patients of 2nd and 3rd group can use our proposed SMS based system. For 30 SMSs patients need around BDT 5 ($0.07). Those who do not have Java enabled mobile needs a onetime purchase cost of around BDT 3500 ($48). We detailed this information to the patients and ask them whether they will be willing to bear this cost by themselves at the end of the study. The answers have been summarized in Table 6.3.

Table 6.3 Summary of Patient Response

Patient Groups	Yes	No	Not Sure
1st group (2)	100%	0%	0%
2nd group (14)	100%	0%	0%
3rd group (16)	43%	24%	33%

Though the statistics seem promising we have to wait to see the actual results.

6.3.2. *Quality of Data (QoD)*

'External factors' like long journey to the health center (on an average 5.19 hours round trip), hot weather and long waiting time (on an average 1.79 hours) work in deteriorating the condition of the patients before they finally meet the doctor. As a result, visiting patients commonly report to have highest level of pain and other symptoms ('current feeling biasness') which sometimes do not reflect their actual regular pain level. During our 1st field trip, we observed 22 patient visits and all the patients reported to have pain level 10. But when MOs are submitting their symptom values each day from the comfort zone of their home, the data is

becoming free from these 'external factors'. The long term availability of data is helping the doctors to easily find out the 'outliers in data' (odd spike in regular data pattern) by looking at the symptom graph. But the next question is how you determine the quality of the submitted data. To ensure this issue we have checked the following criteria.

6.3.2.1. Inter-rater and Intra-rater Reliability

During our 4th field trip we asked all the MOs to come with their attendants (who normally stays with the MOs and sometimes submit data on behalf of the MOs after consulting with her) during their scheduled visit. First we asked the MOs to submit e-ESAS values (1st set) in the absence of the attendant. After 15 minutes we asked the attendant to submit e-ESAS values (2nd set). Then we followed the same procedure after 1 hour to get another set of data from the MO (3rd set) and the attendant (4th set). So we get 1 intra-rater reliability test result using the 1st and 3rd data set and 2 inter-rater reliability test result using the 1st and 2nd data set and 3rd and 4th data set for each of the 10 MOs. Over the 3 months period (Nov '11-Jan '12) we followed this procedure 3 times. The following Figure 6.4 shows the average correlation coefficient of inter-rater and intra-rater reliability for each of the MOs.
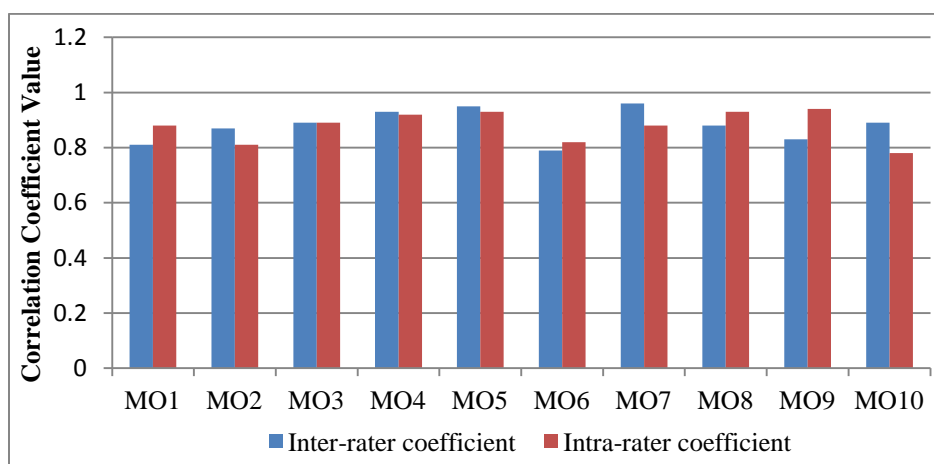

Figure 6.4 Average correlation coefficient value for inter-rater and intra-rater reliability

On an average the correlation coefficient and Fleiss Kappa coefficient of agreement of inter-rater reliability varies from 0.79 to 0.96 and from 0.71 to 0.91. Corresponding values for intra-rater reliability varies from 0.78 to 0.94 and from 0.73 to 0.89. It should be noted that we have found 100% agreement in both cases for current level of pain in all instances.

6.3.2.2. Submission of Same Data

In some scenarios submission of the same data set again and again indicates that patients are not motivated enough to submit actual data regularly. To handle this issue we implemented 2 features in e-ESAS.

- MOs need to touch at least one sliding bar to activate the submission button.
- All the sliding bar values will be reset to 0 at the end of submission.

In the very first month (Nov '11) we found a MO who submitted a specific symptom value pattern (6,0,0,0,0,0,0,0,0,0,0,0,0) for 5 consecutive days. Then we called her and motivated her and the attendant to submit all the values. A thorough analysis on the submitted data of each of the MOs on Aug '12 revealed that there is not a single instance where any of the MOs have submitted exactly the same value of all 13 symptoms in any 2 consecutive days.

6.3.2.3. Error Management of Data

We need to make sure that the patients understand the exact meaning of each symptom otherwise their submitted value will not appropriately reflect their disease condition. Sometimes this can be found by examining the submitted data closely. For example, MOs need to submit the maximum, minimum, and average pain in the last 24 hours. In the very 1st week of deployment (Nov '11), we noted 3 discrepancies regarding these values.

- The maximum pain value is lower than the minimum pain value (e.g. max-7, min-9, avg-8)

- The average pain value is lower than the minimum pain value (e.g. max-8, min-5, avg-4)

- The average pain value is greater the maximum pain value (e.g. max-8, min-7, avg-9)

Then we called the MOs detailing the difference of these 3 symptoms. This solved the 2nd and 3rd discrepancies but we continued facing the 1st issue once in a while (a total of 11 such errors in Nov'11 after the phone conversation). Then we changed our data processing mechanism in the server to automatically consider the higher value as the maximum pain value.

6.3.3. Quality of Treatment (QoT)

6.3.3.1. Better Symptom Management & Decision Making

Since the patients are submitting 13 symptom values using e-ESAS each day, it is creating a long term symptom history for each patient. This data collection and graphical representation of the collected data enable the doctors with a useful tool for better analysis and diagnosis of patient condition. We will show 2 cases here where e-ESAS features helped the doctors for better assessment.

