Delivery of multilingual mHealth service for control of TB/HIV in developing countries

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Abstract

A large number of people living with Tuberculosis/HIV fail treatment and develop resistance to drugs as they fail to maintain proper drug adherence. With the growing crisis of inadequate healthcare workforce in developing countries, mHealth services (healthcare using mobile communication technologies) are gaining support as an effective tool to handle the situation, especially where technological and human resources are limited. This paper illustrates the delivery of one such service where a simple and inexpensive SMS-based mHealth application can be used to assist in TB/HIV treatment.

1. Introduction

Tuberculosis (TB) is a potentially life threatening but curable disease which affects one third of the world’s total population, primarily in developing countries. Global annual incidence of TB is estimated at 9.1 million cases, out of which 1.9 million cases, i.e. nearly one-fifth the global incidence, are from India [1]. Controlling TB in India is a challenge due to the shortage of human resources in the overburdened healthcare system [2]. This disease also affects economic development of the country, incurring US $3 billion in indirect costs and US $300 million in direct costs [3]. Further complications arise due to the emergence and spread of drug resistant TB and also Human Immunodeficiency Virus (HIV) co-infection.

On the other hand, due to the meteoric rise in the usage of mobile phones, even amongst the rural population, outreach to patients and access to information has never been easier. According to Telecom Regulatory Authority of India (TRAI), by the end of March 2010 there were 584.32 million mobile phone users in the country (TRAI, 2010). To overcome the shortage of healthcare workers and improve the access to health care, mobile phones can be of great value for remote monitoring and information dissemination.

E-Health is the delivery or facilitation of health services and information through the Internet, telecommunications and related technologies [4]. e-Health is concerned with the application of Information and Communication Technologies (ICT) in healthcare. e-Health can play a vital role in extending healthcare to remote populations in the world where human resources are lacking, utilizing the rapid proliferation of mobile phones (World Health Organisation, 2005). With mobile (including satellite) technologies, healthcare and services can even be provided in remote settings where conventional telecommunication networks are either not available or have been disrupted.

Mobile Health (mHealth) is a component of eHealth. WHO Global Observatory of eHealth defines mHealth as medical and public health practice supported by mobile devices such as mobile phones, monitoring devices, personal digital assistants (PDAs) and other wireless devices [5]. With the global proliferation of mobile phone services, it is now possible to develop and deploy mHealth services for reaching healthcare particularly in developing countries [6]. The world of information technology (IT) is now moving towards the concept of Software as a Service (SaaS) and Service Oriented Architecture (SOA) that defines IT services (including mHealth) as a service rather than a product.

This paper will explore one such service where a simple and inexpensive multilingual mHealth application can be used to facilitate TB/HIV treatment. The system will primarily use the Short Message Service (SMS) facility available in nearly all mobile phones and can be used in resource limited settings as it is cost effective. The rest of the paper is organized as follows. The background information and motivation to develop the mHealth system is provided in section 2. In section 3 we discuss the potential of mHealth in improving healthcare systems. In section 4 the methodology
used to develop the project is discussed. In section 5 we discuss the service design. In section 6 we discuss the service implementation and analysis techniques. In section 7, we discuss the limitations and generalizability of the service and section 8 concludes with a summary and future work.

2. Background

India has the highest number of TB cases in the world, with 1.98 million new cases of TB and 2,76,000 tuberculosis deaths occurring in 2008, and accounts for 20% or one fifth of the total TB cases worldwide [7]. Also, India has an estimated 2.3 million HIV infected patients, which makes it the third highest HIV burdened country in the world. As TB is the most opportunistic infection in people living with HIV, there is a high risk of the TB epidemic worsening unless treated early. Without HIV, the lifetime risk of developing TB in TB-infected people is 10%, compared to at least 50% in HIV co-infected. TB also accelerates the progression of AIDS and reduces the survival chance of patients with HIV infection. TB in HIV-infected persons is also a transmission risk to non-HIV affected persons and can accelerate the TB epidemic. [8]

India has currently adopted the highly successful Directly Observed Treatment Short-Course (D.O.T.S.) to tackle TB in the country and even though it is proven effective, it is complicated by several factors like shortage of healthcare workers to monitor the large number of patients, drug adherence and social stigma. D.O.T.S. requires the patients to be regularly monitored and their treatments to be supervised by either health workers or any person willing to take the responsibility to do so. Due to the large number of TB patients and shortage of healthcare workers, individual supervision often becomes cumbersome. This situation is further worsened by the social stigma associated with the disease where it is often considered as a ‘death penalty’, a ‘dirty disease’ or ‘only affecting the guilty’ [9]. Despite the benefits of D.O.T.S. therapy, the rigid supervision of treatment may also increase the stigma associated with the disease, as it implies distrust of the patient. Patients often isolate themselves to avoid infecting others and to avoid uncomfortable situations such as being shunned or becoming the subject of gossip. [10]

