The Case for SmartTrack

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***Abstract*—Nearly 40 million people in Africa suffer from HIV/AIDS. African governments and international aid agencies have been working to combat this epidemic by vigorously promoting Highly Active Anti-Retroviral Therapy (HAART) programs. Despite the enormous subsidies offered by governments along with free Anti-RetroViral (ARV) drugs supplied by agencies, the introduction and implementation of HAART programs on a large scale has been limited by two fundamental problems: (a) lack of adherence to the ARV therapy regimen; (b) lack of accountability in drug distribution due to theft, corruption and counterfeit medication.**

In this paper, we motivate the case for SmartTrack, a telehealth project which aims to address these two problems facing HAART programs. The goal of SmartTrack is to create a highly reliable, secure and ultra low-cost cellphone-based distributed drug information system that can be used for tracking the flow and consumption of ARV drugs in HAART programs. In this paper, we assess the potential benefit of SmartTrack using a detailed needs-assessment study performed in Ghana, using interviews with 516 HIV-positive rural patients in a number of locations across the country. We find that a system like SmartTrack would immensely benefit both patients and healthcare providers, and can ultimately lead to improved patient outcomes and better accountability.

***Index Terms*—SmartTrack, telehealth, drug tracking, drug monitoring, patient adherence**

I. Introduction

According to the World Health Organization, effective HIV/AIDS care requires antiretroviral therapy (ART) [1] as a treatment method. Without access to antiretroviral therapy, people living with HIV/AIDS cannot attain the fullest possible physical and mental health and cannot play their fullest role as actors in the fight against the epidemic, because their life expectancy will be too short. While ART is commonplace in developed countries, these life saving medications have reached only a small percentage of the more than 40 million Africans infected with HIV or suffering from AIDS [2]. In order to be successful in combating this deadly disease, strict adherence to a highly active antiretroviral therapy (HAART) [3] program must be followed.

Despite the subsidies offered by pharmaceutical companies for expensive AIDS drugs, and the enormous effort of African governments to promote HAART programs, these initiatives have not been adopted on a wide-scale. The fundamental barriers to large-scale adoption are two-fold. The first problem is one of *lack of accountability* in the system, due to the theft of expensive ARV drugs, counterfeiting of drugs, and corruption. The Global Fund crisis that gripped much of Africa, with losses amounting to hundreds of millions of dollars was directly related to the lack of accountability in the system. In fact, many pharmaceutical companies that provide subsidized AIDS medications are demanding better accountability practices as a prerequisite to their continued participation.

The second serious problem relates to the *lack of patient adherence* to the medication regimen. A typical HAART program requires every patient to consume two to five medications per day; in addition, required medication and dosages may change rapidly based on the side effects observed by the patient. Lack of medical oversight, or inappropriate use of ARVs not only harms the health of patients but may also encourage drug-resistant strains of HIV, posing a substantial public health risk. Hence, to improve patient outcomes, it is essential for doctors to continuously observe the health status and the medication consumption regimen of patients. In fact, it is relatively common for doctors and health-workers to physically track patients who have not reported for regular medical visits.

In this paper, we motivate the case for SmartTrack, a project which aims to address these two fundamental problems with HAART programs. The vision of the SmartTrack project is to create a highly reliable, widely available and ultra low-cost cellphone-based distributed drug information system that can be used for tracking the flow and consumption of ARV drugs in HAART programs, ultimately leading to improved patient outcomes.

The motivation to use cellphones in SmartTrack to track the flow of AIDS drugs is in large part driven by the explosive growth in the adoption of low-cost cellphones in the rural developing world. For example, around 80% of Rwanda has cellphone coverage [4], [5] and the cost of cellphones is so low (less than $50) that the devices have become affordable by the poor [6]. Cellphones have enormous potential for enhancing rural healthcare, given their ability to act as a low-cost computing platform for distributed applications. The open-source movement in cellphone software [7], [8], [9] has also opened up the potential for a wide range of new applications targeting these low-cost devices.

The vision of SmartTrack is to enable patients, health-workers and doctors to use cellphones to record, track and transmit information about pharmacotherapy utilization. The idea is to tag every ARV drug bottle with a "smart" tag: an RFID or a barcode, that will enable patients to identify drugs easily and also enable them to report their drug consumption remotely using a cellphone. The drug information will be compiled on the device, sent to a central server, and stored at different levels (regional level, district level) to be used by the healthcare teams to tailor patient-specific therapies. In addition, the device will also be able to remind patient end-users about when to take their specific medications. Thus, SmartTrack will provide the patient with information about his or her specific regimen, and provide the care provider with information about patient compliance to the regimen.

SmartTrack is based upon eMedonline[1], a technology previously developed and patented by our partner, Leap of Faith Technologies, Inc. [10]. This technology leverages cellphones and RFID technology to optimize medication compliance, track medication usage and extend patient care to remote settings. The previous project has been successfully used in the US for tracking adverse events and improving compliance with oral antineoplastic (anti-cancer) therapy; efficacy is currently being demonstrated among cardiovascular disease populations.