Case 1: D4 stated her experience as,

> *"..it is very common for palliative care patients to suffer from depression and anxiety. This patient (MO5) always put 0/1 for her depression level. But couple of weeks ago she put 5/6 for depression for 4 consecutive days. Then I prescribed medicine for depression along with her regular medicine. Just after that she started putting 0/1 for depression level. Then recently I found that she has started putting similar values (5/6) as before (shown in Figure 6.5). Then I analyzed her depression and anxiety symptom values over long period of time and ultimately found that she puts higher values only days before she is due for chemotherapy. Then I adjusted her prescription. It is impossible to do such analysis without the availability of such visual data."*
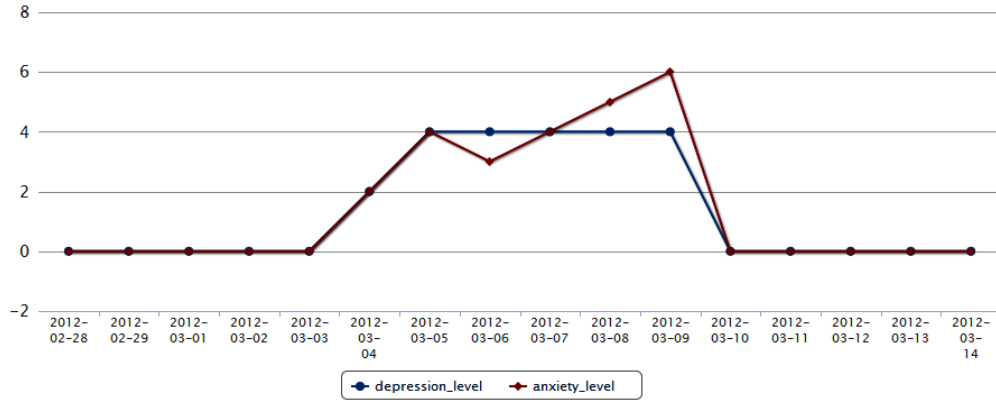
Figure 6.5 Anxiety and depression graph of MO5

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 Figure 6.6). 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."
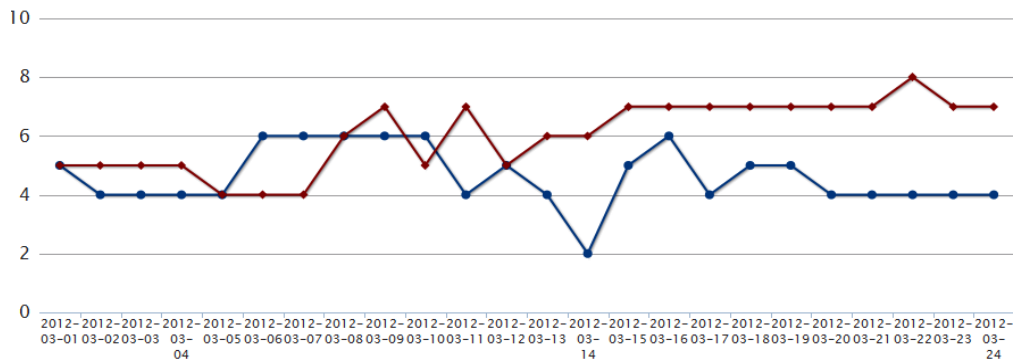

Figure 6.6 Comparison of pain graph for MO1 and MO8

6.3.3.2. Timely Intervention

Patients with advance stage of cancer are very vulnerable and needs timely intervention to avoid turning a minor problem to a catastrophic one. Before the deployment of e-ESAS patients would visit the health center and go home with no further contact with the doctors. Doctors could change the medication only when they visit the health center next time. But now based on the alert message feature doctors can intervene almost real time. D3 stated her experience as,

> *"Last week I received an alert message of MO4 with highest pain (10). I knew she had chemo (chemotherapy) that week. Then I checked her symptom graph (shown in Figure 6.7) and found high level of nausea too. I changed her prescription immediately to make sure things are ok."*
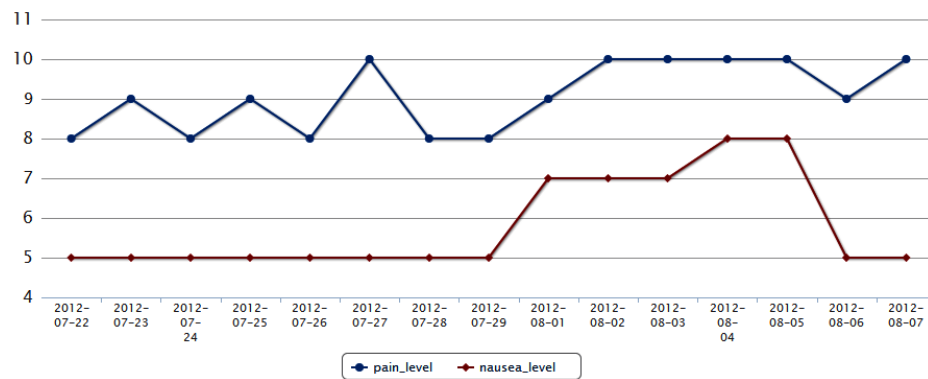
Figure 6.7 Symptom graph of MO4

6.3.3.3. Better Communication between Doctors and Patients

Better communication between patients and doctors ensures better understanding of the disease condition for the doctors which ultimately results in better diagnosis and treatment. During the 1st field trip we found that the only way of communication between patient and doctor is through visiting the health center. Patients never call the doctors and vice versa. Even none of the patients had the mobile phone number of the doctors. But during our 5th field trip the doctors

reported that all the MOs are making calls to them. We asked the patients about this radical change and MO3 said,

> "*I thought of asking her (phone number) before but I was a bit shy and also afraid. And not only me, no one calls the doctor. But the month I started using mobile (e-ESAS), I received 2 calls from her (a doctor) because I put very high pain levels for couple of days. From then I call her if I feel any problem.*"

According to the focus group session held with doctors in Jul '12, they receive at least 1 call per week with various issues from the MOs. When we asked the doctors about the other patients, they said they do not have any contact with them other than the patient visits. Only one doctor (D2) said, "*I once received a call from one of them but I can't recall when.*" When we asked them why they call the MOs but not the other patients D1 said,

