

Improving Care – Improving Access: The Use of Electronic Decision Support with AIDS patients in South Africa

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Abstract: The shortage of physicians and nurses and the lack of patient record systems at rural health facilities have severely limited the ability to expand treatment for AIDS patients in Africa. This paper presents a novel approach to scaling up treatment utilizing counselors with specially developed clinical algorithms on a hand held computer to screen patients and maintain patient records in settings where doctors are limited. Our first application is in South Africa where we are screening AIDS patients to determine whether they can safely continue on their current treatment regimen or if they require a consultation by a physician. We are doing these trials in 2 sites in South Africa. Following these validation trials, we will implement this program on a larger scale, and include linkage of these diagnostic algorithms with electronic patient records that are stored on the device, enabling us to provide better care at lower cost.

Key words: mobile technology, decision support, HIV/AIDS, scaling up, quality of care

Introduction

We face a crisis in health care in developing countries in two critical areas: a shortage of professional staff and a shortage of information. Neither of these problems is new; we have known of their presence for many years. What is new is the ability to address them through the use of technology. This paper presents an approach currently being tested in South Africa to address the shortage of trained doctors treating AIDS patients while using the same technology to collect and use both patient and population based data. The AIDS pandemic has put a spotlight on the shortage of doctors and information, especially in Africa where the shortages are the greatest and the epidemic is most severe. We present a field trial, using mobile technology to enter and process data on patients with AIDS, and to provide decision support to non-physician health workers, thereby reducing the dependence on physicians for management of patients during their visits to health clinics.

Constraints to scaling up treatment of HIV and AIDS

The World Health Report 2006 – “Working Together for Health” focuses on the current crisis in the global health workforce, describing “*an estimated shortage of almost 4.3 million doctors, midwives, nurses and support workers worldwide. The shortage is most severe in the poorest countries, especially in sub-Saharan Africa, where health workers are most needed.*” (The World Health Report 2006) However, despite this shortage of trained doctors and nurses, most HIV treatment programs continue to rely heavily on the use of specially trained physicians to diagnose, treat and manage HIV+ patients. Typically located in hospital settings or specialty clinics for HIV treatment, these physicians act as primary care providers to HIV+ patients, seeing

them frequently to monitor their condition in case additional care or a change of regime is required. Due to the shortage of physicians, this puts a significant strain on the resources available at each treatment center, and limits the number of patients that can be seen. Additionally, this has had an impact on care in more remote clinical outposts, where many infected people live and where the shortage of physicians is exacerbated since physicians tend to want to live in more modern urban centers.

Countries have pursued a variety of strategies to overcome this physician shortage. South Africa, for instance has imported physicians from Cuba and other African countries. However, as the AIDS epidemic intensifies, the total demand for physicians has outstripped the supply necessitating the need for another solution. An alternative approach, already being used to a limited extent in South Africa and more widely in other countries, is the use of non physician medical personnel, including nurses and counselors, to do many of the tasks that would otherwise be performed by physicians. Often this is done via “down referral” of the patient to less specialized clinics, where ARV drugs can be dispensed and counselors can assess patients on a monthly basis.

This system has raised concerns about the quality of care that non-physicians will provide since the triage of HIV+ patients is complex, due to the wide array of symptoms that can vary with age, past history, laboratory test results and presenting signs and symptoms. It is precisely this complexity that has led to the development of treatment guidelines by WHO, PEPFAR and the government of South Africa. These guidelines have played an important role in facilitating the expansion of AIDS treatment. However, since they are necessarily complex and conveyed via paper charts and lists, costly training and follow up has been necessary to educate providers in how to use them. (Lambrechts, 1999) This has caused a significant bottleneck to the rapid expansion of treatment (Ramiah, 2005). Evidence suggests that even after such training, paper protocols are difficult for health workers to follow, and are often not used. (Beracochea, 1995) In the case of AIDS treatment, a further concern is that many providers are themselves infected with HIV, so that rapid turnover of staff due to illness and premature death requires constant training and retraining of staff. A simpler approach is clearly needed.