A key requirement for the success of the SmartTrack is to first assess needs and user acceptability. In this paper, we describe our experiences in realizing this first important step in the SmartTrack project vision. We recently performed a detailed needs-assessment study, interacting with 516 AIDS patients in rural parts of Ghana to determine the potential role and effectiveness of cellphones in improving AIDS care delivery. To this end, we developed simple cellphone-based healthcare applications which we used as part of our study to understand user acceptability issues. Our study was conducted by medical students who interacted with each patient for over 30 minutes and used a translator (when language was an issue) to obtain answers to a detailed survey in combination with user interface testing. Based on our detailed patient study evaluations, we determined that a system like SmartTrack would immensely benefit both patients, healthworkers and doctors and can ultimately lead to improved patient outcomes and better accountability.

[1]developed by Leap of Faith Inc., with support from the National Cancer Institute (Contract No.HHSN261200644005C) and the National Institute on Aging (Grant No.2 R44 AG022271-02A1)

II. Motivation and Related efforts

The SmartTrack project vision is centered on three primary premises: (a) the need for better accountability in ARV drug distribution; (b) the need for improved patient adherence to medication regimen in HAART programs; (c) the utility of cellphones as a healthcare platform for monitoring the flow and consumption of drugs. In this section, we discuss these three aspects in more detail, along with the corresponding related efforts.

A. Maintaining Accountability in the Supply Chain

The first premise of SmartTrack builds on the position of the World Health Organization (WHO), which has argued for the need for a drug tracking system that can monitor the flow of medications from the supplier to the patient. The high cost of ARV drugs makes them an attractive target for theft. This is a particular threat in developing countries where corruption can be widespread and persistent. International HAART programs are not immune to theft, as was illustrated by the Global Fund scandal in Uganda in 2006; in that incident, an investigation revealed that "tens of millions" of dollars in grants intended for AIDS treatment were misspent by officials, often to finance lavish lifestyles [11]. Similar problems have also been reported in other recipient nations [11], and the widespread theft of medicine for resale has been exposed in a number of instances [12], [13].

Perhaps more disturbing than outright theft is the growing practice of replacing legitimate medication with counterfeit drugs. While it is difficult, if not impossible, to determine the actual scope of this problem, WHO has estimated that in parts of Africa, Asia and Latin America, over 30% of all drugs sold are counterfeit [14]. Consuming counterfeit medication can lead to drug resistance and death, and many counterfeits have been found to contain highly toxic substances.

In addition to the serious health consequences that can result from fake or stolen HAART drugs, the phenomenon could also lead to a loss of confidence in the health system as a whole. This threatens to undermine support for aid programs, as well as discourage patients from seeking out and adhering to treatment. A supply-chain management system that could track medicines from their acquisition point to the end user would be able to detect drug theft quickly, and would make it easier to discover sources of counterfeit drug substitution within the supply-chain. This added accountability could greatly improve the safety and effectiveness of HAART programs in developing countries.

B. Tracking Patient Adherence and Symptoms

Proper adherence to a HAART regimen is critical to prevent drug resistance and ensure survival [15]. However, HAART treatment requires multiple drugs, taken multiple times per day, and often results in unpleasant side effects. These difficulties, combined with the high cost of the drugs and the potential stigma of being identified as HIV+ can act as a deterrent to proper adherence. A number of studies have attempted to measure adherence rates in Sub-Saharan Africa, and they have produced promising numbers, with an average of 77% of participants reporting proper and consistent use of the medication [16]. However, these studies rely on unverified self-reporting, which has been demonstrated to exaggerate the level of compliance in studies conducted in developed countries.

Tracking adherence is especially difficult in developing regions, where lack of medical, transportation, and communication infrastructure can limit contact between patients and health-care workers [17]. For example, our study of HAART patients in Ghana found that more than 37% of participants went at least three months between clinic visits, that over 94% had never placed a phone call to their clinic, and that the same number had never received a phone call from their clinic. This lack of contact can make it very difficult for health workers to keep tabs on patient adherence and progress. Likewise, it can prevent patients from notifying health workers of critical symptom information that might require a trip to the clinic or a change in treatment.

A low-cost method of tracking medication, adherence, and symptoms in developing countries could provide great benefit to its users. By preventing fraud, it could save precious financial resources for providers, and ensure that medicine gets to those who most desperately need it. By tracking adherence and symptoms, it could improve the responsiveness of healthcare workers to the needs of patients, and ultimately improve and prolong the lives of those receiving HAART treatment.

C. Cellphones as a Healthcare Platform

In the past few years, several research and developmental efforts around the world have explored [18], [19], [20], [21] the use of cellphones as a potential tool for improving healthcare in both the developed and the developing world. For a detailed overview of globalization and health related issues, please refer to [22]. In developed nations, the problem of tracking medication compliance has been addressed successfully with smartphone-based telehealth tools [23]. Recent growth in cellphone penetration in developing regions has made mobile telehealth solutions a real possibility for users in less-developed nations. In Sub-Saharan Africa in 2006, the overall cellphone penetration level was estimated at 15%, and it has more than doubled in the last two years [4], [5]. Furthermore, certain countries, such as South Africa, have attained adoption rates of over 70% [24]. In our own study, conducted among HAART recipients in Ghana, we found that cellphone usage was quite high in the cities and relatively large even in rural areas: Nationwide, 54% of participants reported using cellphones, with more urbanized areas such as the Greater Accra (77%), Northern (67%) and Volta (57%) regions ranking higher in usage than rural areas, such as the Central region (29%), and Upper West (26%).

