Field Notes

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Community Health Work and Diagnostic Mobile Software in Mobile Communities

Field Notes from Kono, Sierra Leone

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Introduction

Wellbody Amputee Clinic lies on the outskirts of Koidu Town in Kono, Sierra Leone. It's been a decade since the end of Sierra Leone's devastating Civil War, but the infrastructure here—electricity, sanitation, education, healthcare—has yet to recover. Finda sits on a long bench with her feverish infant son on her lap, waiting for the only doctor at the clinic. There are more young women, old men and children from neighboring villages waiting beside her under the intense afternoon sun. They have come to the clinic because community health workers had visited their homes, performed a field diagnosis and referred them to the clinic for further testing and treatment.

However, there are many more people who do not seek help when they are ill. The Wellbody Clinic, which complements the Government-run hospital healthcare delivery system in the Kono District, focuses on primary care and community health work. Despite incentives at the clinic, such as free health care for pregnant women and children under five, many locals are reluctant to visit the clinic or the hospital. Some do not have the money to pay for check-ups and treatments. Others consider it a waste of time to take a day off from working in the fields and travel over long distances to the Government Hospital, only to be given no diagnosis or a single pill for their troubles. Still others fear the stigma of visiting a clinic and place their trust in superstitions or traditional healers in their own villages instead. Classified by the U.N. as one of the least developed countries in the world, Sierra Leone's health statistics are also some of the worst. The infant mortality rate is 89 out of 1,000 live births, while 140 out of 1,000 children die before their fifth birthday. The maternal mortality rate stands at 857 per 100,000 births (SLDHS, 2009). In addition to prenatal and postnatal health issues, the leading causes of death in Sierra Leone are malaria, tuberculosis, pneumonia, anemia, nutritional deficiencies and now HIV/AIDS. Most deaths and illnesses in Sierra Leone are preventable and treatable.

The community health work Wellbody does in Kono is especially effective given that there is a shortage of trained physicians in Sierra Leone. According to the Sierra Leone Ministry of Health and Sanitation, there are only 75 medical officers in the country where 534 are needed, creating a gap of 459 medical professionals (2009). Even more troubling for a country with one of the highest infant mortality rates is that there is only one pediatrician in all of Sierra Leone, who incidentally works at Wellbody. With few monetary incentives for doctors to stay, most who graduate medical school leave the country to work in the U.S. or U.K. Since there are few social or political indications that this exodus of medical professions will be ending anytime soon, training more community health workers would simultaneously alleviate some of the burden on local doctors and nurses and increase the reach of health initiatives.

Goals and Objectives

I visited Wellbody with a team of four other undergraduate students to pilot a program that would train local Community Health Workers (CHWs) on diagnosing patients with the aid of smart phone technology. Employing CHWs not only creates jobs locally, but also helps ensure the sustainability of the project by helping locals help themselves. Our goal was threepronged: (1) To keep a comprehensive health record and history of all inhabitants in the rural communities; (2) To screen for sick patients during home visits and to provide triage or one free referral to the clinic; (3) To follow-up on HIV, TB or malaria treatment management and side effects, as well as provide pre- and post-natal screenings. Additionally we would be providing standardization and accountability in the screening and follow-up process for CHWs when they did house visits. We used Sana, an open-source Android-based medical diagnostic and documentation platform, to design a smart phone logic that would be able to distill a diagnosis from a list of symptoms, thus emulating a doctor's decision-making process.

Prep Work: Training the Community Health Workers and Rewriting Software Protocols

After undergoing a community health training program with Dr. Mohamed Bailor Barrie, co-founder and director of Wellbody Alliance, which is modeled after Dr. Paul Farmer's Partners in Health, 11 CHWs were selected and hired by the clinic. Most of the CHWs hired had been traditional birth attendants or healers in their villages and were already trusted in their villages to dispense medical advice. Each CHW had an area of expertise, whether it was a disease specialty such as TB, or a geographical region they were familiar with. There was an even mix of men and women, and most were middle-aged adults, with the exception of a few young men. The clinic paid for their transportation to Kono's district capital (some were coming from as far away as a day's ride) and covered their meals during their training, with the promise of a steady salary at the end of the sessions. In contrast to UNICEF and some other NGOs in the region that maintain a policy of only supporting voluntary community health work, Wellbody views CHW salaries as necessary monetary incentives that increase the longevity of the program.