> "*Look, we only call the MOs when we get some kind unusual symptom level in the data they have submitted or sometimes when we get alert messages. When a graph of a patient in front of my eyes show something wrong, I feel moral obligation for calling the patient and listen to why it is happening. I don't have any information or such message for the other patients. So I don't have that motivation (to call).*"

6.3.3.4. Improvement in Self-consciousness

During our 5th field trip we asked the MOs and 17 other BC patients (these patients are not using e-ESAS and came to AGBCC for their regular visits) whether they call the doctors to update them with latest information. For all the 17 patients the general answer was negative. Their common reasons were 'we do not have the number' or 'it wouldn't be right to call her (doctor)' or 'she knows everything, what more to tell'. But for MOs we have found that they are not only calling the doctors they are trying to provide whatever information they have and ultimately taking part in the decision making process of their own medication. This is a huge positive change in the thought process of the MOs considering rural contexts. MO3 said in this regard,

"..once I put high pain values for 2/3 days due to pain in my leg. Then I thought she (doctor) might think that it is because of my disease condition. So I called her to explain."

e-ESAS has motivated the MOs to become proactive and more cautious about their health. Even one of the authors received a call in USA from Bangladesh where MO7 said,

"I am trying to get a schedule for chemotherapy but couldn't get one. My pain levels are becoming higher. Can you please look in to this?"

6.3.3.5. Satisfaction with Doctors

We have performed t test on 10 MOs and 15 OPs during our 4th field trip to measure the satisfaction level with doctors and the treatment process. The MO group (n=10) reported slightly greater satisfaction with both doctors (t test = 2.19; P = .05) and treatment process (t test = 2.34; P = .04) than the OPs. We found that both the MOs and their family members are very satisfied and serious about using e-ESAS. One of the authors received a call during our 5th field trip from MO1 saying,

"My phone is out of order and I have submitted the phone to the office 7 days ago. I haven't got it back yet. I know I will not live long. I don't want to miss submitting data now."

She believed that since she is not being able to submit data for those days, her treatment especially pain management is being compromised. This patient later died and her husband sent an emotional letter to AGBCC saying,

"..my wife got a better life for you in her very tough time specially in her last days..I pray to the Almighty for those who worked behind this..."

6.3.4. Dignification of Life

6.3.4.1. Improvement in Family Life

Receiving the mobiles, visiting of foreign doctors in their houses branded the MOs as an important member of the family. Motivational videos helped the 2 most powerful members of any rural home in Bangladesh, the husband and mother-in law, to understand more about BC and to

change their attitude towards the BC patient. MO7 described her experience with the mother-in-law saying,

> *"..she was rude on me and did not want to come close to me (thinking BC is infectious). But after seeing the videos her attitude has changed. Even she expressed to me that she has a lump in her left breast. I accompanied her to the health center though it was good lump (benign). Now I have very good terms with her."*

During our visits to the houses of MOs we have found 2 husbands who went out with the mobile to show the videos to others. According to the husband of MO4 who has a little store in the market,

> "*I sometimes take the mobile with me when I go to the store. There many people come and I show them the videos. They kind of honor me for this.*"

6.3.4.2. Improvement in Social Life

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 the neighbors. When we asked why, 31 of them said that their neighbors believe they would also be infected by the disease if they keep contact with them. We have found 2 instances where possible bridegrooms have denied having matrimonial relationship with their daughters assuming they might also have been or will be infected by BC. All the MOs said that they are having family difficulties due to the disease and 8 of them hardly have any relation with neighbors. It was noted that the 2 of the MOs still having some kind of social relationships with neighbors belong to a relatively higher social class compared to rest of the MOs which is one of the possible reasons for this exception. During our house visits in 4th and 5th field trip we observed a much better social life for the MOs. In 4 occasions we found MOs with neighbors. Motivational videos played a big part here. MO10 described her experience about the change in social life saying,

> "*..once detected by this disease (BC) my neighbors, even some of my family members, started avoiding me. One day my husband showed the videos to her (neighbor) husband. After that she wanted to see the videos and came to me. Now someone comes almost every day. True to say I eagerly wait for the moment*

when someone comes to see the videos and I feel very happy talking with them and showing the videos."

The following Figure 6.9 shows the average number of videos played per month by the MOs considering first 4 months of deployment (Nov '11-Feb '12).
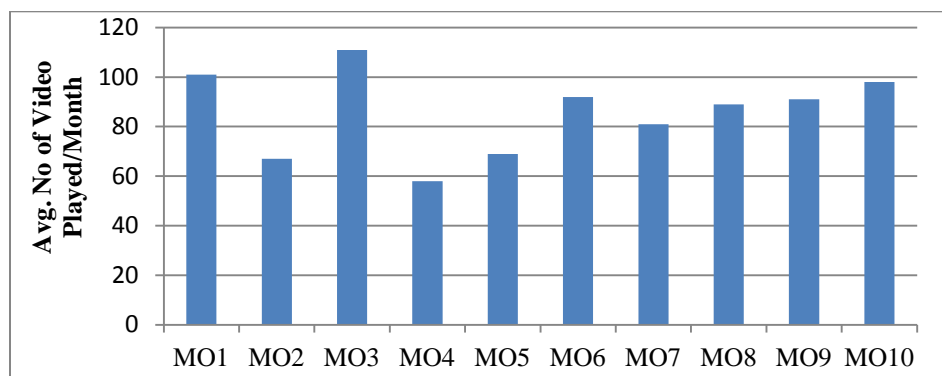

Figure 6.8 Average number of video played/month

6.3.4.3. Improvement in Psychological Issues

Discussion and counseling about psychological issues with doctors is very important for terminally ill patients [Dubenske08]. From our clinic observation during the 1st field trip we found that this topic is completely absent among patients and doctors. When asked, doctors mentioned different reasons including 'do not have enough time', 'not intimate enough to discuss about death' and 'patients are not ready'. But the deployment of e-ESAS is helping both the doctors and MOs to change this scenario. As D2 said about MO2,

"*Since I do not need to spend time on filling out the ESAS chart, I started talking about other issues during patient visit. In the beginning we talked about the social and family issues. After a month or so we became intimate enough to talk about the preparation of death. Actually since I am monitoring her day to day progress through submitted values, calling her when necessary, I felt it like my personal fight against BC and I became emotionally attached to her. I talked with her last time in the week of her death when she told me that she has asked her husband to forgive her (a cultural norm in Bangladesh is to ask forgiveness from spouse before death)."*

One of the MOs (MO3) added that,

"Previously I used to answer only the questions she asks me during my visit. After talking with her couple of times over phone I became very free with her. Now I share my stories with her. I also told her my plan for my children."