Inspired by the growth of mobile communication technologies, global health policy-makers and providers are strengthening mHealth as a new tool to tackle the global crisis in inadequate workforce and patient monitoring. [11] Also, mHealth in the follow up and management of TB/HIV patients can provide a secondary benefit in addressing the issue of stigma by avoiding face to face contact [12], and as a result better results of the treatment can be expected. The massive penetration of mobile phone networks, especially in developing countries, (i.e., about 4 billion people have mobile phones) potentially enhances access to ubiquitous healthcare services. This is an encouraging sign for the use of mHealth with mobile phone networks as a cost-effective alternative to the more traditional Web based eHealth applications to facilitate the TB/HIV treatment.

The Asia-Pacific ubiquitous Healthcare research Centre (APuHC-www.apuhc.unsw.edu.au) at the University of New South Wales, Australia has been leading an evidence-based study on the Assessment of eHealth for Health Care Delivery (eHCD) for WHO since 2006 in a number of Asia Pacific countries including India and China.

3. Potential use of m-Health

m-Health describes the application of mobile telecommunication and multimedia technologies in mobile and wireless health care delivery systems [13]. Broadly, it involves using wireless technologies to transmit and enable various data contents and services which are easily accessible through mobile devices such as mobile phones, smart phones, PDAs, laptops and tablet PCs. [14]

In many developing countries, health services are often inadequate as they are generally neither accessible nor cost-effective. The situation is worse due to a major shortage in health work force to handle large populations [13]. Even when health services are available, they are mostly of poor quality and do not cater to the actual needs of the patients [15]. Table 1 reflects the poor quality of healthcare available to people in developing countries [16].

On the other hand, 70% of the population have access to mobile phones [17] and the numbers are growing extremely fast. Indeed, mobile phones, as an ICT platform, have far greater penetration than computers, and are potentially capable of meeting the health needs of patients. The exponential growth in mobile phone usage in the country is reflected in Figure 1. [17]

A recent study by WHO Global observatory on eHealth states that nearly 83% of the WHO member states reported offering at least one type of mHealth services and most of these projects are in the pilot or informal stage [2]. These programs are gaining strong support across regions as well as from different stakeholders like technology providers, government and academia. Different
types of mHealth services are in practice, which include text (SMS) & video contents and voice (medical call centres) service.

Table 1 - Health indicators of countries

<table>
<thead>
<tr>
<th>Countries</th>
<th>Infant Mortality rate (per 1000) in 2006</th>
<th>Maternal Mortality (per 100000) in 2005</th>
<th>Years of Life lost due to communicable disease (%) in 2002</th>
<th>Births attended by skilled health personnel (%)</th>
<th>Hospital beds (per 10000)</th>
<th>Total Health workers (per 10000)</th>
</tr>
</thead>
</table>

Figure 1 - Growth in mobile phone users in India

TB patients in Thailand were given mobile phones so that healthcare workers could call these patients on a daily basis to remind them to take their medication. Medical compliance rates reached 90% due to the introduction of this remote monitoring application [18]. Such a system would be of great help in a country like India but due to a much larger patient base, SMS can be used to remind patients to take their medications instead of calling each patient individually.

4. Methodology

The mHealth Service Development in this project is based on the 8-stage iterative methodology [19], shown in Figure 2, which helps us gradually improve the design of software and service with time. For example, we can improve the contents and frequency of the messages substantially to motivate patients better.

Based on the 8-stage iterative methodology, stages 1 and 2 i.e. the initial requirements and benchmarking attributes for the system were framed and developed by APuHC, UNSW, Australia in collaboration with doctors and technical experts from Christian Medical College (CMC) Vellore, India and KINSPARC, Kalyani, India. The system development and planning involved communication between partners from both countries via email, phone and organized visits. The requirements were eventually found to be development of a multi lingual system to remind patients periodically to adhere to their medication. Also a gateway for easy communication between the patients and health workers needed to be created.

Stage 3, where the need of such a system is evaluated, involved carrying out surveys in one of the pilot locations. It was found that, out of all the families surveyed (n=50), 74% (n=37) of the families had access to a mobile phone. Also, when asked if they would find such a system useful, 74% (n=37) responded with yes, 8% (n=4) did not believe it would help, while 18% (n=9) were unsure.

