Mobile Based health Care Solution for Breast Cancer Patients

Munirul M HAQUE[1], Ferdaus KAWSAR[1] , Md. ADIBUZZAMAN[1], Sheikh I. AHAMED[1], Richard LOVE[2], Rumana DOWLA[3], David ROE[2], Reza SELIM[4]
[1]*Marquette University Ubicomp Lab Milwaukee, WI 53233, USA*
Email: {mhaque, fkawsar, madibuz, iq}@mscs.mu.edu
[2]*International Breast Cancer Research Foundation*
Email:richard@ibcrf.org,davidroe@charter.com
[3]*Bangabandhu Sheikh Mujib Medical University, Shahbag, Dhaka, Bangladesh*
Email: rumanadowla@hotmail.com
[4]*AGBC Center, Khulna, Bangladesh*
Email: rezasalim02@yahoo.com

Abstract: Breast cancer patients in advanced stage of the disease need palliative care as well as traditional treatment which aim to cure and prevent cancer. For such patients, treatments and interventions concentrating on reducing the suffering and improving the quality of life might be the best possible alternative. In this paradigm, long term care is provided through an adaptive feedback-oriented treatment mechanism. It is essential that patients be assessed regularly and if needed, adjustments to the treatments be made without delay. This whole issue is almost absent in rural scenario of developing countries like Bangladesh. Here we have proposed a mobile and sensor based solution named AutoCare, which has been outlined with the assistance of International Breast Cancer Research Foundation (IBCRF). As part of AutoCare we have designed and deployed a mobile based remote patient monitoring system named e-ESAS. We have also summarized the desired design principals of such systems found through 3 field studies in rural Bangladesh.

1. Introduction

According to Bangladesh Bureau of Statistics cancer is the sixth leading cause of morbidity and mortality in Bangladesh [1]. Breast cancer is the 2nd most common type of female cancer in Bangladesh. Around 24.3% female cancer patients suffer from breast cancer with only 98 oncologists present in the whole country [2]. National Institute of Cancer Research and other hospitals in Bangladesh have the capacity to provide treatment to only 2% of all cancer patients per year (20,000 out of 1 million) [2]. In this scenario Government of Bangladesh has devised 'National Non Communicable Diseases Strategy and Plan of Action' with technical support from WHO in 2007. Government has committed to develop 'National Cancer Control Strategy' but the field study depicts a poor and concerned scenario. As part of this only 2 institutes (NICRH and BSMMU) have started hospital based cancer registry [4]. More than 22,000 new BC patients being added each year and 70% of them die due to lack of treatment [3] though it is possible to prevent at least one-third of the cancers based on early detection, availability of resources, and effective treatment [4].

In order to get first hand view we conducted 3 field studies (Jul '10 – Aug '10, Dec '10 – Jan '11, Jun '11 – Aug '11) in Bangladesh. In a religiously conservative and low-income country like Bangladesh, the health-care facilities are scarce and other socio-economic factors become decisive in how regularly a patient can visit the facility in person, especially when

the patient is a female. An assessment system that can monitor the patient's health status regularly without requiring her to visit the health-care facility in person will be of great value. Fortunately, in Bangladesh, like many of the low-income countries, cellular phones have become ubiquitous. According to [22], the number of cell phone users in Bangladesh had reached 76.434 million by June, 2011. Cellular phones along with a body-area sensor network of small, wearable sensors can serve as a low-cost and suitable assessment system for regularly monitoring a patient's health-status. Thereupon, as our initial step, we decided to use cell phones to build a remote symptom monitoring system (RSMS) for patients, which may notably reduce the necessity of visiting the doctors' facility coupled with the benefit that doctors will have by getting regular patient data. We have developed the first version of e-ESAS based on Edmonton Symptom Assessment System (ESAS) [10].

In our paper, we propose the outline of a mobile based solution (AutoCare) for monitoring rural breast cancer patients from their home environment. We begin with the background information for setting up the environment in section 2. The challenges faced by patients have been elaborated in section 3. Section 4 contains the objective of the project AutoCare followed by supporting concepts in section 5. Design principles followed in designing e-ESAS have been elaborated in section 6. The design and development of e-ESAS have been stated in section 7. Section 8 contains the related work followed by conclusions and future work in section 9.