An additional challenge to the down referral of patients is how to capture and manage the patient data, required for effective care and for reporting on program outcomes to managers and donors. In the case of HIV+ individuals, provider access to information about past conditions, treatments and lab results is particularly important to assess and manage a patient’s care. For example, if a patient has a chronic cough, one might suspect tuberculosis. However, if the patient is already being treated for tuberculosis and the cough has been thoroughly investigated in the past, the cough is of concern only if it is getting worse. Yet, one of the hardest tasks in a clinical information system is collecting follow up data on patients in chronic treatment (Fraser, 2006). While resources for collecting data at larger urban centers are becoming available, there are few resources for collecting patient level data in smaller rural clinics.

Current practice in most clinics is to use paper records on which physicians write their findings and recommendations, and where laboratory data is entered. Paper records are often incomplete because paper is lost, data from laboratory or other sources is not entered, and many providers, busy with a large number of patients, do not write pieces of information critical for future

assessment. The records are also not portable; i.e. a patient going to another clinic for treatment does not have a record available at this second site. Moreover, paper records note what was done rather than what is needed, and thus don't inform the provider of potential problems. These issues have been partially addressed through the use of electronic records: HIV/AIDS program health workers are asked to fill in multiple paper forms, and later a data entry clerk transfers this to electronic format. However, due to the difficulty of training and managing data clerks, accurate data entry is often not completed in time to be of use to clinicians and program managers. System failure leads to frustration and a lack of interest in continuing to collect accurate data using paper forms.

Electronic Decision Support in the treatment of AIDS patients

The approach we are testing towards scaling up treatment of AIDS patients is the development of an electronic patient assessment tool, that incorporates HIV treatment guidelines into an electronic format running on mobile devices such as PDAs and/or cell phones. Evidence suggests that the time is ripe for this approach to succeed.

The use of electronic protocols has been limited in developing countries by concerns about adequate infrastructure, the durability of the technology, the skills of the health workers, and the cost. Handheld computers and cell phones are now overcoming these issues by combining rapid technological advancements and plummeting pricing. Handhelds are available today for less than \$200, with adequate computing and storage capacity to easily support the use of electronic protocols for a wide variety of problems, while storing several thousands of health records of patients. Open source software has additionally lowered development costs and broadened the portability of systems from one setting to another. Handhelds have also been tested for durability and use by less skilled workers, and have shown their practicality in developing countries for applications as diverse as collecting health data in India (Anantraman, 2002), Uganda (Healthnet, 2005) and Tanzania (Evaluation, 2006) to tracking wildlife in Kenya (Cybertracker, 2005).

In the industrialized world, electronic protocols have been introduced for use by both patients and physicians. A few programs (e.g., PKC, DXplain, ePocrates) have developed web based decision analysis modules for physicians. Increasingly, these and other applications are being made available on handheld computers that are more convenient to use at the point of care. Many nurses and physicians currently use handhelds to track patients, and to store useful reference materials, such as pharmacopoeias, medical calculators, billing and coding, and medical documentation such as pictures of rare rashes (Adatia, 2003).

As a result of both the advances in technology and the clear need for non-physicians to participate more fully in the care and treatment of AIDS patients, we have developed and are currently testing the use of clinical screening and treatment algorithms and patient data storage using mobile technology (either PDAs or cell phones) as a platform. The algorithms are provided to non-physician health personnel in a format that is easily taught and understood. Our first application is in South Africa, where we are screening AIDS patients to determine whether they can safely continue on their current treatment regimen or require a consultation by a physician. This judgment is based on identifying potential opportunistic infections and other medical problems and/or drug side effects that indicate the need for a further referral to a physician.