Stage 4 and stage 5 required system design and implementation and are discussed in detail in sections 5 and 6 respectively.

Once the pilot period is complete, stage 7 will be carried out where user satisfaction will be assessed and based on the results, stage 8 (improving the system) will follow.

Stages 1-4 of this methodology are primarily design steps while stages 5-8 are primarily the management of service. Thus this model provides a way of integrating design and management functions of any service including health care. To ensure Total Quality Management (TQM) of this
system, House of Quality (HoQ) matrices (Figure 3) is used. [19]

Figure 3 - House of quality (HoQ) matrix

5. Design of m-Health service for TB treatment

The barriers to mHealth implementation in India include diverse population across the country and the multi-lingual set up. There are officially 14 languages in India, but in reality there are over 20 widely used languages and dialects. Most of the population, especially in rural areas have no exposure to English and hence any system that does not incorporate local languages will have difficulty in reaching out to the audience. The multilingual m-health system that has been developed addresses this issue.

The system has three main functions

i. Maintaining a database of TB Patients
ii. Sending out SMS reminding patients to take their medication
iii. Tracking responses from patients confirming drug adherence.

It also has the following auxiliary functions

iv. Send awareness and motivational messages to encourage patients and reduce stigma
v. Be a channel of remote communication between patient and health worker

i) Maintaining Patient database –

The patient database contains information relating to a particular TB patient. It contains personal details like name, age and sex and medical history relevant to the TB. The most important data items from the eHealth perspective will be the mobile number of the patient and the preferred language of communication. With this information all future interactions with the patient are carried out in the specified language whenever possible. The database also contains the medication schedule of the patient.

ii) Sending reminder SMS –

One of the major problems related to TB treatment is drug adherence. TB medication is known to cause many side-effects which include nausea, vomiting, dizziness, etc. Therefore once the patients start feeling a little better, they assume that the drugs are no longer needed and stop taking their medication. This is dangerous as the chances of relapse increase amongst these patients and there is a high risk of the TB bacteria developing resistance to primary medication, making it much more difficult and expensive to treat later on. This problem can easily be avoided if the patients understand the risks and follow their drug regime rigorously.

The purpose of this module is to assist the patients in following their drug regime by sending timely medication reminders in their language of preference. Even though D.O.T.S. requires health workers to visit patients and supervise each dose, sometimes it is difficult to do so due to the disproportionate health worker-patient ratio. There might be cases where the health worker taking care of a particular group of patients becomes unwell or the patient is out of station. In either case, it is essential that medication continues and the SMS reminders aid in doing so.

Depending on the medication schedule of the patient, the system retrieves reminder messages from the message database in the patient’s preferred language of communication and sends the SMS to the patient through a mobile gateway (e.g. FrontlineSMS) reminding them to take their medication. The flow of the SMS system is given in Figure 4.

Figure 4 - SMS flow to patients

iii) Tracking drug adherence response from patients –
Once the reminders are sent, the system looks for responses from the patients for the rest of the day. The system maintains a daily list of all the patients to whom the reminder messages are sent and they are taken off the list the moment a positive response is received. At the end of the day, a list of patients who have not responded to the reminder along with the patients' phone numbers are reported to a health worker. Health workers call these patients on their phone to find out the patients' problems and why they did not respond to the message. If the patient fails to respond regularly or does not respond to the phone calls, the health workers visit the patient personally to sort out the issue and encourage the patient to follow the drug routine. Figure 5 shows the flow of the reminder service.

This allows the health workers to monitor drug adherence amongst patients regularly and helps them assist the patients in maintaining their drug routine with timely action. It also lets them target their focus on individual patients who resist following the regime and are more susceptible to relapse. In the long run, the drug adherence information collected based on region can help the healthcare agencies distribute health workers better.

iv) Sending out motivational and awareness messages –

From time to time, awareness and motivational messages in the patient’s preferred language are sent with the hope of educating the patients about their disease and removing the stigma associated with it. Once the patients understand the disease better and are aware of the facts related to their disease, they are able to face society with greater confidence. Figure 4 shows the flow of the SMS system.

v) Channel for remote communication between patient and health worker-

Often patients are not confident of speaking about their problems face to face with the health workers due to their inhibitions regarding the disease. This system allows the patients to SMS their queries or problems to the health workers who in turn can reply to the messages in the preferred language. Additionally, patients can also call the health workers if required and vice versa. A screenshot of communication in local languages using this system is shown in Figure 6.

Once the system design was in place, the software was developed in India.