2. System Background

Amader Gram (literally 'Our Village') is an initiative of Bangladesh Friendship Education Society (BFES). In 2006 Amader Gram partnered with International Breast Cancer Research Foundation (www.ibcrf.org) to open Amader Gram Breast Care (AGBC) center and became one of 9 countries to participate in a clinical trial for breast cancer patients. The mission for AGBC is to reduce morbidity and mortality from breast cancer and other breast diseases in women. AGBC has three parts: The AGBC center Breast Care Center in Khulna, Primary Breast Care Centers in Bagerhat, Rampal, Tungipara, and Jessore, and a Research Unit. A trained female doctor and medical assistant attend each clinic, 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. Patients need to pay one time registration fee of 100 taka ($1.5). Then the patient is given a registration card and her ultrasonogram and medical checkup is performed. From 2006 till 2010, the total number of patients diagnosed with breast cancer is 1405. Number of women receiving referrals for further care is 239. Total number of registered cancer patients is 53. Till now 21 patients have died. Nine of the patients have discontinued after being registered. AGBC center acted as our local base in Bangladesh. We held several meetings, interviews, and focus group sessions with breast cancer patients, doctors from Bangladesh and IBCRF, health workers to outline the features and design principals of AutoCare and e-ESAS. In total we met 39 breast cancer patients and 12 doctors in Khulna and Dhaka division.

3. Challenges

Based on the view of doctors and patients we have categorized the existing problems in the following categories.

3.1 Identification and Disclosure

Due to lack of familiarity most of the women identify BC really late. They are very shy and sometimes afraid to talk with anyone regarding breast problems. Most of the time they think this will be automatically cured as time goes by. According to P3, "*This is the 2nd time I am coming to hospital in my life. I am having this lump for more than six months but I thought it would go away automatically after some time. But it did not. How can I talk about this with my husband or others? But for the last couple of days the pain became unbearable. So I*

asked one of my neighbors to come with me and requested her not to tell anyone". At the same time they put their need as the last thing to be taken care of in the family. All these issues make it difficult even to identify BC patients in the rural villages.

3.2 Difficulties in Achieving Treatment

After being identified and decided to visit the health center patients become doubtful about getting female doctors. According to Oxfam there are only 0.26 physicians per 1000 people [23]. In this scenario it is even hard to get physicians let alone female doctors. 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 think of spending money for the women as complete wastage where as the male members of the family are treated differently. The statement of P23 summarized these issues: "*At first my husband did not permit me to go to the health centers saying they have only male doctors. He was also worried about what others will say about this. Later he told me to bring money from my parents for my treatment. "* All the patients had complaints about the physical pain of the communication. Almost everyone had the same story like P33, "*..this time it took more than 2 hours to reach here. I had to take rickshaw, then van, then bus, and finally rickshaw again. The bus was very crowded and I had to wait a long time to get a chance to get in the bus. I am feeling very sick now and I do not know how I will get back through this again..*" Long traffic jam, poor road condition, and long distance to the health center create not only unbearable communication but also put the patients in health risk.

3.3 Continuation of Treatment

From patients point of view the common complaint is the lengthy nature of treatment. At some stage the BC patients become habituated with the disease and start neglecting the treatment (fading out issue). They also mentioned about the problems of managing a companion who will accompany her to the health center. The patients visit the doctors with long delay and miss appointments on regular basis. One patient (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…I don't remember when I came here last time to visit doctors but I think it would be 2 months ago..*"

3.4 Environmental Issues

Though there are connectivity issues in some rural villages, in general the mobile network is quite strong throughout the country. Load shedding remains a long standing issue for charging the mobiles. During our visit to Khulna we have faced around 5 hours of load shedding per day and this increases during summer. We also found that there is no concept of privacy regarding health information among village people. Rather it seems that the concept of privacy is new term to rural women. All the patients echoed what P7 said: *"many people see my file (prescription and other documents) and I don't mind. I also always ask other patients about what the doctors said to them.*" Loss of mobile is also a quite common issue. Sixteen patients said either they or their family members have experience of mobile theft.