We anticipate the current trial of this technology to be completed in July or August 2007, and we will then proceed to implement it on a larger scale, to ensure its operability in a wider array of settings. This phase will also include linking these diagnostic algorithms to patient records that are stored on the device, which would enable better care at lower cost. In this second phase, historic patient data including past lab tests will be available to and used by the system in the assessment process. The software will include user interfaces for entering data, procedures for querying the Electronic Health Record (EHR) (e.g. past weight), and procedures for updating the EHR with new information. Furthermore, we will develop software to provide context specific assistance for the provider, to assess signs and symptoms. This would include, for example, help with diagnosing thrush if the provider is unsure how to make that diagnosis. We believe this system can allow non-physicians to safely triage patients while maintaining very high standards of quality of care. This should significantly alleviate the demand for physician time as studies have shown that only 7% of patients need to change regimes for toxicity issues (Harvard School of Public Health, 2005) and during monthly visits many patients present without any evidence of opportunistic infections.

An additional benefit of this electronic approach is that in answering questions posed by the system to evaluate a patient's condition, providers will be directly entering patient data into the system where it will be stored and later compiled. Consequently, the data does not need to be re-entered or aggregated by health workers, data entry clerks or clinic management. There is good evidence that this will not only improve efficiency, but also improve the quality of the collected data. (Grimshaw, 19993) Work in Uganda (Bridges, 2005), India (Anantraman, 2002) and South Africa (Herbst, 2003) on EHRs coupled with electronic point of service data input indicates that in developing country settings, health care workers will reliably enter patient data if they can use the data in real time for patient care. Systems like the one we are developing combine point of care data entry with decision support to the clinician and thus gives the provider the incentive to accurately enter data during each visit.

Challenges to Implementing HIV Electronic Decision Support Systems

Protocol Development Issues: The greatest challenge to the development of an HIV electronic decision support system is the development of appropriate screening questions. Attempts at this are currently underway by several groups including the World Health Organization Integrated Management of Adolescent and Adult Illness (IMAI) guidelines, NGOs such as Doctors Without Borders and Partners in Health, and individual clinics in South Africa and elsewhere. However, these guidelines are not sufficiently specific for electronic use and continue to rely to a considerable extent on the clinical judgment of the health worker. This approach is fine when the health worker is a nurse or doctor who has received intensive training in the care and treatment of AIDS patients, but is not adequate if non-medically trained workers such as counselors or village health workers are to be used to screen AIDS patients.

The approach that we have found most successful to date is to begin with a set of screening questions about the most common presenting symptoms such as weight loss or vomiting¹ and then refine these questions based on the clinical judgment of physicians who are seeing large numbers of AIDS patients. The key to this approach is to translate these questions into an electronic format that can be easily followed by health workers at the point of care and is easily and unambiguously interpretable by the provider using a computerized decision support model. For example, when assessing for weight loss, one must consider the period of time since the patient was last weighed, whether a scale is currently available, and whether this is the first occurrence of weight loss or is a pattern that has been occurring over a period of time. While intuitive to a clinician, these possibilities need to be codified in order to ensure that the protocols cannot be misinterpreted. As part of this process, we will identify data needs for each protocol element. For example, past weights must be accessible to the decision support software to assess weight loss. See figure 1 for examples of questions.

		Doing Well	Needs Referral	reason for question
1	How have you been?	No different than before	Not well	General assessment
2	How is your weight?	same or little change (< 2 kg)	change of > 2 kg.	General assessment, TB
3	How is your energy/power?	The same or better	Worse or unable to do old activities	Possible treatment failure
4	Have you needed medical care since your last visit?	No	Yes	Possible OI, drug failure
5	Are you taking any new drugs or traditional medicines?	No	Yes	Possible side effects, OI

Figure 1

As part of this process, we will also identify data needs for each assessed condition. Using the previous example, past weights will need to be made available to compare with current ones to see the difference between them, as well as the time period during which the change took place. We will also include thresholds for symptoms that should alert providers to possible worsening illness, side effects of medications or drug adherence issues. In some cases, such as weight loss, these thresholds (e.g., “10% weight loss”) are established in the national HIV treatment protocols. In other cases, the critical range is not specified. Through collaboration with specialists experienced in the care of HIV+ patients in South Africa, we will identify the critical ranges to be used as thresholds in order to generate alerts.