6.3.4.4. Improvement in Self-esteem

Many of the rural women have lump in their breast but did not have the courage to tell anyone or come to the health center. Once they found that one of their neighbors (MOs) is taking treatment in a 'novel way' and has better knowledge about BC, they preferred to come to this MO first. Being diagnosed with BC, the MOs have the knowledge about the primary and secondary symptoms. 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. This role gave them a higher status in rural villages satisfying 2 important features of dying patients 'feelings of being important' and 'doing something meaningful'. 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). Figure 6.10 shows the number of patients referred by the MOs.
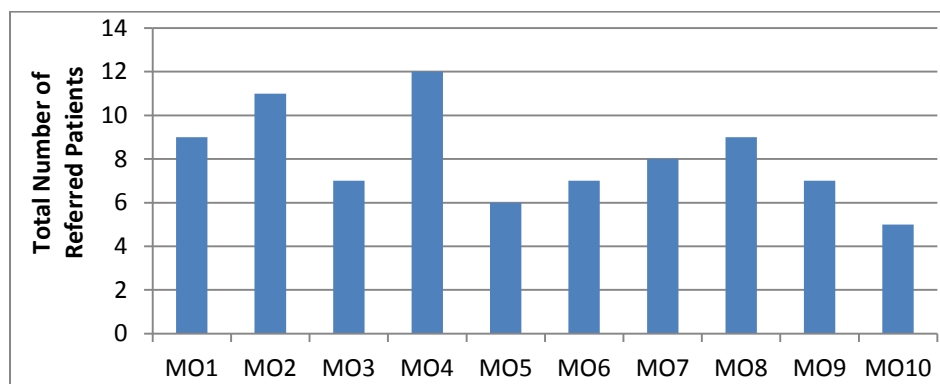

Figure 6.9 Total number of patients referred by MOs

Belonging to a higher status compared to other MOs might have an impact on higher number of referrals on the part of MO2 and MO4.

6.4. Discussion

As our design evolved through the field study and real life patient feedback we learned the following lessons.

6.4.1. Surprised with Satisfaction Result?

We were very surprised to find that the MOs and OPs have almost identical satisfaction levels with doctors and the treatment process. We expected the MOs to have a higher satisfaction level since they are receiving better pain management, timely intervention, communication and psychological treatment. Then we asked the OPs why they are satisfied with doctors and the treatment process. We found that the expectation of these poor rural patients is really low and they are satisfied with simply visiting a doctor. OP2 states this as,

> "*I have visited only to local doctors (local herbalists who are not actually doctors) before and here I am being treated with actual doctor (who has a professional degree). Big (specialist) doctors are talking with you and treating you. What else you want?*"

Since the MOs received similar treatment like these OPs before joining our pilot study, we asked them to rate the satisfaction with doctors and the treatment process before and after using e-ESAS. This time we found that MOs have significantly greater satisfaction level with both doctors (t test = 6.3; P < .005) and treatment process (t test = 5.9; P < .005) after using e-ESAS. Though we normally use t test on the control group (here the OPs) and the treatment group (here the MOs) after the study ends, in such cases where the control group does not have exact idea of what they are suppose to receive, the t test should also be performed on the treatment group before and after the study.

6.4.2. 4 Way QoL Feedback

In any QoL survey questionnaire the feedbacks are given by the patients only. But based on our 4 domain classification of QoL, it is no longer a patient centric scenario. We have identified the following 4 types of feedbacks.

Case 1: Features whose answers are solely given by the patients (e.g. improvement in family and social life, satisfaction with doctors and treatment process).

Case 2: Features where only doctors are giving feedback (e.g. better assessment, overall quality of data).

Case 3: Features that require feedback from both doctors and patients (e.g. better communication, timely intervention, satisfaction with the system).

Case 4: Features that do not require anyone's answer but proven by facts (e.g. improvement in longevity, inter rater reliability of data).

We believe such 4 way feedbacks will help us to define a new type of scale that captures the contribution of the system towards improving QoL.

6.4.3. 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) [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 results in section 'Quality of System' 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 triggered the MOs to continuously submit data.

6.4.4. Missing Part of Good Death

According to [Byock95] a good death consists of 3 issues:

- o Effective management of pain and other symptoms

- o Preparation for death and aftermath

- o Achievement of significant goals in life

The main goal of e-ESAS was to ensure the 1st issue. Since a bonding was created between the MOs and doctors through better communication, doctors started addressing the 2nd issue. During the final discussion during our 5th field trip, doctors revealed an interesting finding. None of the doctors finds it difficult to talk with the MOs about death as they had predicted before. And they all agreed on the fact that this is because all these rural women are very pious and reliant on the Almighty. When we asked the MOs about their reaction of being terminally ill the most common answers were 'Life and death are in the hand of the Almighty' and 'The Almighty has given this to me. I have to accept it.' This issue shows that the predefined thought of the doctors that 'these patients (rural and uneducated) are not ready' is not exactly correct. So along with considering the 1st issue, it is the time for CHI community to explore the other 2 issues of good death which are commonly missed by mobile health projects.

Chapter 7:   Design of Pain Tool

There is no objective tool to measure pain which is a subjective experience. Pain is clinically defined as "Pain is whatever the experiencing person says it is, existing whenever he/she says it does". The existence and intensity of pain is determined by the self-reported measure of the patient himself. Different types of scales (verbal descriptor scale, numerical rating scale etc.) are used to manually measure the intensity of pain which requires understanding and training of both nurses and patients, significant amount of time, and manual interaction of patients. These scales also need to be reshaped based on culture, tradition, language differences and so on. The most challenging barrier is posed by the patients who cannot provide self-reported pain verbally, in writing, or by other means (pointing finger or blinking eyes as yes/no answer). Two broad category of population of such cases are elderly people with dementia and infants. The inability to express pain of these patients due to cognitive, developmental, or physiologic factors is the single biggest factor in achieving appropriate pain management. Developing a mobile based pain assessment tool from facial images may greatly increase the quality of life of these patients who fail to adequately communicate their pain levels. But first we plan to develop a mobile based pain intensity detection tool and verify its accuracy against our cancer patients of who are submitting pain data everyday through e-ESAS.