Several groups have examined the use of PDAs and cell phone-based tools to augment patient monitoring relative to ARV therapy, and to extend medical follow-up capabilities [17], [25], [26], [27], [18], [19], [20], [21]. One important project was led by Satellife [25], which tested the use of PDAs in healthcare environments in Ghana, Uganda, and Kenya. The project put PDAs into the hands of physicians, medical students and community volunteers in different settings in order to demonstrate their viability and usefulness, especially for the collection of health data and dissemination of medical information.

Bridges.org, a technology NGO, performed an independent evaluation of the Satellife PDA trial [28], in which it validated the use of handheld computers in healthcare environments in Africa. Specifically, it found handheld computers to be an appropriate technology for use in the African context, and concluded that they provide an inexpensive alternative to PCs in terms of computer power per dollar. The technology of Satellife was found to be simple to use and easily integrated into the daily routines of the healthcare professionals.

Cell-Life [29], [30], a research team at the University of Cape Town, has demonstrated the effectiveness of an information gathering system using cellphones for improving the health outcomes in ART. Their system leverages health workers to collect real-time information on HIV/AIDS along with the spatial infrastructural requirements (person, their environment, and access to basic amenities). Cell-Life has been deployed in South Africa and Zambia.

III. SmartTrack

The SmartTrack project was in part motivated by prior successful research and development by our partner, Leap of Faith Inc., of a cellphone-based telemonitoring system for improving medication adherence. This system, called eMedonline[2] uses smartphones equipped with RFID scanners to read smart-tags attached medicine bottles. The phone provides reminders to the patient, and the patient scans each bottle with the phone when taking that particular medication, updating a remote database and providing doctors with detailed information on regimen adherence. The system validated the integration of cellphones and radiofrequency identification (RFID) as a therapeutic solution to medication compliance and supply chain management. Feasibility and functional tests of the system in a sample of oncology patients demonstrated that drug and compliance-related data can be reliably collected, analyzed, and exported for use in other clinical monitoring systems. Patient acceptance and value of the system was very high.

Building on this prior success, the SmartTrack project vision aims to develop and deploy a cellphone-based telemedicine and supply-chain sytem that exploits this trend, with the twin goals of tracking the flow of drugs to the field, and of monitoring the status and adherence of HAART patients. In addition to tracking adherence, we also envision a system that acts as a reminder system, that allows users to record symptom information which can be tracked and analyzed by their doctor, and that allows health workers to contact patients. There are, however a number of limitations on the ground that prevent

[2]developed by Leap of Faith Inc., with support from the National Cancer Institute (Contract No.HHSN261200644005C), and with support from the National Institute on Aging (Grant No.2 R44 AG022271-02A1)

us from simply deploying a modified version of our existing system or equivalent in rural Africa.

- The prohibitive cost of smartphones: Smartphones are quite simply out of reach for most users in developing environments, so we must design a system for standard, low-end cellphones.
- Limited data communication infrastructure: We must rely on simple Short Message Service (SMS) protocols to communicate between the local client and the central database.
- Cost of communication: Every 160-byte message costs the patient money, so we must minimize the number of messages and be economical with data.
- Language: In our Ghana study, we found speakers of 11 different languages, many of whom required interpreters to conduct the interviews. Our system would have to accomodate all of them.
- Illiteracy: A great proportion of potential users are unable to read or write in any language, requiring us to develop a simple, non-textual interface.

Later, we describe our detailed needs-assessment user study based on interactions with HIV positive patients in Ghana that seeks answers to these specific questions. Based on our user study assessments, we feel that it is possible to design an appropriate and usable SmartTrack system that can be used by (potentially illiterate) users, health workers and doctors to improve accountability and patient adherence.

A. *SmartTrack Architecture*

Figure 1 illustrates the supply chain flow of drugs in SmartTrack. Drugs in the supply chain system flow through a hierarchy of suppliers, distributors and customers. In SmartTrack, we require a mechanism to track the flow of drugs at every level in the drug supply chain system.

The basic architecture of SmartTrack can be described as follows. Every drug bottle is tagged with a “smart” tag (RFID or barcode) which uniquely identifies a bottle. All the identities in the bottles should be generated by the supplier of the drugs. Each such identity should be generated from a secret key that makes it hard to generate new valid identities to primary deal with counterfeiting of bottles. The trusted central authority provides the medicines or drugs along with the tag (RFID or barcode) embedded in the bottle for tracking the flow of each drug. The *Tag* information of every item or supply is stored in the *central server*.

Each intermediary point in the supply chain is managed by an *Agent* who is equipped with a cellphone and a tag reader (barcode or RFID reader) . Upon receipt of any goods, the *Tag* information is captured by the corresponding agent in the supply chain, who stores the *Tag* information in the cell phone. The cellphone acts as the local-store at each supply chain point.