3.5 User Issues

Lack of education plays a big role in keeping women within closed doors. We found only one patient who completed grade 12 with 35% of the patients we interviewed as illiterate. Though 47.8% of them have mobile, 26.1% of the patients only know how to receive a call. None of them has ever used any mobile application. Finally harsh poverty is hindering the patients from coming to the health center. The average family income of 61% of the patients is less than BDT 3000 ($42) per month. In many cases health care is at the bottom of their priority list.

4. Objective

The goal of the proposed project is to design and develop AutoCare (AC), a cellular phone and other wearable sensors based health-assessment system that facilitates palliative care for breast cancer patients in advanced stage of the disease in Bangladesh. To achieve the proposed goal we plan to accomplish the following objectives:

1. Develop cell phone based the Edmonton Symptom Assessment Scale (ESAS) in both English and Bengali.
2. Using cell phones and sensors, we will design and develop a system that automatically:
    - Detects and quantifies pain, anxiety, and depression from facial expression
    - Analyze the sleep pattern of the patient
    - Measures the amount of verbal interaction of the patient
    - Quantifies the fatigue of the patient
    - Measures physical activity of the patient in a certain period

All these objectives share the following processes:

2.1 Data collection

- Collection of assessment data using e-ESAS application
- Baseline and longitudinal collection of data via cellular phones and other wearable sensors.
- Data uploading to server

2.2 Data analysis

- Algorithms to extract relevant information from the uploaded data

2.3 Information presentation and feedback

- Presentation of information in suitable formats to health-care personnel
- Recording of feedbacks from health-care personnel

5. Supporting Concepts

The proposed research makes provision for economically assessing the patient's health-status in a regular basis without requiring the patient to visit the health center in person. Our system is a novel one, because automatic assessment of a patient's emotional states along with physical states has not yet been covered by any cellular phones and sensors based health-care system. Figure 1 shows the high level architecture of the proposed system.

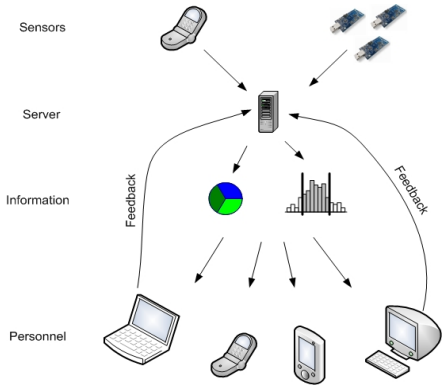


Figure 1: Architecture of AutoCare

We have made the following assumptions in discussing the features of our system.

- **Level of pain, anxiety, and depression:** Muscular action units of the face changes in recognizably different amount depending on the level of pain, anxiety, and depression.
- **Fatigued gait**: Gait pattern changes recognizably depending on the tiredness of the person.
- **Sleep pattern:** Quiets in acceleration data from the wrist-worn tmote correspond to quiets in the person's activity.
- **Fatigue:** A person's level of fatigue can be effectively determined from his answers to well-posed questions.
- **Verbal interaction:** A person's social interaction is reflected effectively in how frequently she involves in verbal interactions.
- **Physical activity:** The more a person walks, runs, uses stairs, the more he is physically active.

Following are some innovative features of our system:

5.1 Pain, anxiety and depression from facial expressions

Research in Psychology has established that facial expressions can be objectively codified in terms of muscular action units (AU's) and a sequence of these AU's can be interpreted as an indication of the presence of a particular emotion like pain, sadness, joy, etc. We have already developed a lightweight Matlab module that can detect six basic expressions namely happiness, sadness, anger, fear, anxiety, and depression. The algorithm has been developed based on Principal Component Analysis (PCA) based Eigenface method and tested on a small database of 8 persons.

5.2 Gait pattern

We have acquired data from the cellular phone's 3-axis accelerometer corresponding to a person's gait. We were able to show that people have distinct gait patterns.

5.3 Sleep pattern

If a person has a tmote attached to his wrist, it is natural that acceleration data will be different for the time when he is sleeping from the time when he is awake. The acceleration pattern is different for sound and disturbed sleep.

5.4 Verbal interaction

The reason we want to quantify verbal interaction is that patients' quality of life is reflected by social interaction and verbal interaction is a reflection of social activity.

