

Findings of Mobile based Palliative Care System: Towards Formulating a Generic Framework for Measuring QoL

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ABSTRACT

Here we present the final analysis result of e-ESAS, a mobile based symptom monitoring and management system for terminally ill breast cancer (BC) patients in rural Bangladesh. These patients need palliative care support whose goal is to meet patients' social, spiritual and psychological needs as well as alleviating pain and other symptoms. But in the context of rural Bangladesh, doctors find it very difficult to control even the most significant symptom 'pain' due to a lack of history of symptom data. In this scenario we have deployed e-ESAS which has been used by 10 patients to submit symptom values from their home for 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 quality of life (QoL) of the patients.

Categories and Subject Descriptors

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

General Terms

Measurement, Design, Performance.

Keywords

Health, Breast cancer, mobile computing, QoL.

1. INTRODUCTION

Breast cancer (BC) is responsible for 16% of all female cancers and regarded as the most common type of cancer among women worldwide. Although breast cancer is commonly taken as a disease of the developed world, 69% of all BC deaths occur in developing countries [1]. It is the sixth leading cause of mortality in Bangladesh [2]. Unlike western countries where 89% of the women have a survival rate of more than 5 years [3], most BC patients in Bangladesh die because majority of cases are diagnosed in late stages [5]. These patients need palliative care (treatment process for terminally ill patients through symptom management

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to improve QoL) which is almost absent in rural Bangladesh.

Based on our field studies on 39 BC patients, we have found that they hardly come to the health center (on an average once a month) due to various reasons including physical condition, family/social environment, monetary status etc. Doctors do not have any communication with the patients once they leave the health center until they return after a month or more. Instead of the day to day monitoring required for palliative care patients, doctors rely on the patient information they get only when the patient visits the health center. In this scenario, a mobile based remote symptom monitoring system can be very effective. Fortunately mobile phones penetrated the masses of Bangladesh and our field study found 43 out of 45 rural BC patients have access to mobile phones. Therefore we have developed and deployed e-ESAS which can be used by the patients to submit their symptom values each day from their home. For doctors, e-ESAS is like a palliative care tool which can be used to view the graphical representation of the symptom values and change prescriptions in real time.

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 QoL is a much talked about topic in medical science, behavioral science and psychology, it has been an almost unexplored topic to measure a system's contribution in improving QoL. It is a question that CHI 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.



Figure 1. a) Patient, neighbor and family members watching motivational video. b) Patient using e-ESAS from hospital.

The contribution of the work can be documented as:

- First and only mobile based solution for rural palliative care patients.

- Development of a sequential database of non-biased symptom values from BC patients helps the doctors for better assessment, real time symptom monitoring and timely intervention thus improving their quality of life.
- First attempt to evaluate the characteristics of a system towards improving QoL. We tried to formulate a generic framework that be used by health care researchers to evaluate the contribution of a system in measuring QoL.

2. RELATED WORK

We have searched related works from 2 perspectives. Firstly, we have searched for health care projects of developing countries and tried to see whether they have measured QoL based on the deployment results of their systems. Secondly, we have analyzed the current QoL surveys to check whether they evaluate the contribution of the system.

Mobile applications have been used in many developing countries including India [11], Tanzania [7] and Uganda [15] to collect health care data. Improving Care [13] in South Africa, e-IMCI [7] in Tanzania and Early Diagnosis and Prevention System [12] in India helped the doctors to implement a decision support system through PDAs or computers. But these systems are only used by doctors/health workers (not by the patients) and only when the patients come to the health center or the health workers go to patients' houses. None of these systems are a feasible option for palliative care patients where doctors need day to day data submitted/reported by the patients (or attendants) themselves. Home monitoring for patients with chronic diseases like asthma [16], cancer [18], and diabetes [28] using web based services has been proven successful in urban settings but such internet based services are not practical for rural women. WiLDNet [29] and iPath [20] used real time video streaming for distant patient-doctor communication which is not feasible in the rural Bangladesh scenario. Haque *et al.* [14, 30, 31, 32] showed some initial results of a mobile based system but left out any long term analysis on QoL. Ramachandran *et al.* [8] showed the impact of motivational videos for HWs but we showed it for patients and society. We have not found any mobile based integrated system like e-ESAS which is simultaneously used by both patients and doctors for long term symptom monitoring of rural palliative care patients. e-ESAS not only helps with symptom management but also impacts the holistic (social, psychological) needs of such patients. None of these systems have measured the improvement of QoL.