The *central server or Trusted authority* uses cellphones to remotely track the flow of goods. This type of remote authentication is possible by transferring the *Tag* information attached to the goods, from a cell phone to or from the *central*

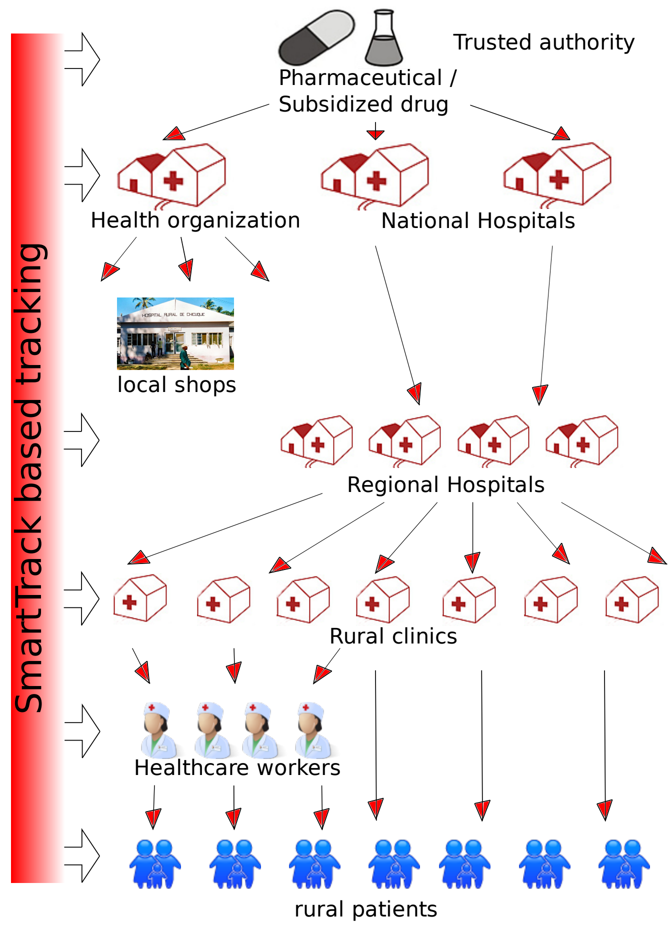

Fig. 1. A generic design of *tag* based supply chain management system. The *Trusted authority* provides the *Tag* along with drug bottles. The users at each point in the supply chain use the cell phone based tag reader to identify and authenticate drugs. *Trusted authority* can remotely track items at every node in the supply chain and check for fraud using the cell phone based system.

server using SMS/MMS or GPRS connectivity. To verify the authenticity of a tag, an agent has three options: *online, offline, batch* authentication. In online authentication, the agent signals the tag information to the central server using the cellular network and verifies the authenticity of the tag. In offline authentication, the agent prefetches the list of “admissible” tags from the server into its local-store and verifies each tag with the set of admissible tags. In batch authentication, the agent can assume that the goods are genuine and merely store the tag information in the cellphone locally. In this scenario, the agent can collect several tags and perform bulk verification in a lazy manner. An important benefit in this delayed batch verification is that it can significantly reduce the communication cost using cellphones and does not require immediate connectivity. In summary, this architecture represents a distributed data-store of cellphones, where each node maintains a local store of authorized signatures and nodes communicate with each other using cellular connectivity.

While what we have described is a basic overview of the

SmartTrack architecture, we need to address several technical research challenges to make SmartTrack into a *low-cost, secure, highly reliable* and *widely available* system. We briefly outline the basic technical ideas that we intend to use in SmartTrack to achieve these properties.

1) *Information aggregation:* Using an inbuilt network cost model, SmartTrack will intelligently aggregate multiple updates from a cell-phone and semantically compress (not standard compression) to the smallest number of messages possible to reduce transmission costs.
2) *Strong identity and secure updates:* To provide strong security properties, the system will leverage public-key and symmetric-key cryptographic operations to develop an unforgable identity for every cellphone and also provide the ability to verify the validity of individual updates using aggregate signatures.
3) *Privacy:* To provide privacy, the system will develop an anonymized indexing system that cannot be traced back to individual patients without appropriate information.
4) *Reliability and Availability:* the system increases availability without incurring additional operational cost by maintaining a detailed local data-store within every cellphone that contains most of the appropriate information required by the end-user (health-worker, doctor or patient). This local-store is constantly synchronized with the main information store either using aggregate updates or physical synchronization. To improve reliability, SmartTrack will intelligently replicate and partition critical information in the data store between the local server and the smart-phones.

While these technical issues are certainly important, a detailed discussion of them is outside the scope of this paper. The primary focus of this paper is to make the case for why rural users need a system like SmartTrack, and, if provided, will they actually use such a system. The rest of the paper will focus on answering these user-centric questions.

IV. Needs-Assessment User Study

When working on any "technology for development" project, two fundamental questions always arise: *the need for the technology* and *user acceptability of the technology*. Many projects in the development space have been successful in the beginning phase but have often not been adopted on a wide scale. It is this barrier that we wish to cross in SmartTrack. Hence, we began with the endeavor of performing a detailed needs-assessment study to answer the two questions about need and user acceptance: (a) Do rural users need a system like SmartTrack? (b) If provided with a system like SmartTrack, will they use it? Rather, how would one build SmartTrack to maximize user acceptance.