5.5 Fatigue/Weakness

Fatigue is acknowledged to be the most frequent symptom experienced by patients with cancer. Fatigue is subjective, differs from normal tiredness and it decreases capacity for physical and mental work. Most of the instruments to measure fatigue are based on questionnaires. Some of these are BFI [5] and Revised Piper Fatigue Scale [6].

5.6 Physical activity

There are 3 main reasons why we want to measure physical activity of patients: a) to estimate the true effect size, b) to specify which dimension of physical activity is of most importance for a particular health outcome, and c) most importantly, to quantify physical activity in order to measure the effect of interventions.

6. 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.

6.1 User friendliness

The user interface should be designed considering the background of the target people. Their familiarity with certain technology, education level, physical condition, and above all social and cultural norms should be considered during the design of the system.

6.2 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.

6.3 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.

6.4 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 mode 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. Recording data in a natural setting should increase the quality of the data. Another way to increase the quality of the data is to record 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.

6.5 Local dialect

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

6.6 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.

6.7 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 be smooth with minimum possible obstructions.

6.8 Extensible

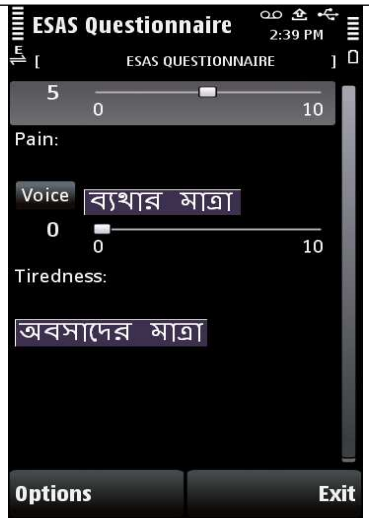
System design should ensure that some other useful services can be incorporated into the system later, i.e. the system should be extensible. Also it should be easy to incorporate suggestions from users during the later versions of the system.

7. Implementation

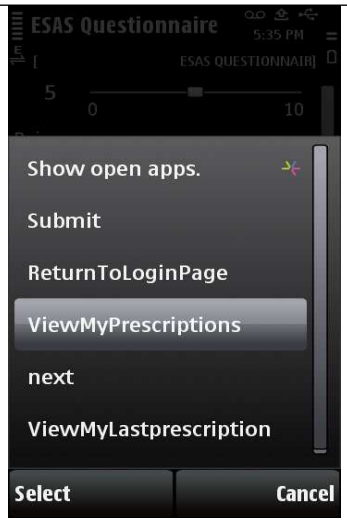
Based on our research findings we have designed and implemented a cell phone-based ESAS application. The application was developed for Nokia X6 phone. The reason behind is the widespread use of Nokia phone in Bangladesh. There are actually two parts of the system: A server and a client. On the server side, we used Tomcat 6.0 as the server and MySQL as database. The client in turn has two modules. We call these modules as doctors' modules and patients' module. For our first prototype, these two modules are integrated into single application. The reasoning behind this is flexibility. Anyone, doctor or patient, can use the application. A person can login as a doctor or as a patient.

If a user logs in as a patient, she is provided with an ESAS page. The page has 10 sliding bars each followed by a button. The sliding bars are labeled as pain, tiredness, nausea etc. Patient can drag the sliding bar to left or right by touching and set the value of it to any value between 0 and 10. The default value of the sliding bar is 0. Each button corresponding to a sliding bar has a Bengali text as a label. If pressed, it will play a voice in Bengali. The voice is an instruction on how to use the sliding bar. When the user presses the 'submit' button located at the bottom, it will send all the sliding bar values set by the patient to the database server as a string. Sample figures of e-ESAS have been given below in figure 2.