QoL studies mainly focus on i) measuring QoL with different questionnaires like SF-36 [24], FACT-B [25] and Missoula Vitas Quality of Life Index (MVQOLI) [26], ii) finding expectations or needs of palliative care patients [27, 17] and iii) comparing among different questionnaires including paper based and electronic QoL data collection systems [19]. Instead, we focused on evaluating the impact of e-ESAS in the improvement of QoL based on analyzing the results from our field studies. Though the existing QoL surveys cover several aspects (physical, social, emotional, functional and sometimes spiritual) of patients' lives, 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 QoL, have been covered in this work.

3. METHODOLOGY & TIMELINE

We partnered with a local NGO named 'Amader Gram' (literally 'Our Village') for our pilot study. 'Amader Gram' started a clinic named 'Amader Gram Breast Care Center' (AGBCC) with the help of International Breast Cancer Research Foundation (IBCRF) in 2006. Currently there are 4 branches of AGBCC with 67 registered BC patients. For our pilot study, we conducted 5 field trips so far to rural Bangladesh. The first 2 field trips focused on identifying the

challenges faced by doctors and patients in providing and receiving treatments and how emerging mobile technology can solve these challenges. The deployment of e-ESAS was done in the 3rd field trip. The last 2 field trips focused on analyzing the data collected from the patients. Here we provide a summary of tasks and milestones completed in each of the field trips.

3.1 Field Trip 1 (4 weeks, Jul '10-Aug '10)

First we observed 22 doctor-patient interactions during patient visits. We measured the average duration of patient meetings, the steps followed by the doctors, common questions asked by both patients and doctors. One researcher was present during these sessions. The sessions lasted between 6 and 11 minutes. Later we interviewed a total of 39 BC patients. The interviews took place in 3 different scenarios- patients' homes (5), AGBCC (22) and a hospital (12). One research team member and one doctor or health worker (HW) took part in the interview with each patient separately. The interview session had 2 parts. In the first part we measured their experience level with mobile phones and in the 2nd part we collected demographic information and had an open discussion regarding the socio-cultural barriers they face as BC patients. We also collected information about average time spent in transportation, average waiting time to visit doctors and average number of visits per month. We had 2 focus group sessions with doctors. One session was with 8 doctors in AGBCC, Khulna and the other was in Dhaka with 4 doctors.

During our clinic observation we found that doctors use a paper based graph named ESAS (Edmonton Symptom Assessment System) [6] to record 10 symptom values (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well being, shortness of breath and others) for each patient only when these patients visit the AGBCC. The symptom values are scored from 0 to 10. Doctors' biggest concern was lack of availability of symptom data for patients. On the other hand patients complained about transportation hazards and their inability to visit health centers regularly for various reasons. Based on these findings, we decided to develop a mobile based solution named e-ESAS.

3.2 Field Trip 2 (3 weeks, Dec '10-Jan '11)

We showed the 1st version of e-ESAS to 31 BC patients and 10 doctors and collected their feedback.

3.3 Field Trip 3 (12 weeks, Jun '11-Aug '11)

We deployed the 2nd version of e-ESAS on 12 Nokia X6 mobiles. 10 of them were given to 10 selected patients and the 2 others were given to doctors. Chronic pain level ≤ 5 on ESAS scale, life expectancy > 6 months and performance status ≤ 2 on ECOG scale [4] were the main selection criteria. We will call these patients MOs (Mobile Owners). We also interviewed a separate number of other BC patients (registered with AGBCC) during different field trips. We call this patient group as OPs (Other Patients).

3.4 Field Trip 4 (12 weeks, Nov '11-Jan '12)

Due to delayed BMRC (Bangladesh Medical Research Council) approval, we started collecting data in Nov '11. 2 of the MOs were replaced since they no longer met the selection criteria. In Dec '11, we made 10 house visits to learn the experience of MOs' using e-ESAS. We observed a total of 77 patient visits (both MOs and OPs) to evaluate the difference between doctor-MO interaction and that of doctor-OP. We also had focus group sessions with the doctors.