To address these questions, we began with the modest goal of designing a detailed survey covering a wide-range of questions. We also designed two simple user-interfaces as part of this study:

Smartphone based system: We tailored our smartphone based telehealth system for cancer patients into a system for AIDS patients. This system used a voice and text interface to prompt users to respond to various questions. In addition, the system used RFID tag identification which we did not use in our study. We used a HTC P6300 phone for this implementation.

Cellphone based system: As a comparison point, we developed an alternative implementation using JavaME [31] on Nokia 3110 phones that used a text-free pictogram based user interface of specific healthcare symbols to primarily understand whether the end-user population would be conversant with a pictogram-based interface.

A. Methodology

The user study for SmartTrack was performed at several sites across Ghana. To perform the study, we developed a survey tool that was administered to cohorts of HIV+ patients in each location. The cohorts were patients affiliated with either the West Africa AIDS Foundation (WAAF) [32] or Korle Bu Teaching Hospital. Participants were referred to us by these organizations, and we did not attempt to implement a randomized study. The ages reported by patients ranged from 17 to 101, and 73.3% of the patients were female, 26.7% male. 77.3% of patients were currently receiving ARV therapy.

We interviewed 516 HIV+ patients with a survey consisting of 72 questions divided into eight categories:

1) Laboratory values: CD4 count, viral load and WHO HIV stage (taken from blood tests/patient records).
2) Demographics: Age, housing, occupation, education, language skills, access to water and electricity (11 questions).
3) Health Care Access: Health practices, frequency of medical care, frequency of contact with health worker, distance to the hospital (9 questions).
4) Symptoms: HIV-related symptoms, typical response to certain symptoms, and histories of other conditions like tuberculosis or malaria (11 questions).
5) Medications: Medications being taken, adherence to regimen, acquisition of drugs (10 questions).
6) Narrative Text: Difficulties of the disease, difficulties of treatment, perceived effectiveness of treatment (9 questions).
7) Mobile Phone Usage: Access to mobile phone, usage habits, amounts paid for service and hardware (20 questions).
8) Patient Education: What is the patient's primary source of health information (1 question)?

The patients gender and use of a translator were not asked directly, but were recorded. When necessary the aid of a translator was enlisted.

278 patients were interviewed via healthcare associations for patients living with HIV, coordinated through WAAF. Researchers traveled to five cities in four different regions of Ghana to interview a total of six cohorts of patients: Volta Region (Ho), Central Region (Cape Coast), Northern Region (Tamale), Upper West Region (Wa and Lawra). Blood draws to be used for CD4 counts were provided free-of-charge by

WAAF in these locations. After having their blood drawn, the patients were asked to participate in the survey. Before beginning the survey, patients gave verbal consent.

A further 238 outpatients at Korle Bu Hospital Fevers Unit were interviewed. The patients had come to the hospital to refill medication or to draw blood for CD4 T lymphocyte count. At that time, patients who were willing to participate were required to give written consent. The written consent forms were collected by Korle Bu Hospital staff to be included in the patients chart, and will not be published or disclosed in this or any other report to maintain patient confidentiality. The HIV+ patient population at Korle Bu Hospital was separated into groups of those taking ARV therapy, and those that had not yet started ARV therapy. Only patients who were currently taking ARV therapy were interviewed as their experiences are more relevant to the study.

Adjustments were made to the survey and methods during the course of the study. The survey itself was edited after the first two administration sessions in order to more effectively elicit the target information. Several questions were altered, discarded, or added. The changes have been recorded and will be taken into account. The overwhelming majority of patients were interviewed individually. In certain situations however, there were time constraints and patients were interviewed in pairs. In these situations each patient answered individually.

V. User Study

In this section we present the results of our user study and observations made while interviewing 516 HIV+ patients in Ghana.

A. Literacy & Education

Illiteracy is one of the most serious challenges facing the developing world, and is particularly severe in rural areas. We gave participants a number of questions designed to gauge the level of literacy and education within our population. Questions we asked included: i) what languages does the participant speak? ii) in which languages is the participant able to read or write? iii) what is the participant's highest level of education?

We found that 55.6% of interviewees in urban areas, and 60% in rural areas needed a translator for our interviews. Interviews were conducted in English, which is also the official language of Ghana. Additionally, our survey showed that urban areas tend to have higher literacy rates than rural regions. Figure 3 shows the distribution of educational attainment among patients, and Figure 4 shows the percentages of patients able to read or write in each of the locally-used languages. Notably, at least 35% of patients had never attended school of any kind, and only 46% reported being able to read English.

This high rate of illiteracy, particularly when combined with the lack of a common language among patients, presents a fundamental challenge to the deployment and acceptance of any telemedicine application. In order for SmartTrack to be effective, it must be operable by a patient with no reading skills whatsoever. Either a voice-based or a pictogram-based solution might solve the literacy problem, though the voice-based UI would not solve the multiple language problem, and would have the additional drawbacks of lack-of-privacy, in addition to feasibility and cost problems when using low-cost phones with expensive network access.