End User Interface Issues: The system must be easy to use for the health worker and minimizes the time required for data input, so that using electronic data entry and protocols won’t increase the amount of time needed for patient assessments. It is also very important that the potential for data entry errors is minimized, as such errors could effect patient care. Consequently, screen graphics need to be readable and easy to use, data entry needs to be consistent from question to question, and questions should have a discrete set of displayed possible answers and data entry buttons. Consequently, considerable care has been put into the development of a very user-

¹ The care pathways we used as a first step were those developed by doctors and nurses at Hlabisa hospital in KwaZulu Natal, South Africa.

friendly interface. The one that we have developed is based on a scrolling interface similar to that used in a “chat” program where a summary of the previous question and response scrolls up the screen as each question is answered. This provides a visual cue of past responses making it easier to identify errors and make corrections.

Figure 2 shows a screen highlighting this interface. The current question and possible answers are displayed at the bottom of the screen. When a question is answered, it is scrolled upwards: a short version of the question and the selected answer appear above the current screen. In initial testing in South Africa counselors have found the system quick and easy to use.

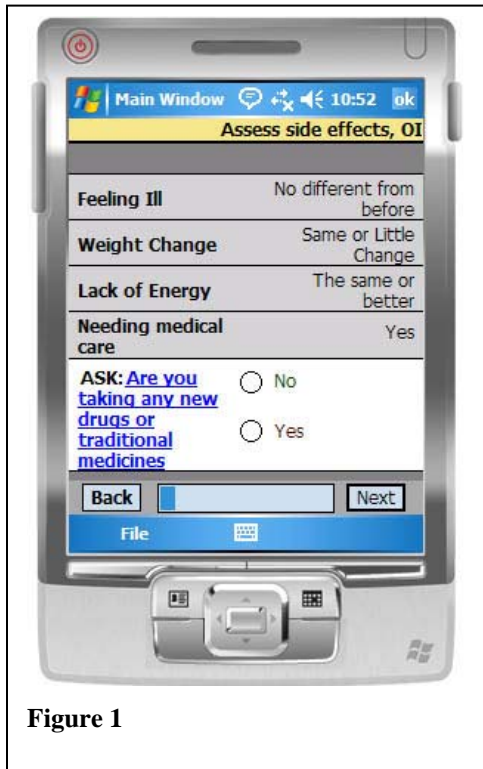


Figure 1

Data Storage and Management Issues: Some issues arise with the development and use of an electronic medical record that is linked through mobile technology to point of care data entry and decision support. The first is the need for confidentiality. While this is an issue for paper based records as well, it becomes of particular concern with electronic records since these are more easily copied or analyzed outside of the clinical facility and thus have the potential to generate personal confidential information about patients. Further, because of the mobility of the storage devices, they can easily be taken from the facility and the data downloaded. There are several ways to address this, including the use of provider specific password protection of encoded files, physical security of the devices in the clinic when they are not in use, and access tracking software that maintains files of who and when a patient’s record is accessed.

A second critical issue of data storage is that the system should be very robust in a variety of situations including lack of electricity, lack of internet access, and dusty conditions. Even countries with relatively good infrastructures suffer period interruptions in power or internet access, and the systems must be designed so that they can continue to work and patients can continue to be seen even when the lights go out. This is one of the advantages of the use of mobile technology over fixed computers for both data entry and decision support. In our system, connectivity will be done locally through the use of either Wi-Fi or Bluetooth, and then connected at least daily through a cellular network to a central server where all patient records are being stored. However, other models of connectivity are also possible depending on the local situation.

A third consideration is of the data model itself in the medical record. The system being run on mobile technology will seldom be the only application using electronic medical records, so the system must be designed to interact with existing data structures. The approach we plan to use is to build the system on top of a newly developed record system, OpenMRS which is an open source system being developed for use in developing countries. This tool is being supported and developed by the Medical Research Council of South Africa, The Regenstrief Institute at Indiana

University and Partners in Health, and is being implemented in several facilities in that country as well as in Rwanda and Kenya. By linking to a general use patient record system we will be able to contribute to rather than compete with the existing record systems in use, a key to the long-term sustainability of the system.