7.1. Our Overall Approach

A mobile based pain intensity recognition system can be very useful for verbally impaired patients and an also work as a secondary tool for verbally capable patients. Our proposed system has to work from the scratch since there is no pain intensity database available. We will first build a pain intensity database where each subject will have six pain images corresponding to pain level 0, 2, 4, 6, 8, and 10. Since the expression of pain varies among people of different race, ethnicity, sex, pain type, disease status and so on, we need to include as much variety as possible while creating the database. Each of the images needs to be preprocessed to

ensure all the images have similar brightness, contrast etc. to avoid counting these unwanted features as part of the differential characteristics. The proposed algorithm needs to extract the face portion of the subject from the overall image and features from the cropped image needs to be analyzed for detecting the crucial pain characteristics. Based on the output of the mathematical model a classification system will be built which is capable of identifying the pain intensity level.

7.2. Intellectual Merits

The proposed research involves the decades old problem of pain assessment especially for verbally impaired patients from a completely new look. All current pain assessment scales require significant amount of manual interaction with the patients where many of them are not in a stage to participate in such assessment activities on a regular basis. Our system will replace the clumsy and lengthy nature of current pain assessment procedure with an easy to use, simple mobile based system which will benefit both patients and nurses. Identifying the intensity of pain automatically through mobile phone is first of its kind. Though different types of pain scales are currently being used to determine the pain level for patients, most of these are infeasible for cognitively impaired patients. The total system encompasses the following novel characteristics: *1) First system aims to measure the intensity of pain automatically through mobile phone by simply analyzing the facial features, 2) A mathematical model based on Eigenface method for pain intensity classification from facial features, 3) A generalized model to work with all types of pain (chronic or instantaneous) of all sorts of subjects (irrespective of age, sex, race, and medical condition).* Along with that a comparative study can be formed to evaluate the performance of our automatic tool with current paper based tool that need manual operation.

7.3. Related Work

The first descriptive approach for assessing pain was introduced by Charles Darwin [Darwin55] who depicted pain expression as:

> *"...[in pain] the mouth may be closely compressed, or more commonly, the lips are retracted, with the teeth clenched or ground together...the eyes stare wildly as if in horrified astonishment."*

Pain is a subjective issue and currently verbal or behavioral report of pain is the only means used by professionals to identify when pain is present in subjects. Often a Visual Analog Scale (VAS) is used with rankings. The lowest ranking '0' denotes no pain and the highest one denotes 'most acute pain possible'. On occasion these scales also have pictures starting with smiling face (indicating no pain) to a face distorted with a strong grimace (indicating worst pain possible). Examples include Numeric Rating Scale (NRS) [Jacox94], Verbal Descriptor Scale [Flaherty08, Hicks01], and Faces Pain Scale-Revised (FPS-R) [Flaherty08, Hicks01]. This approach to pain assessment is popular because of its convenience and simplicity. But these paper based scales suffer from a) significant manual interaction by patients and nurses, b) time requirement, c) training of nurses, d) scales need to be changed (question style, language) based on the target population, and e) infeasible for cognitively impaired patient groups.

Thus the importance of automatic pain evaluation is drawing the interest of researchers and other communities working with computer vision, pattern recognition, and artificial intelligence. Many research studies have been done describing facial expression of pain at different age levels (neonatal, adult etc.) [Craig88, Craig94, Craig93, Grunau87, Grunau90] and location of pain (shoulder pain [Prkachin89], knee pain, and chronic pain etc.). Limited work has been done on the topic of automatic detection of pain from facial expression. Several researches are based on Facial Action Coding System (FACS), first introduced by Ekman and Friesen in 1978 [Ekman78]. It is a method for finding taxonomy of almost all possible facial expressions initially launched with 44 Action Units (AU). Computer Expression Recognition Toolbox

(CERT) has been proposed in [Littlewort06, Smith01, Bartlett06a, Bartlett06b, Littlewort09, Braathen02] to detect facial expression by analyzing the appearance of Action Units related to different expressions. Different classifiers like Support Vector Machine (SVM), Adabooster, Gabor filter, and Hidden Markov Model (HMM) have been used alone or in combination with others to achieve greater accuracy. Researchers [Ashraf09, Ashraf07] have used active appearance models (AAM) to identify specific facial features associated with pain. The Eigenface-based method was deployed [Monwar07] in an attempt to find a computationally inexpensive solution. Later the authors included Eigeneyes and Eigenlips to increase classification accuracy [Monwar06b]. Several authors have relied on artificial neural network-based back propagation algorithms to make pain/no pain decisions from extracted facial features [Monwar06a]. A Bayesian extension of SVM named Relevance Vector Machine (RVM) has been adopted [Gholami10] to increase classification accuracy. Authors in [Becouze07, Niese09] tried to measure pain for ICU/post-operative patients. An algorithm [Becouze07] has been built on the hypothesis of forming and detecting extra wrinkles due to pain. Researchers [Niese09] used a photogrammetric technique for finding features and later an SVM filter with RBF Gaussian kernel was deployed for detecting pain. Brahnam et al. [Brahnam07, Brahnam06] worked to find pain in neonates. Almost all of these approaches suffer from one or more of the following deficits: 1) laboratory based solution not feasible for real life hospital scenario, 2) considerable amount of manual interaction, 3) inability to handle noise, illumination, glass, facial hair, skin color issues, 4) high computational cost, 5) lack of mobility, 6) failure to classify intensity of pain level (just pain/no pain scenario), and finally 7) lack of reliability.

Our proposed mobile based pain intensity classifier will be free from these limitations. The system will need least amount of patient interaction and no verbal communication. No training will be required for nurses and the system can perform equally with patients from different diversities (age, sex, ethnicity, pain type etc.).

7.4. Design of Modeling Pain Intensity Using Mobile Phones

7.4.1. Detection of Facial Contour

Pixels corresponding to skin have difference with other pixels in an image. Skin color modeling in chromatic color space [Wyszecki82] has shown the clustering of skin pixels in a specific region. Though the skin color of persons vary widely based on different ethnicity, research [48] shows that still they form a cluster in the chromatic color space. After taking the image of the subject we first crop the image and take only the head portion of the image. Then we use skin color modeling for extracting the required facial portion from the head image.