To this end, we are exploring pictogram interfaces for this application. We developed a demonstration interface for our Ghanaian study in order to test our ability to convey healthcare-related concepts through graphical symbols. Although extremely preliminary, this demonstration was well-received by users and showed promise for expressing health concepts. Using simple pictograms, combined with shape or color symbols to represent different medications, it should be possible to make an effective interface that is usable despite barriers of literacy and language.

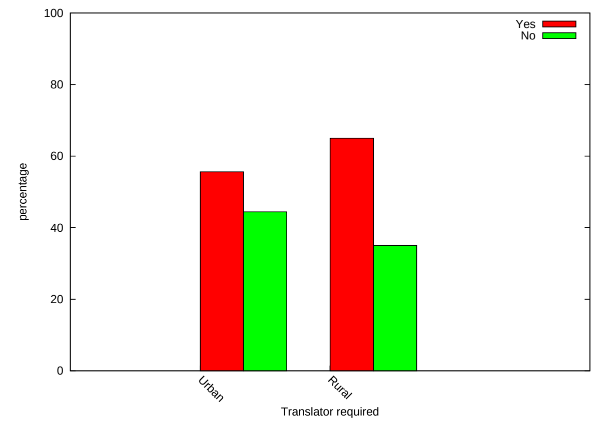

Fig. 2. Percentage of patients requiring translators, with urban compared to rural

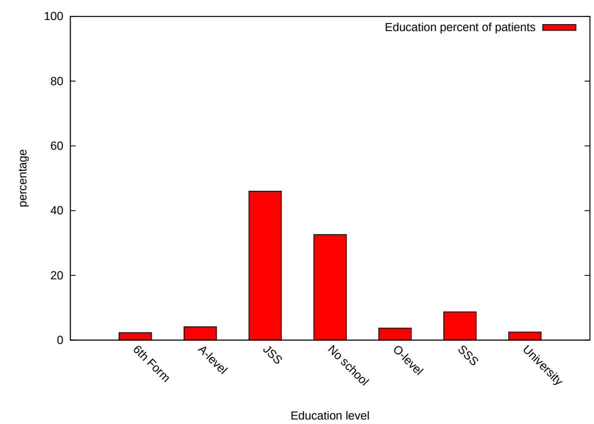

Fig. 3. Maximum education level

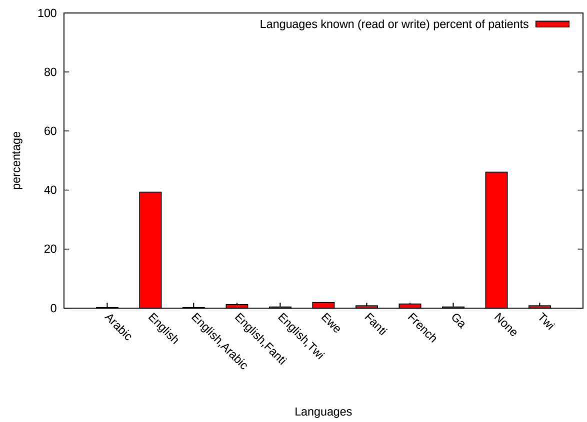

Fig. 4. Percentage of patients able to read or write, by language

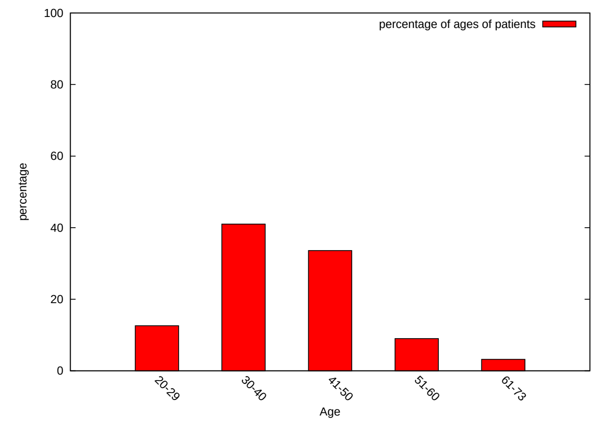

Fig. 5. Age distribution of participants

B. Age and Sex

A patient's age is an important factor in determining proper medical care, and age statistics can offer some insight into the impact of AIDS on the society at large. Figure 5 shows the age distribution of the patients, and illustrates the disproportionate number of people seeking treatment who are in the 30 to 50 year-old range, with over 69% of patients falling within that group. For so many people in the prime of their work and family lives to be stricken can only have devastating effects on a society. The lost productivity of working-aged people slows the economic development of an already-depressed region, and the death or debilitation of so many parents will have social ramifications we have barely begun to understand [33].

Improving adherence can prolong lives and improve the quality of those lives. In addition to the direct and obvious benefit to the patient, this can also have the wider benefit of allowing the patient to be more productive economically, and to play a greater role in the lives of family and the community.

Interestingly, 73% of patients were female. While it is estimated that almost 61% of HIV+ people in Sub-Saharan Africa are female[34], it is not clear if our higher number reflects the actual proportion of women with HIV in Ghana, or if it is a result of our non-random selection process. It is even conceivable to us that it is a result of the self-selection process of people seeking HIV treatment or getting diagnosis. [34]

C. Economic and social issues

It is impossible to divorce the problem of medical treatment in the developing world from the economic environment in which the patients live. The cost of care is only the most obvious element. The patient also must contend with the expense of travel to distant clinics, and the cost of missed work during time spend traveling. The frequent lack of electricity, clean water, and safe, sanitary conditions makes staying healthy even more difficult.