Technology Decisions: Although the goal of our system is the expansion of care and the improvement of quality, most people focus on the specific technology platform we are using. The project will thus often be referred to as “a PDA project” or “cell phone project.” However, the technology is evolving so rapidly with convergence between cell phones, PDAs and other technologies, that the distinctions are blurring and it is impossible to say which technology (or technologies) will be most appropriate for this application in the future. For this reason, we have tried to minimize the reliance on specific technologies and be able to move across platforms as the technology changes. Indeed, our first prototype was developed for the Palm OS, while subsequent iterations have been based on the Windows mobile platform both for ease of use and due to its increasing prominence in the mobile domain. However, as cell phones evolve and contain more memory and processing power, we anticipate that these will be the platform of choice due to their wide availability, long battery life and ease of use.

Cost Issues: One of the greatest barriers to the acceptance of “high tech” solutions to problems in developing countries is the perception that the cost will be too high. The response to our approach has often been that there isn’t enough money for medicines and staff, so why waste money on computers. However, although large sums have been spent on technology with often little effectiveness for patient care, it still holds true that the judicious use of low cost technology can both save money and improve and expand care. In the case of mobile technology decision support, the cost of use could be easily offset by the savings that come from the “down referral” of patients to health facilities, and the substitution of expensive doctors and nurses with more economical health workers such as counselors. Key to these savings is to show that the care provided by lower cost (and less scarce) health workers is as good as that provided by the current system of highly trained doctors and nurses seeing all AIDS patients.

There are of course other elements to the cost. The use of technology should reduce the training costs, as health workers are taught to follow specific protocols rather than try to learn for themselves all the potential problems in a busy clinic. Furthermore, electronic teaching aids or help screens can update health workers’ knowledge on a particular topic. Thus, help screens are built into the screen protocols to provide the health worker with information about what the question is asking and how to enter specific responses.

When comparing the use of technology to the costs of other aspects of treatment for AIDS, one important consideration is the impact that technology may have on the rate of default of patients coming in to their appointments. Since strict adherence to treatment protocols are critical to effective treatment and to slowing the resistance to the first line drug regimens, any intervention that enhances adherence will reduce the per patient costs of treatment. Although it is too early to tell if the use of mobile technology can increase adherence by bringing treatment closer to the patient, the cost per treated patient may be substantially reduced if patients come more reliably to their appointments by bringing treatment sites closer to the patient.

Staff Acceptance: The development of an electronic screening tool for AIDS patients is only the first step in the process of reducing the reliance on doctors and improving access to information. Many other elements of this approach need to be addressed. A key one is staff acceptance. Even when physicians and managers understand the potential of electronic decision support for expanding care, local staff may be reluctant to use the technology for a variety of reasons. One concern that staff raised was whether this would mean extra work for them. Many clinics are already overwhelmed by the vast numbers of patients coming in for care. Introducing a technology that requires additional time from already overworked staff will be rejected as not feasible. For this reason, one of the design features that we have built in to the system is careful attention to the time requirements of its use. We have done that by limiting the numbers of questions asked to patients, making the response quick, and ensuring that screen to screen navigation is either automatic or fast and easy. In this way, our initial trials took only 8 minutes for a complete assessment and we anticipate that with more use, this time would be further reduced.

Another issue in terms of staff acceptance is whether a machine is replacing one cadre of health worker. Although sometimes the doctors are the ones with this concern, it applies also to the nurses who see their role as threatened by this approach to care. We have found a good way to alleviate this concern is to make clear that there will always be a need for doctors and nurses, but they are needed to treat the more complex patient problems and that routine screening does not require the specialized skills for which nurses and doctors are trained. Indeed, according to the World Health Report “Working Together for Health” the shortage of trained nurses in most countries means that some of their work will necessarily need to be job-shifted to other, less trained health workers. *Tasks related to service delivery can often be carried out as or even more efficiently by less senior staff. Task delegation is especially important in resource- constrained settings where skilled staff are in very short supply* (The World Health Report, 2006).