a. Patient log in page

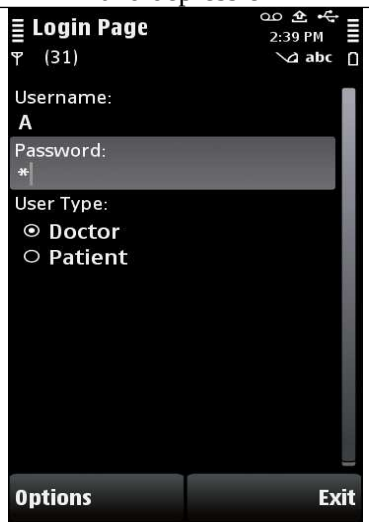


b. Sample sliding bar for pain and depression



c. Option list for patients

d. Patients' can view their prescriptions



e. Doctor log in page

f. Patient list of the doctor

g. Doctor is viewing the tiredness chart

h. Doctor can view his prescriptions for a patient

i. Doctors can write a new prescription

Figure 2: Screenshots of the application e-ESAS

When a user logs in as a doctor, he/she is provided with an alphabetically ordered patient list. The doctor can choose a patient and select a menu item called 'view chart'. Then he can choose one of the ten symptoms (pain, tiredness etc.) and the start and end date. For example, selecting pain will show a line graph of pain against the chosen duration of time. The starting and end date are shown below the graph. Doctor can change these dates anytime and choose to view a graph for a different time period.

8. Related Work

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

Based on urban setting, Hayes *et al.* [17] summarized the detailed overview of cancer treatment process and possible use of pervasive technology in several different stages of cancer care. Although, the use of pervasive technology is basically restricted in information collection and information management [18,19]. These projects focus on collecting information when the patients are at home only. Our proposal is free from this limitation. In recent works, Klasnja *et al.* [8] investigated the information work that breast cancer patients do in unanchored settings. In another approach, Skeels [9] *et al.* tried to utilize the power of social network to improve the quality of life for the cancer patients. Such approach is not feasible in rural settings of the developing countries.

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

Decision Support System

Several projects work based on implementing a guideline set by WHO or other standard organizations in computer or handheld devices [7,12,13]. Early Diagnosis and Prevention System [12], 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 to decide about physician referral, and simple treatment advice. Mitchell et al. [13] implemented a HIV screening algorithm in PDA and tested the performance in two AIDS treatment centers in South Africa. e-IMCI [7] describes a PDA based system for administering the Integrated Management of Childhood Illness (IMCI) protocol. 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 system feeds doctors with continuous, regular data and presents them in longitudinal fashion to help them in decision making in a better and efficient way.

Data Collection/Survey

The feasibility of mobile applications for collecting health data or survey information has been proven in many developing countries including India [11], Ghana [14], and Uganda [15]. SATELLIFE PDA [14] demonstrated the viability of PDAs by successfully addressing the digital divide among healthcare workers and professionals in Ghana. HealthNet Uganda [15] incorporates PDAs to grant practitioners to access vital information in real time. PDAs have also been used in replacing paper based questionnaire in the context of HIV/AIDS programs in Angola [16]. 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. 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.

Telemedicine

Telemedicine is the other major area where computing technology proved to be crucial. Several projects like WiLDNet [21], Asynchronous Remote Medical Consultation [11], iPath [20] aim to connect physicians from urban areas or foreign countries to patients residing in rural areas. Telemedicine is especially useful in regions where transportation infrastructure is poor but the network infrastructure is capable of performing real time media connections in a cheaper way. Though we are using the mobile data networks we are only sending 10 bytes of information rather than using costly data network.

Current literature review shows that mobile applications intended to help cancer patients of developing world is yet to be implemented. Along with that, our paper is fundamentally different from the above-mentioned 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 field study has been analyzed minutely to accrue primary elements of interface design. In contrast to other projects the primary user of AutoCare is the patients. We have exploited the data network of mobile carrier to reduce the huge burden of regular communication from remote villages to health care centers. As this data collection is done from home we would be able to collect data on a daily basis which will help us to develop a sequential parametric database for each patient. Graphical representation of these data would help the doctors to make better decision that they failed to make so far for lack of information.

9. Conclusion

Mobile technology can play a big role in improving the health care services for developing countries. Here we have proposed the high level architecture of AutoCare and design and implementation details of e-ESAS. The features and design principals of the proposed system have been accrued by conducting thorough filed study in rural Bangladesh. The field studies also helped in understanding the psychology of the target users and their acceptance to mobile and sensor technology which is a ‘must do’ precondition for any application project to be a success. Along with that we have showed the design and deployment of initial version of e-ESAS. In future we will accommodate the user feedbacks of the system. We will evaluate the user perception based on easiness, comfort of use, impact of the system etc. Based on the success of the project we plan to implement electronic version of ESAS in cheaper cell phones. We believe the overall system will be able to bridge the information gap between patients and doctors and ultimately improve the quality of life of rural patients in Bangladesh.