7.4.2 Identification of Pain Intensity

For this part we have used a combination of Eigenfaces, Eigeneyes, and Eigenlips methods based on Principal Component Analysis (PCA) [Turk91, Pantic00]. This analysis method includes only the characteristic features of the face corresponding to a specific facial expression and leaves other features. This strategy reduces the amount of training sample and helps us to make our system computationally inexpensive. These resultant images will be used as samples for training Eigenfaces method and M Eigenfaces with highest Eigenvalues will be sorted out. Here is a step by step break down of the whole process.

1. The first step is to obtain a set S with M face images. Each image is transformed into a vector of size N^2 and placed into the set, $S=\{\Gamma_1,\Gamma_2,\Gamma_{3..} ,\Gamma_M\}$

2. Second step is to obtain the mean image Ψ

$$\Psi = \frac{1}{M}\sum_{n=1}^{M}\Gamma_n$$

3. We find the difference Φ between the input image and the mean image, $\Phi_i = \Gamma_i - \Psi$

4. Next we seek a set of M orthonormal vectors, u_M, which best describes the distribution of the data. The kth vector, u_k, is chosen such that

$$\lambda_k = \frac{1}{M} \sum_{n=1}^{M} \left(u_k^T \Phi_n \right)^2$$

5. λ_k is a maximum, subject to

$$u_l^T u_k = \delta_{lk} = \begin{cases} 1, \text{if } l = k \\ 0, \text{otherwise} \end{cases}$$

where u_k and λ_k are the Eigenvectors and Eigenvalues of the covariance matrix C

6. The covariance matrix C has been obtained in the following manner Ω

$$C = \frac{1}{M} \sum_{n=1}^{M} \Phi_n \Phi_n^T = AA^T \text{ Where, } A = [\Phi_1 \Phi_2 \Phi_3 .. \Phi_m]$$

7. To find Eigenvectors from the covariance matrix is a huge computational task. Since M is far less than N^2 by N^2, we can construct the M by M matrix,

$$L = A^T A, \text{where } L_{mn} = \Phi_m^T \Phi_n$$

8. We find the M Eigenvectors, v_l of L.

9. These vectors (v_l) determine linear combinations of the M training set face images to form the Eigenfaces u_l

$$u_l = \sum_{k=1}^{M} v_{lk} \Phi_k , \qquad l = 1,2,...,M$$

10. After computing the Eigenvectors and Eigenvalues on the covariance matrix of the training images

- M eigenvectors are sorted in order of descending Eigenvalues
- Some top eigenvectors are chosen to represent Eigenspace

11. Project each of the original images into Eigenspace to find a vector of weights representing the contribution of each Eigenface to the reconstruction of the given image.

When detecting a new pain image, the image will be projected in the Eigenspace and the Euclidian distance between the new image and all the pain image categories (here there will be six pain intensity categories) in the Eigenspace will be measured. The pain intensity category that represents the closest distance will be assumed as a match for the new image. Similar process will be followed for finding results using Eigenlips and Eigeneyes methods. The mathematical steps are as followed:

- ○ Any new image is projected into Eigenspace and find the face-key

$$\omega_k = u_k^T(\Gamma - \Psi) \, and \, \Omega^T = [\omega_1, \omega_2, \ldots., \omega_M]$$

where, u_k is the kth eigenvector and ω_k is the kth weight in the weight vector $\Omega^T = [\omega_1, \omega_2, \ldots., \omega_M]$

- ○ The M weights represent the contribution of each respective Eigenfaces. The vector Ω, is taken as the 'face-key' for a face's image projected into Eigenspace.
- ○ We compare any two 'face-keys' by a simple Euclidean distance measure

$$\epsilon = \|\Omega_a - \Omega_b\|^2$$

- ○ An acceptance (the two face images match) or rejection (the two images do not match) is determined by applying a threshold.

7.5. Building Training Database

Building a reliable and diversified training database is one of the most important parts of our system. Since the system will be trained using this database, the performance of the system is dependant by some part on the versatility of the training database. We have included people in such a way that ensures participation from different race, ethnicity, sex and different facial characteristics (presence of beard, glasses, facial hair etc.). We have followed a specific step by step protocol in taking the pictures.

- First a research team member will explain the reasons for taking the pictures. This will also be mentioned that these pictures will be used solely for research purpose and will never be published anywhere without volunteer's consent.

- Then the volunteers will be shown the numeric scale of pain as shown in figure 7.1 where six expressions of pain are drawn. The volunteers will be explained all six different levels of pain. Volunteers should clearly understand what do pain levels (0, 2, 4, 6, 8, 10) mean.
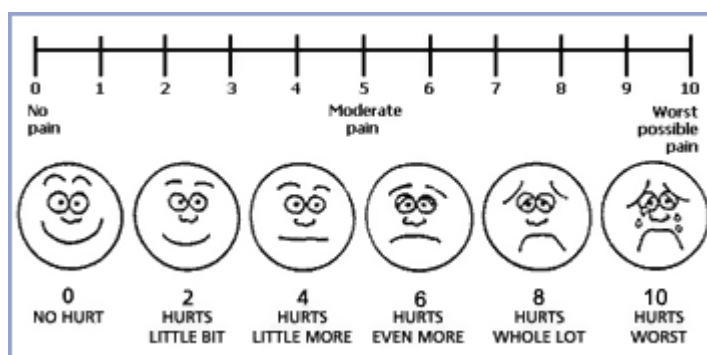
Figure 7.1 Wong-Baker face pain scale

- Then the volunteers will be asked to imitate the pain levels. In order to get notable differences among the pain levels, the team member will tell the following things before taking pictures of each of the pain levels:

  Pain level 0 – Smiling face

  Pain level 2 – Almost Neutral face (hurts just a little bit)

  Pain level 4 – Sad face (hurts just a bit more)

  Pain level 6 – Something is really hurting

  Pain level 8 – Just before crying (hurts a whole lot)

  Pain level 10 – Crying in excruciating pain (hurts as much as you can imagine)

- While taking the pictures the member should maintain the following guidelines:

    i.   The image must contain the full face, neck, and shoulders of the applicant in frontal view

    ii.   Avoid extraneous objects, additional people, parts of the body below the applicant's shoulders or other artifacts

    iii.   No distracting shadows on the subject or background

    iv.   Image must be in color but it can be of any resolution

    v.   We prefer bare eyes but eyeglasses are fine if the volunteers do not feel comfortable without glasses. But sunglasses or obstructing objects are not allowed

We have taken six pain images (0, 2, 4, 6, 8, 10) from each of our 8 subjects.