Validation of the protocols

The specific protocols and the process must undergo trials to ensure the recommendations of the electronic decision support is equal to the current standard of care - at most clinics this means being seen by a physician. To achieve this, counselors at the clinic are provided the electronic screening tools on a hand-held device and they are led through a series of questions to determine whether the patients are currently having any medical problems or side effects from their treatment for which further assessment is needed.

The counselors participating in this research are already screening patients who come to the clinic for psychosocial problems and the tools tested extend this screening capability to other medical problems that can be easily detected by non-medically trained personnel. During the study period, counselors recruit eligible patients into the study at the beginning of each patient visit. Eligible patients are those on ART coming to the clinic for routine follow up care who have been on treatment for at least 3 months. After being read an informed consent script (displayed on the PDA) and asked for consent to participate, the patients who agree are screened by the counselor using the electronic protocols. The system generates recommendations from that encounter, such as no change in treatment or a referral to a physician, and this is stored on the PDA.

The physician then assesses the patient as he or she normally would. Any clinical findings are noted in the patient's record. In addition, the physician will be asked whether the patient could have safely been sent home without being seen by a physician. If the physician feels the patient did need to be seen by a physician, they will be asked to note what the particular reason was that necessitated this.

The results of the PDA screening is downloaded to a computer in a secure location in the clinic at the end of each day, along with the physician's responses to the study specific questionnaire that asks the following question: *In your judgment, could the patient have safely gone home on their current regimen of treatment or did they require a consultation with a physician?* Using the physician's answers as the "gold standard", we can compare the results of the decision support algorithm with that of the physician to determine whether the electronic algorithms' recommendations were appropriate.

Implications of Research

The model of treatment expansion that we are suggesting differs from the current approach taken in most countries. Rather than focusing on intensive training programs and centralized treatment facilities, we are suggesting the use of simple, proven technologies to make diagnostic and treatment protocols available to existing health workers with only minimal additional training, and using this same technology for the collection and storage of individual patient records for use by the provider. This approach offers several advantages over the current method of service delivery for HIV/AIDS.

1. **Rapid expansion** of access to AIDS treatment using existing facilities and staff but making more efficient use of non-physician staff at peripheral facilities.
2. Ability to **rapidly change protocols**, as needed, based on new information about drug resistance, drug availability or local conditions.
3. **Point of care data entry** of and access to patient data including past history, laboratory test results and previous levels of patient adherence to treatment regimens, including the ability to provide alerts to providers when a change of regimen is needed (for example when weight changes occur.)
4. **Tracking of ARV drugs** at the point of service, allowing for inventory control and logistics management, and reducing loss from theft.

In addition to these direct benefits to patient care, we also anticipate that this approach will have wide applicability beyond its immediate use in the treatment of AIDS patients. Patients with AIDS can have other medical problems as well, and this research contributes to a wider research agenda to test the feasibility and effectiveness of point of service decision support for a wide range of clinical decisions including staging of HIV+ patients, diagnosis and treatment of common infections such as thrush, diarrheal disease, respiratory infections, and malaria. We also anticipate the development of systems that prompt the health worker to provide preventive care such as immunizations, family planning advice, counseling, and growth (or weight) monitoring

to children whom they see. Recent evidence from developing countries suggests that adherence to diagnostic and treatment algorithms can have a dramatic impact on the quality of care and health outcomes (Health Facility Survey Study Group, 2004). Eventually, we hope that our research will lead to the development of a wide array of diagnostic and treatment guidelines appropriate to the environment in which health workers in developing countries see their patients. An added benefit of this approach is the ease of gathering and aggregating point of care data that leads to a more complete understanding of population health, and evolving patterns of disease and resistance.

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