To better understand the economic situation of our population, we asked a number of questions pertaining to their basic employment, income, and living conditions. The following are some selected findings:

- Type of house: 58.3% lived in a compound house, 24.4% in a self-contained house and 16.3% in a rented house. The rest were either homeless or lived in mud huts.
- Water source: 75.6% used piped water and 15% used well-water.
- Electricity: 26% did not have reliable access to electricity.
- Refrigeration: 56% lacked any sort of refrigeration.
- Occupation: The most common job categories reported by patients were petty trading(34.7%), service work(23.1%) and agriculture(12.6%).

To live in such a setting can be challenging enough for a healthy person, but for an HIV+ person, the difficulty is multiplied. People with AIDS can experience weakness and any number of other symptoms that interfere with their ability to work and earn money. Of our study participants, 64% responded that AIDS has a considerable effect on their ability to work, and 60% reported missing work as a result of HIV symptoms.

Social stigma for those with HIV has been reported to be a serious issue in many cultures, particularly in parts of Africa, but interestingly, 61.5% of our participants said that they did not have any social problems due to AIDS. If true, this is wonderful news, but we suspect the response does not tell the whole story. One possibility is that patients were hesitant to admit that they had experienced such discrimination. Another is that they had not experienced discrimination because they had successfully hidden the fact that they had HIV.

All of these details bring home a key point: Any designer of a telehealth system for the developing world must be keenly aware of the tenuous existence its users may lead. Costs must be kept to a bare minimum, as the pennies charged even to send simple SMS messages may accumulate to become a serious burden. On the other hand, such systems also provide the opportunity to ease burdens by reducing the amount of travel required to see doctors, or by increasing the ease and affordability of communication with clinics. Furthermore, by helping to manage difficult medication regimens, a system like SmartTrack can improve the patient's health and boost his or her ability to cope in a challenging world.

1) Regimen Compliance: Following a strict medication regimen for HAART treatment is essential for survival. To evaluate the current state of adherence among our population, we asked about frequency of missed doses, reminder methods for medications, and patient action upon missing a dose. 90% of patients admitted to frequently missing dosages, a disturbing figure given the risks associated with drug resistance against ARVs. 75% of the patients of did not use any kind of external reminders, relying on habit alone to take their pills at the scheduled time. In the case of a missed dose, 70% reported taking their pills when they remember.

Findings like these boldly underline the need for better adherence management. Cellphone-based tracking tools have the potential both to serve as reminder systems, and to alert doctors to problems with compliance before they result in tragic consequences.

2) Response to drugs: In addition to adherence questions, patients were asked about their perceived response to and tolerance of ARV treatment, and their plans for future treatment.

- 81.8% said that they felt much better after starting ARV medication.
- 98% said that the medication was controlling their HIV symptoms.
- 96% said that they had plans of continuing medication.

Clearly, patients are happy with the results of treatment, and participants also expressed interest in a cellphone-based reminder system for taking medications, if one were made available to them. Perhaps with the right tools, patients would be better able to manage their ARV treatments and achieve better outcomes.

D. Mobile phone usage

We asked a number of mobile-telephone-related questions to better understand cellphone usage among the study population and gauge the potential for telehealth applications using mobile phones.

- Usage of cellphones: 54% of patients use cellphones and the division of cellphone usage across various regions are as follows: Greater Accra (77%), Northern Accra (67%) and Volta(57%), which are urban areas rank higher than Central region(29%) and Upper West(26%), which are rural regions. In other uses of cellphones, only a small percentage of people used cellphones for playing games and listening to music. 82% of users used cellphones as alarms.
- Would a cellphone reminder be useful? 91% said that it might be helpful in maintaining their HAART regimens.
- Sharing of phones: About 80% of patients who use cellphones have their own phone and 16% share their phone with family and friends. 70% felt that a shared cellphone would still be useful for a healthcare application.
- Frequency of calls & text messages: 75% make more than one call a day. 22% receive text messages daily and 18% send text messages daily.
- Cost: 45% of users spend less than $50 on their cellphone handsets, and 69% spend less than $20 per month on cellphone services.

Disease/symptom	% of patients	% of doctor visits
Tuberculosis	84	-
Malaria	98.8	-
rashes/lesions	52.7	85
weight loss	60	85
pain while swallowing	26	81.2
weakness	60	79.4
stiffness,tickling,numbness	41	-
Diarrhea	34	85
shortness of breath	28.5	74.1
coughing up blood	9.4	84

TABLE I
VARIOUS DISEASE & SYMPTOMS; PERCENTAGE OF PATIENTS WHO HAVE THESE DISEASES OR SYMPTOMS AND PERCENTAGE OF PATIENTS WHO VIST A DOCTOR

The adoption of mobile phone technology among HIV+ patients in Ghana is quite widespread. This presents an outstanding opportunity to bridge some of the gaps that have prevented adequate healthcare from reaching those who most need it. Potential users have shown an interest and a willingness to try a system like SmartTrack.