10. Acknowledgements

We thank the doctors, health workers, and patients of AGBC for their participation and valuable suggestions with this project. This work was supported by grant from International Breast Cancer Research Foundation.

References

[1] Bangladesh Bureau of Statistics. (2008).Ministry of Planning. Statistical Yearbook of Bangladesh, 2007.
[2] http://english.ohmynews.com/articleview/article_view.asp?menu=c10400&no=335342&rel_no=1
[3] http://english.peopledaily.com.cn/90001/90782/6521649.html
[4] http://www.whoban.org/LinkFiles/Publication_Cancer_Strategy.pdf.pdf
[5] http://www.npcrc.org/usr_doc/adhoc/painsymptom/Brief%20Fatigue%20Inventory.pdf
[6] http://www.ncbi.nlm.nih.gov/pubmed/9599351
[7] DeRenzi, B., Lesh, N., Parikh, T., Sims, C., Mitchell, M., Maokola, W., Chemba, M., Hamisi, Y., Schellenbe, D., Borriello,G. e-IMCI: Improving Pediatric Health Care in Low-Income Countries. In *Proc. CHI '08*,(2008)
[8] Klasnja, P., Hartzler, A.C., Unruh, K.T., Pratt,W. Blowing in the Wind: Unanchored Patient Information Work during Cancer Care. In *Proc. CHI '10*,(2010)
[9] M. Skeels, M.M., Unruh,K.T. Powell, C., Pratt, W. Catalyzing Social Support for Breast Cancer Patients . In *Proc. CHI '08*,(2008)
[10]http://www.empainline.org/linked_site_content/pdf/Edmonton%20Functionl%20Assess%20System.pdf
[11] Luk R., Ho M., and Aoki M. P. Asynchronous remote medical consultation for Ghana. In *Proc. CHI '08*, 743-752, (2008).
[12] Peters, D., Kohli, M., Mascarenhas, M. Can computers improve patient care by primary health care workers in India? *International Journal for Quality Health Care*. 2005 18 (6): 435-445.
[13] Mitchell, M., Lesh, N., Crammer, H., Fraser, H., Haivas, I. Wolf, K. Improving Care – Improving Access: The Use of Electronic Decision Support with AIDS patients in South Africa. *International Journal of Healthcare Technology and Management.* In process.
[14] http://www.bridges.org/case_studies/351
[15] http://www.healthnet.org/hnuganda.php
[16] Cheng, K.G., Ernesto, F., Truong, K.N. Participant and Interviewer Attitudes toward Handheld Computers in the Context of HIV/AIDS Programs in Sub-Saharan Africa. In *Proc. CHI '08*,(2008) 763-766.
[17] Hayes, G.R., Abowd, G.D., Davis, J.S., Blount, M.L., Ebling, M., Mynatt, E.D. Opportunities for Pervasive Computing in Chronic Cancer Care. In *Proc. Pervasive Computing '08*, (2008).
[18] Frost, J., Smith, B. Visualizing health: Imagery in diabetes education. In *Proc. DUX '03*, (2003).
[19] Mamykina, L., Mynatt, E., Davidson, P., Greenblatt, D. MAHI: investigation of social scaffolding for reflective thinking in diabetes management. In *Proc. CHI '08*, (2008).
[20] Brauchli, K., O'Mahony, D., Banach, L., Oberholzer, M. iPath – A Telemedicine Platform to Support Health Providers in Low Resource Settings. J. IT in Healthcare 3, 4 (2005), 227-235.
[21] Patra, R., Nedevschi, S., Surana, S., Sheth, A., Subramanian, L., Brewer, E. WiLDNet: Design and Implementation of High Performance WiFi Based Long Distance Networks. *USENIX NSDI* (2007).
[22]http://www.btrc.gov.bd/newsandevents/mobile_phone_subscribers/mobile_phone_subscribers_june_2011.php
[23]http://www.nationmaster.com/graph/hea_hos_bed_per_1000_peo-beds-per-1-000-people