3.5 Field Trip 5 (3 weeks, May '12-Jun '12)

We had open discussions with the MOs and their family members during this time period. We also had 2 open discussion sessions with the doctors. We all shared our thoughts and talked about the future of e-ESAS.

4. e-ESAS DESIGN

e-ESAS has been developed for the Nokia X6 mobile phone. On the server side, we used Tomcat 6.0 server and MySQL database. 3 modules of the client side (patient, doctor and video) are integrated as a single application for flexibility.

4.1 Patients' Module

Initially the patient module had 10 sliding bars (2 sliding bars/page) corresponding to 10 symptoms mentioned in ESAS. According to the suggestion of local doctors we added 3 more sliding bars corresponding to maximum, minimum and average pain in the last 24 hours. The following figure 2 shows the paper based ESAS and e-ESAS.



Figure 2(a). Classification of QoL.

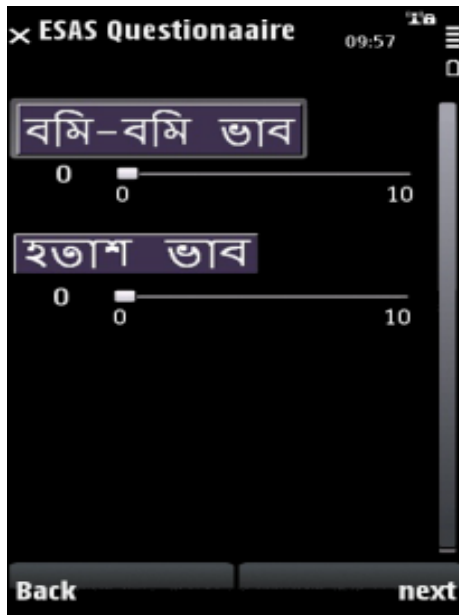


Figure 2(b). Screen shot of e-ESAS.

Patients can drag the sliding bar to left or right setting any value from 0 to 10. The default value of the sliding bar is 0. Each sliding bar is followed by a button containing Bengali text as a label. If pressed, it will also play a voice in the local Bengali dialect that provides instruction on how to use the sliding bar. 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.

4.2 Doctors' Module

When a user logs in as a doctor, he/she is provided with an alphabetically ordered patient list. Doctors can choose a patient, start-end date and single or multiple symptom values to see the graphical representation of the selected symptoms for the chosen period. They can also compare a single symptom of multiple patients over a selected time period. If needed, doctors can change a prescription which will generate a 'changed prescription' message for the patients. Doctors' module generates alert messages for doctors based on predefined threshold values. Currently an alert is generated if the pain level of any patient exceeds 7.

4.3 Video Module

We have created 2 motivational videos: Motivational Video for Women (MVW) and Motivational Video for Society (MVS). Both doctors and MOs can view the motivational videos. One MO took part in MVW sharing her experience regarding BC. She talks about the primary and secondary symptoms of BC and encourages village women to go to the health centers without feeling shy or being afraid. In MVS a local influential person urges the family heads (normally husbands) not to undermine women's health. He also conveys 2 important pieces of information regarding BC: i) BC is not infectious and ii) BC is not exactly hereditary.

5. 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' [22]. In order to assess a system's impact on HRQOL we have classified it in 4 domains (figure 3).

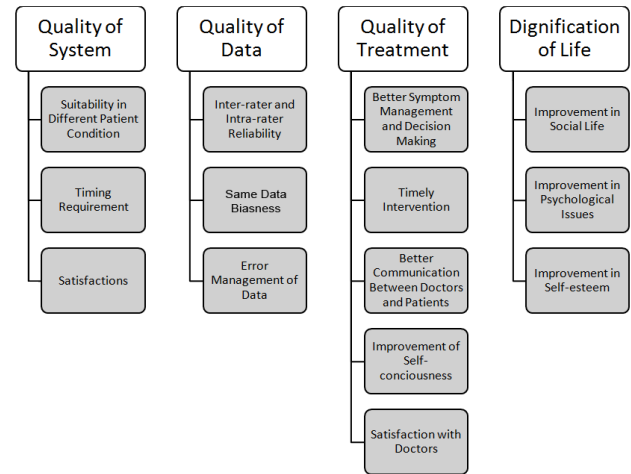


Figure 3. Classification of QoL.