7.6. System Architecture

Building a reliable and diversified training database is one of the most important parts of our system. The ultimate goal is to use the application from any device, mobile, or browser. Because of the huge computational power needed for the image processing for pain expression detection, we needed software like MATLAB. Hence the total design can be thought of the integration of two different phases. First, we need MATLAB for pain intensity detection. Second, that MATLAB script needs to be called using a web service. That way, we ensure that the script is available from any platform, including handheld devices.

After training, we implemented the client side for web service call using PHP and javascript. In the server side we have used Apache Tomcat container as the application server with Axis2 as SOAP engine. Then using a PHP script we called that web service from a browser. User uploads a picture from the browser and then the pain intensity is detected using the web service call. Figure 7.2 shows the high level architectural overview.
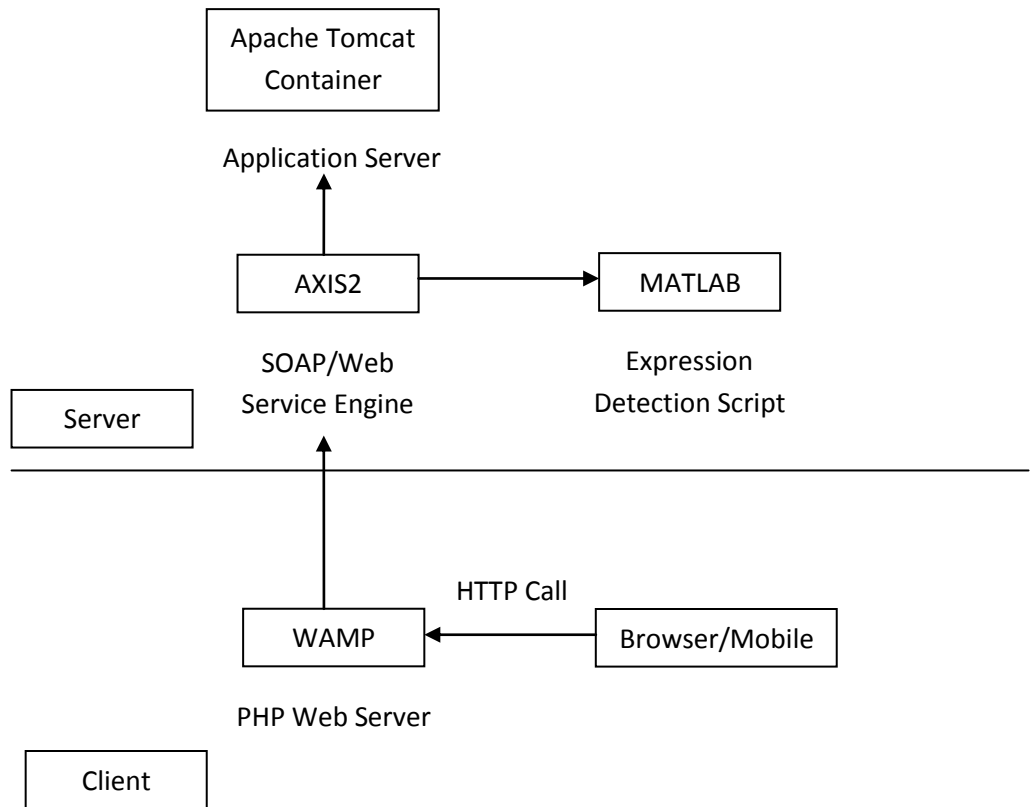
Figure 7.2 System architecture

Here we provide a screenshot of a sample user with corresponding detected pain intensity level in figure 7.3.

Figure 7.3 Pain intensity detection example
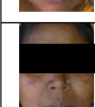
7.7. Validation Results

In order to validate our pain tool, first we tested the system with the training set images. The system was able to correctly identify all the training images with the exact pain level associated with that image. Then we have focused on testing the model with images that are not in the training database. For this, we have collected pain images from 7 MOs with random pain intensity levels. We asked a doctor who is not familiar with the patients to rate their pain level from their pain images. We also determined the pain level of these images by our pain tool. Then we evaluated the difference between the pain intensities reported by the patient and determined by our system. We also determined the difference between the pain intensities evaluated the doctor and our system. Table 7.1 shows the results.

Table 7.1. Pain Tool Validation Summary

Patient Image	Subject id	Original pain value	Doctor's assessment	System's pain value	System's round off pain value	Diff. doctor-system	Diff. patient-system	Image information
	1	3	6	5.1	5	1	-2	These 4 photos correspond to the same patient taken in 4 different days.
	1	4	6	5.3	5	1	-1	
	1	5	6	5.3	5	1	0	
	1	6	6	5.3	5	1	1	

	2	6	5	5.2	5	0	1	These 2 photos are taken in the same day.
	2	6	5	4.8	5	0	1	
	2	6	5	5.1	5	0	1	These 2 photos are taken in the same day (not the day when the previous pictures were taken).
	2	6	5	5.1	5	0	1	
	3	9	7	4	4	3	5	All these 3 pictures are taken 3 different days.
	3	9	7	3	3	4	6	
	3	8	7	3	3	4	5	
	4	2	4	5.9	6	-2	-4	All these 3 pictures are taken 3 different days.
	4	3	4	5.2	5	-1	-2	
	4	3	3	3.6	4	-1	-1	
	5	5	6	4	4	2	1	
	6	0	1	1.8	2	-1	-2	

	7	3	4	3.9	4	0	-1	These 2 photos are taken in the same day.
	7	3	3	3.6	4	-1	-1	
	7	4	3	4.1	4	-1	0	These 2 photos are taken in the same day (different day from the previous one).
	7	4	3	3.7	4	-1	0	
	7	5	4	3.7	4	0	1	These 2 photos are taken in the same day (different day from the previous 2 sets of images).
	7	5	3	3.6	4	-1	1	

Out of the 22 images, our system was able to determine the pain intensity level within ±1 range of the pain intensity value determined by the doctor on 17 occasions. When compared with the patient reported pain intensity level, our system was within ±1 range for 15 images. We have identified 3 possible reasons for the margin of error.