Patients are already quite reliant and comfortable with their phones, as shown by their frequent voice calls. In addition to the primary voice function, significant minorities of patients use their phones for music and games, and a large proportion of respondents use them for clocks and alarms. Few people use their phones for SMS texting, and any cost-effective telehealth system would be based on SMS for the forseeable future. However, the low rate of text-messaging is presumably related to the lack of literacy among users and language-barrier issues. This would not be a problem for an application that used SMS for data-transport, however, as the user would not be exposed to the underlying messages.

With a current adoption rate of 54% among our participants in Ghana, and a worldwide growth rate in mobile phone adoption hitting 25% per year [24], cellphone-based telehealth systems promise to become more and more feasible as time goes on.

E. Diseases & symptoms

We also collected information on various symptoms, health practices, secondary diseases, and conditions not related to HIV. This was for the purpose of understanding symptom information that may be communicated by SmartTrack, assessing the applicability of SmartTrack to conditions beyond HIV, and getting a sense of the participant's general health and medical habits.

Symptom and disease information that we collected is summarized in Table I. These are symptoms and secondary diseases which may be common to people suffering from AIDS, and the percentages of patients who reported having these conditions at any point. The second column contains the proportion of patients who traveled to see a doctor as a result of the corresponding condition. These trips can be quite difficult for patients, and might be avoided in certain cases if the doctor can consult with the patient remotely and recommend a course of action. Again, a cellphone-based health system could enable doctors to track patient symptoms remotely and act appropriately, contacting the patient if necessary.

VI. User Reactions and Lessons Learned

When we experimented with two different cellphone platforms with each user, the reactions were fairly varied across users. Many users were completely new to the concept of smartphones and had difficulties navigating the screen. This is not to rule out smartphones completely from such an environment, but it is well known that rural populations are not accustomed to sudden changes. The cellphone has been considered a user friendly device due to its similarity with the telephone. While many users found the voice option fairly attractive, our voice interface was based on English which was not understandable to over 50% of the users. The users we interviewed spoke several languages/dialects that made it hard for translators we used in our study to converse with local Ghanaians in rural areas. Another concern that patients expressed with voice was that a "talking" phone could disclose the HIV status of a patient.

In contrast, users found pictograms very easy to understand. While we used only a limited set of universal healthcare symbols as pictograms in our study, it remains to be seen as to how many different types of questions can be phrased purely using pictograms. For example, to represent different drugs, we found that simple color and symbol coding would work sufficiently well for several illiterate users. Overall, we felt that a pictogram based user interface holds much promise and can also deal with the stigma issues that voice based interfaces sometimes might present.

The overall response to a system like SmartTrack was very positive. The vast majority of patients (91%) seemed extremely positive and interested in a reminder system that could be placed on their cellphones. Typically, patients have to travel great distances to reach their treatment facilities; hence, being able to remotely communicate with the doctor is a huge positive factor for most patients. Social workers, nurses, community health workers, and doctors seemed very positive and amenable to the system. Many health-workers also wanted a similar system for other common diseases like malaria, TB and Cholera.

Other important lessons we learned include:

1) From a cost perspective, smartphones are much more expensive than cellphones. In Ghana, users can purchase unlocked cellphones at extremely low cost, thus we felt the system should be built around people's cellphones.
2) From a communication perspective, many rural areas we surveyed did not have GPRS coverage. Even if available, it was much more expensive than SMS. Given that the information per patient is extremely limited, we felt that SMS is a much cheaper alternative than voice or data services.
3) The system can potentially be extended to other chronic illnesses like malaria, TB and Cholera.
4) It is critical to perform a needs-assessment study before performing the actual design. While this may seem obvious in retrospect, doing a detailed needs assessment study is a tedious and time consuming process that is often ignored.

VII. Conclusions

As Bill Easterly wrote in *The White Man's Burden*, *"2.3 trillion dollars of aid over 50 years and we have nothing much to show for results."* [35] This so poignantly summarizes the current state of affairs of many philanthropic organizations funding AIDS relief efforts in Africa. While it is indeed true that some organizations have made significant progress in specific areas, this is more of an exception than the norm.

Our effort is largely centered around technological issues facing the adoption of AIDS relief schemes. We believe that, a combination of technological and sociological approaches are needed to tackle the healthcare(HIV/AIDS) problem in developing regions.

From a technical perspective, to make AIDS relief efforts more effective, it is essential to improve accountability in the health system, and to enhance patient adherence to medication regimen through constant monitoring. The vision of SmartTrack is to address these two problems, using a distributed cellphone-based platform to achieve these goals. Though this project is still in a relative state of infancy, it has undertaken a detailed needs-assessment study using interviews with over 500 AIDS patients in Ghana. Our next step in future work is the actual deployment of SmartTrack with the aid of the West Africa AIDS Foundation and Korle Bu Hospital. We plan to use the lessons learned from the needs-assessment study, with particular attention to the user interface issues, to deploy a widely acceptable version within Ghana to non-English-speaking and non-literate populations. If successful, this effort can be replicated in other rural developing parts of the world.

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