5.1 Quality of System (QoS)

Usability tests are needed to verify the ability and satisfaction of the target users who are using the system. Usability issues (effectiveness, efficiency, satisfaction) will show whether the target population is capable and motivated enough to use the proposed system.

5.2 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. For this, we adopted statistical measures like inter-rater reliability and intra-rater reliability.

5.3 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) to create a better treatment environment. As 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 change in life expectancy.

5.4 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.

Conceptually QoT is dependent on QoS and QoD and QoL in turn depends on QoT and ‘Dignification of Life’.

6. FINDINGS

We have grouped our findings in the abovementioned domains.

6.1 Quality of System (QoS)

6.1.1 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) on a scale of 0 to 10. Figure 4 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 the rest of the features.

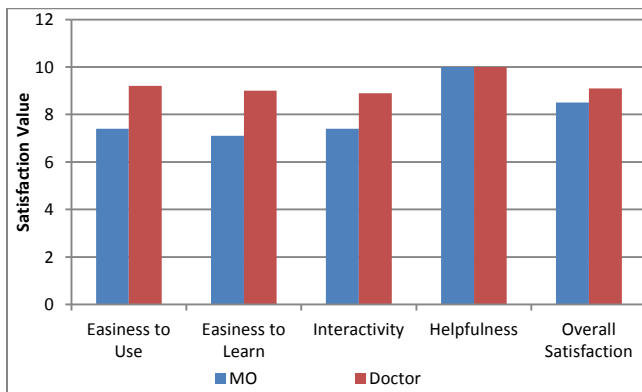


Figure 4. Usability results of e-ESAS.

6.1.2 Suitability in Different Patient Condition (Effectiveness)

A recent study [23] 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 1 summarizes the results.

Table 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.

6.1.3 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 5 shows the average number of missing data per month.

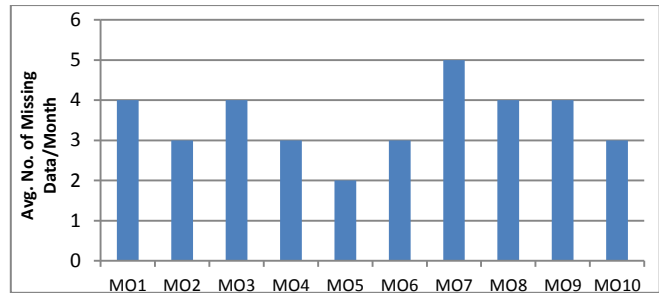


Figure 5. Average no. of missing data/month (MO wise).

From the doctors’ point of view they expect that any new system would be more useful in analyzing data and take less time and complexity compared to the existing system. On average, the paper based ESAS chart that doctors used to fill prior to the deployment of e-ESAS, takes 8 minutes (based on 35 observations) to complete. 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 visits, 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.

6.2 Quality of Data (QoD)

‘External factors’ such as a long journey to the health center (on average 5.19 hours round trip), hot weather and long waiting times

(on average 1.79 hours) deteriorate the condition of the patients before they finally meet the doctor. As a result, visiting patients commonly report having the highest level of pain and other symptoms ('current feeling biasness') which sometimes do not reflect their actual regular pain levels. During our 1st field trip, we observed 22 patient visits and all the patients reported having pain level 10. But when MOs are submitting their symptom values each day from the comfort zone of their homes, the data is becoming free from these 'external factors'. The long term availability of data is helping the doctors easily find the 'outliers in data' (odd spikes 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 used the following criteria.

6.2.1 Inter-rater and Intra-rater Reliability

Inter-rater reliability measures the extent to which the results vary when different persons measure the same system using the same method. On the other hand, intra-rater reliability describes how closely the results of a specific test resemble each other. To measure these reliability coefficients, 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 our 4th field trip. 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 next 3 months period (Nov '11-Jan '12) we followed this procedure 3 times. The following figure 6 shows the average correlation coefficient of inter-rater and intra-rater reliability for each of the MOs.