1. Several times we have found that it is even hard for naked eye to distinguish between 2 images submitted by the MOs which correspond to different pain intensity values. For example subject 1 has labeled 4 images with pain intensity level 3, 4, 5 and 6. The doctor assessed all 4 images to have pain level 6 and our system has determined the pain level of all those images as 5. Patients need more training to express their pain level through facial features.

2. The system has the worst performance for subject 3. We believe this is due to the shadow present in her images.

3. The system's performance is not that good for subject 4 too. This patient had her forehead covered and the most notable pain features occur in the forehead. We plan to take more images from her not covering the forehead.

4. It should be noted that these pain images are not included in the training database.

Chapter 8:   Conclusions and Future Work

We have summarized the key contributions of the dissertation and possible future research directions in this chapter.

8.1. Research Achievements

According to Dr Catherine Le Galès-Camus, WHO Assistant Director-General for 'Noncommunicable Diseases and Mental Health',

"Everyone has a right to be treated, and die, with dignity. The relief of pain - physical, emotional, spiritual and social - is a human right".

Given the current statistics of palliative care patients in developing countries, a feasible and easy to use solution for palliative care is an urgent need. Yet the research from current literature shows there is hardly any such system that can provide the required goals of palliative care for terminally ill patients. In our dissertation we have shown how we can develop such a system along with the methodologies to do so. The mobile based pain intensity detection tool can also open a new direction for measuring pain for verbally impaired patients.

The main achievements of this dissertation have been summarized as follows:

- **A Low Cost Palliative Care Solution for Developing World:** Since we have not found any mobile based low cost palliative care system directed for poor rural patients of the developing world, we have started from scratch. We have identified the challenges which in many ways are pretty much similar for any developing countries. The design lessons and methodologies have been summarized for future researchers. We have shown the importance of 'motivation' and a possible solution through video module. The successful results of the pilot project have been shown. We have used breast cancer as a sample disease that requires long term monitoring. Our

system can be used for other diseases under similar context. For example, monitoring AIDS patients in rural Africa.

- **A New Framework for HRQOL:** In chapter 6 we focused on the possible domains that have to be considered as a first step of quantifying QoL from a system's point of view. We have tried to identify the key features under each domain and make them as generalized as possible. For example, the most important design features of any such system need to ensure effectiveness, efficiency, satisfaction and sustainability. That's why we measured QoS based on these design features. Then based on our experience with e-ESAS we have shown an evaluation mechanism for each of these features. We have tried to show the measurements using quantifiable techniques (facts and statistical tests) where possible. The goal is to give similar researchers a generalized framework with feature extraction ideas and possible evaluation techniques so that they can adapt the framework based on their system to measure the improvement of QoL.

- **Mobile based Pain Tool:** In Chapter 7 we elaborated on our idea on mobile based pain intensity detection tool. The success of such a project can bring lab work to the side of patients' beds and help the nurses to reduce their workload. Classification of pain intensity rather than focusing on the traditional 'pain'/'no pain' scenario itself is a novel idea. At the same time we have used mobile phones to make sure the tool can be easily used in a real life scenario. Moreover we have tested our tool for validation on actual pain images of cancer patients where as all other 'pain'/'no pain' classification projects have relied on fake pain image database.

8.2. Future Research Directions

As we walked through the time line of the project we got exciting ideas that we decided to add in future. We plan to develop the following extensions.

- **SMS based ESAS:** In order to make this project a real success we need to reach the mass poor people of the villages. We are working on developing an SMS based e-ESAS system for low end mobiles. For this system client software will be developed and deployed onto patients' mobiles. The software will ask questions, collect answers, and then send the data as SMS. There will be an 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 mobiles will be required to run this software. We have decided to build the SMS based system in a java enabled phone due to mass penetration of Nokia phones in rural Bangladesh. In our field study 32 out of 43 patients who have access to mobile phones possess a Nokia phone and 46.7% of these phones were java enabled.

- **Forum for BC Patients:** People always like to feel like they are a part of a homogeneous community. BC patients, either in rural or urban settings, always find it difficult to mix with other members of society. Rather they prefer to interact with other BC patients whom they think are in the same boat. Based on this finding we plan to develop a forum among MOs where they can submit audio based questions and answers. We prefer the audio version since most of the MOs do not know how to write. At the same time it will have a FAQ section with answers from experienced doctors. We believe such a platform is highly needed by the BC patients to express their closed thoughts and to increase their social interaction.

- **Long Term Data Analysis:** Currently we are getting 10 symptom values and 3 pain related values from each BC patient each day. This is going to build an enormous database which can be used by medical researchers for analysis. We plan to analyze these data for finding behavioral patterns of terminally ill patients. Also we have received very promising results in increasing the life expectancy of the MOs compared to that of other BC patients of similar status (same physical, mental, and disease state). But a pilot study of only 10 MOs is too small to make

any remark on this most crucial issue. Based on the success of this study, the Government of Bangladesh has already agreed to conduct the study on 200 BC patients.

- **A QoL Scale:** We are now identifying questions that capture the essence of the 4 domains detected for QoL. Then we will find weight parameters for each of the questions and use Cronbach's alpha [Cronbach] to verify the construct validity. This final product will help the researchers to determine the role of their application or system in improving QoL of the patients or target subjects.

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Appendix A

Glossary of Terms

Term	Definition
Palliative Care	An area of healthcare that focuses on relieving and preventing the suffering of patients.[*]
Load-shedding	An intentionally engineered electrical power shutdown where electricity delivery is stopped for non-overlapping periods of time over different parts of the distribution region.[*]
ECOG Scale	The ECOG score denotes the performance status of cancer patients and runs from 0 to 5, with 0 denoting perfect health and 5 death.[*]
Homeopathy	Homeopathy is a system of alternative medicine originated in 1796 by Samuel Hahnemann, based on his doctrine of *similia similibus curentur* ("like cures like"). Scientific research has found homeopathic remedies ineffective.[*]
t Test	A *t*-test is any statistical hypothesis test in which the test statistic follows a Student's *t* distribution if the null hypothesis is supported.[*]
Inter-rater Reliability	Inter-rater reliability denotes the degree of agreement among raters.[*]
Intra-rater Reliability	Intra-rater reliability is the degree of agreement among multiple repetitions of a diagnostic test performed by a single rater.[*]

[*] Definitions have been collected from wikipedia