<table>
<thead>
<tr>
<th>Time</th>
<th>From</th>
<th>Message</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00</td>
<td>12345</td>
<td>Have you taken your medicine today?</td>
</tr>
<tr>
<td>12:30</td>
<td>67890</td>
<td>क्या आपने आयुर्वेद की दवाएं लिया हैं?</td>
</tr>
</tbody>
</table>
| 14:45 | 11223344 | कृपया आयुर्वेद की दवाएं लिया हैं?

Figure 6 - Screenshot of multilingual mHealth communication system

6. Service Implementation

Initially a randomised, controlled clinical trial of m-Health intervention is conducted to improve TB control in two study sites, Kalyani, West Bengal where the primary language of communication is Bengali and Vellore in Tamil Nadu where the primary language is Tamil. People with active TB are randomly allocated to receive standard care, which comprises Directly Observed Therapy, Short Course (D.O.T.S.), or D.O.T.S. plus a m-Health initiative to assist with TB management. D.O.T.S. involves the direct administration of medication by a health worker to the patient, who then observes the patient swallowing the pills. This ensures adherence with treatment.

Officers in charge at the D.O.T.S. centres, who have been informed about the study, are requested to provide necessary information about newly detected TB cases to the investigation team. On receiving patient details, a study investigator will talk to the patients about the study design and explain to the participants the risks and benefits of participating in the trial in their local language (Bengali and Tamil). If they consent to participate, they are administered informed consent (translated in local languages, Bengali and Tamil) and asked to sign the same.

This randomized, controlled clinical trial aims to evaluate the efficacy of an m-Health initiative, not in place of face to face care, but as an additional access point to improve control of TB. Our pilot data show that often patients, faced with long travel times and difficulties of access to care, may default
from treatment. If an alternative were available, such as access to advice by mobile phone, this may improve treatment outcomes. At the end of the trials, the following outcomes will be measured –

- Treatment completion and cure rates (as defined by W.H.O)
- Treatment adherence rates
- Adverse drug reaction rates
- Stigma associated with TB
- Patient satisfaction
- Usage of the m-health initiative

7. Discussion

Limitations - The project is still in its nascent stage and has a few limitations. The only languages supported currently in the trials are Bengali and Tamil even though there might be a few patients who cannot read either. Of course once the program is implemented in a larger scale, any number of languages can be incorporated. Another limitation is that some phones do not support messages in all languages. Alternatives like sending picture and audio messages are being explored to support such phones in the future. In the current study, the patients in both cases are placed in the group which receives standard D.O.T.S. treatment without SMS reminders.

Generalizability - The primary purpose of this service is to develop a channel of communication between patients and health workers and therefore does not have to be limited to only TB/HIV treatment. It can be applied to tackle almost any illness where a strict or long term drug regime is prescribed e.g. chronic diseases like diabetes, high blood pressure, etc. Similarly, a low cost service can also be developed to assist in clinical trials where it can help patients remember their medication schedule and also provide an alternate channel of communication between clinics and patients where the patients can ask questions, report problems and drug reactions, etc. It will be interesting to carry out future studies on the efficacy of this service in controlling diseases in different environments.

8. Conclusion and future work

In this paper we have discussed the delivery and evaluation of a low cost multilingual SMS service to monitor TB/HIV patients in developing countries, with special focus on India where TB is most rampant. The system works on a widely and cheaply available technology i.e. mobile phones with SMS facility and is extremely user-friendly with minimal training required for operation. Two locations in India have been selected for the pilot study, Vellore, Tamil Nadu and Kalyani, India. These two locations have very different cultures and languages. On completion of the pilot study, we shall determine the success by taking into account factors like drug adherence, cure rates etc. Surveys will also be conducted to determine patient satisfaction and possible improvements to the system.

Once the first round of trials are completed, data will be collected and entered into SPSS and bivariate and multivariate analysis will be carried out to examine the relationship between treatment delay, perceived stigma, patient satisfaction and adherence to treatment. Usage of the e-health initiative will also be measured in the intervention arm and analysed to determine characteristics and clinical features of high versus low users of the telephone line.

Focus groups will be analysed qualitatively to examine the successes, barriers and other issues around the use of the e-health initiative. The cost-effectiveness of e-health in TB control will be studied and the cost-effectiveness of the e-health intervention compared to standard treatment will be calculated using sensitivity analyses to determine the key drivers of cost-effectiveness. Surveys will also be carried out to receive feedback from the primary users of the system, the patients and health workers, to assess their level of satisfaction.

Based on all the data and user feedback, modifications and changes will be incorporated into the system.

This study will later be extended to other Asia-Pacific countries as part of the global mHealth study.

9. References