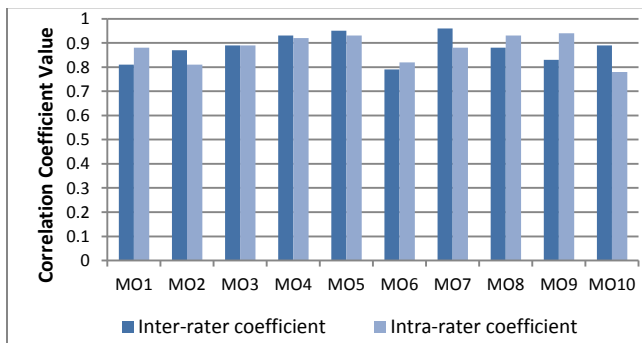


Figure 6. Average correlation value for inter-rater and intra-rater reliability.

On average, the correlation coefficient and Fleiss Kappa coefficient of agreement of inter-rater reliability vary from 0.79 to 0.96 and from 0.71 to 0.91. Corresponding values for intra-rater reliability vary from 0.78 to 0.94 and from 0.73 to 0.89. Since a correlation coefficient value greater than 0.6 is considered as good, our result indicates that the data submitted are highly consistent and reliable. It should be noted that we have found 100% agreement in both cases for current level of pain in all instances.

6.2.2 Same Data Biasness

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 an MO who submitted a specific symptom pattern (6,0,0,0,0,0,0,0,0,0,0,0,0) for 5 consecutive days. We called her and motivated her to submit all the values. A thorough analysis on the submitted data of each of the MOs in 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.

6.2.3 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 and explained 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 conversations). Then we changed our data processing mechanism in the server to automatically consider the higher value as the maximum value.

6.3 Quality of Treatment (QoT)

6.3.1 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 gave the doctors a useful tool for better analysis and diagnosis of patient condition. D4 shared the following experience where e-ESAS features helped her to make better assessment. According to her , "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 7). 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."

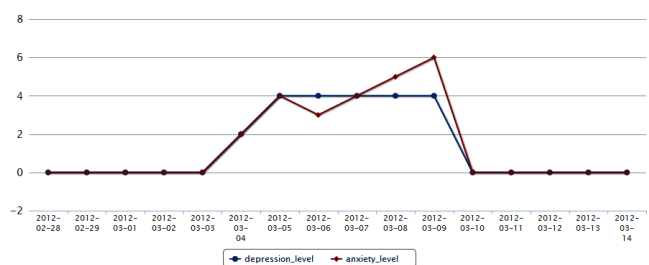


Figure 7. Anxiety and depression graph of MO5.

6.3.2 Timely Intervention

Patients with advanced stages of cancer are very vulnerable and need timely intervention to avoid a minor problem turning into 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 visited the health center the next time. But now based on the alert message feature doctors can intervene in 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 8) and found high level of nausea too. I changed her prescription immediately to make sure things are ok.”

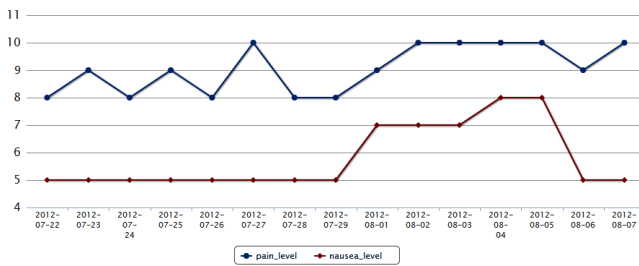


Figure 8. Symptom graph of MO4.

6.3.3 Better Communication between Doctors and Patients

Better communication between patients and doctors results in better diagnosis and treatment [21]. During the 1st field trip we found that the only method of communication between patients and doctors is through visiting the health center. Patients never call the doctors and vice versa. 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. 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 phone contact with them. When we asked them why do they call the MOs but not the other patients D1 said, “We only call the MOs when we get unusual value in the data or when we get alert messages. When a graph of a patient in front of my eyes show something wrong, I feel obligated to call the patient. I don't have any information or such message for the other patients. So I don't have that motivation (to call).”

6.3.4 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 their 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.”

6.3.5 Satisfaction with Doctors

We have performed a 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...”

6.4 Dignification of Life

6.4.1 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 their neighbors. When we asked why, 31 of them said that their neighbors believe they would also be infected by the disease if they come in contact with them. 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 the 4th and 5th field trip we observed a much better social life for the MOs. On 4 occasions we found MOs with neighbors. Motivational videos played a big 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 9 shows the average number of videos played per month by the MOs during the first 4 months of deployment (Nov '11-Feb '12).

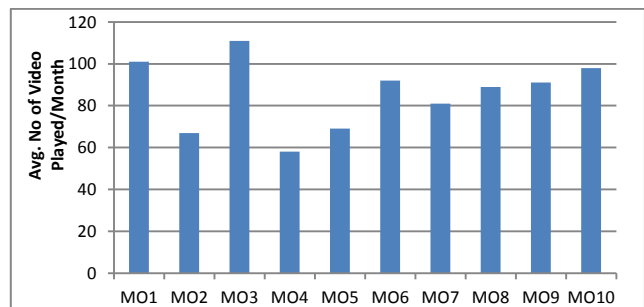


Figure 9. Average number of video played/month.

6.4.2 Improvement in Psychological Issues

Discussion and counseling on psychological issues is very important for terminally ill patients [18]. 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. After a month or so we became intimate enough to talk about the preparation of death. 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 visit. But now I share my stories with her. I also told her plan for my children.*”

6.4.3 Improvement in Self-esteem

Many of the rural women have a 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 receiving 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 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). The following figure 10 shows the number of patients referred by the MOs.

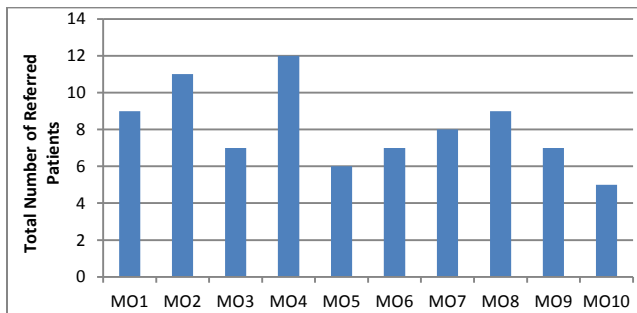


Figure 10. Total number of patients referred by MOs.

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.

7. DISCUSSION

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

7.1 Surprised with Satisfaction Result?

We expected the MOs to have significantly higher level of satisfaction with doctors and the treatment process since they are receiving better pain management, timely intervention 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 higher satisfaction level with

both doctors (t test = 6.3; P < .005) and treatment process (t test = 5.9; P < .005) after using e-ESAS. Though we normally use t test on the control group (OPs) and the treatment group (MOs) after the study ends, in such cases where the control group does not have an 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.

7.2 Four Way QoL Feedback

In any QoL survey questionnaire the feedback is given only by the patients. 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 feedback.

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 are proven by facts (e.g. improvement in longevity, inter rater reliability of data).

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

7.3 Missing Part of Good Death

According to Byock [10], a good death consists of 3 issues:

- Effective management of pain and other symptoms
- Preparation for death and aftermath
- Achievement of significant goals in life

The main goal of e-ESAS was to ensure the 1st issue. Since a bond was created between the MOs and doctors through better communication, doctors started addressing the 2nd issue. During the final discussion on 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 time to explore the other 2 issues of good death, which are commonly missed by mobile health projects.

8. NEXT STEPS

8.1 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 [9] to verify the construct validity. These weight parameters will ensure higher weight on QoT and ‘Dignification of Life’ features thus ensuring no system can achieve high QoL value by just providing high QoS and QoD values. The final QoL scale will help the researchers to determine the impact of their systems in improving QoL of the patients or target subjects.

8.2 Monitoring Physical Activity

The amount of physical activity is a good measure to assess the condition of BC patients. Especially the amount of walking and sleeping can be a good estimate in understanding the state of well

being of the patient. This was the reason for choosing Nokia X6 in our pilot study since it has an accelerometer and gyroscope sensors needed for measuring physical activity.

8.3 A Big Scale Study

We have got very promising results in increasing life expectancy. 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, Government of Bangladesh has already agreed to conduct a study on 200 BC patients.

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