Although all the CHWs owned cell phones, most had never been exposed to smart phones with touch screens before. They only had a couple of days to familiarize themselves with the logistics of the phones and the health software protocols. Aside from some of the young men, who picked up the technology quickly, we had to start from the basics of teaching how to gently and lightly touch a screen, as well as how to scroll and type on the keyboard. Although all CHWs hired were proficient in English, due to our differences in accents and diction, we always had a clinic staff member translating our instructions into Krio, the local language. Among various teaching methods, we found hands-on demonstrations and role-playing to be the most effective. One particularly effective method involved splitting the CHWs into small groups after a powerpoint lecture, then verbally guiding the more tech-savvy ones through the testing protocols while others watched. When it came to their turn, not only would the non-tech-savvy CHWs have seen the process demonstrated multiple times, but there would also be a collaborative support group. This method generated a high level of engagement and initiative, since during breaks, many of the CHWs

would take out a phone and practice on their own. At the end of the sessions, we also designed a picture-based training manual for the phones and software that the CHWs could refer to when they were making house visits without us.

Based on the input from the CHWs during these sessions, we worked closely with Dr. Barrie and a graduate fellow in computer science at Wellbody to tailor the software to our diagnostic purposes, and to adjust for socio-cultural sensitivities. The template for the software was quite straightforward: a CHW enters the patient's identification information (name, age, gender), uses the camera on the phone to take a picture of the patient and close-ups of any rashes or wounds, and checks off symptoms to reach a diagnosis. However, Sana's testing protocols and setup was targeted towards a locale with greater medical resources and urban infrastructure than the one we found ourselves in. Many of the hard-coded screens asked for addresses, phone numbers and birthdates, which were not applicable in Kono, since there were no house numbers or streets, few villagers had phones and only the year of birth was known. As a result, we spent a substantial amount of time re-writing protocols. We also recoded the software logic to use symptoms to come up with recommendations, such as testing in the field (i.e. perform a rapid diagnostic malaria test), administering treatment (i.e. give the first dose of ACT, emergency malaria treatment) or referring to a clinic for further testing. Since the interface needed to be easy for the CHWs to use, we translated the medical terms into Krio, the most widely spoken language in Sierra Leone. We also had to account for cultural and linguistic differences. For example, the question of "how many months ago," was a difficult concept to express in Krio. There was also a stigma surrounding HIV in Sierra Leone, where HIV is considered a death sentence and those who have HIV are ostracized. Under these circumstances, not knowing their own HIV status is preferred over the stigma of going to the clinic for tests. CHWs had to be discreet when asking HIV-related questions on sexual partners and condom usage, which was reflected in the code.

Field Testing: Results

We accompanied the CHWs into the field as they did home visits in four nearby communities, testing the HIV and malaria protocols only. There were two CHWs to one volunteer. On the first day we split up to Dorma Amputee Camp and Sinatown, where we brought malaria kits and screened everybody. But due to the overwhelming number of false positives with malaria, the cause of which will be addressed later, we ran out of malaria kits early on. Thus, in the days that followed, we revised our strategy: we selectively screened individuals that had noticeable symptoms and gave them paper referrals to the clinic.

Following the screening protocol recommendations, the CHWs used rapid malaria tests to confirm on average seven to eight patients (mostly young children) who were infected in each community. Since this was a pilot program that was partially aimed at the early detection of diseases, we were encouraged that 100 percent of our referred patients came to the clinic for further testing. The referral slips the CHWs gave patients, which included which illnesses they were being referred for, were useful to the doctors and nurses. They sped up the initial survey process since the patient's entire basic medical history and symptoms were already on record.

Field Testing: Implications

There were unexpected gains in training CHWs to use smart phones in these rural communities in the areas of accountability, maximizing use of medical staff and creating comprehensive records. Since CHWs were asked to document all home visits on the phones and keep detailed records, the CHWs could be held accountable for actually visiting the patients. Furthermore, with the tests recommended for each patient already on record, the clinic processing speed increased while the strain on clinic staff resources was mitigated. There were things, such as prescribing medication, which only doctors and medical professionals could do, but the CHWs could help take the blood pressure or perform a malaria test out in the field before the patient even visited the clinic. This alleviates the burden placed on the limited medical staff.

Lastly, the CHWs took the first steps toward generating comprehensive records with patient histories, which will eventually be compiled into an electronic medical database. Considering the staff's frustration with keeping consistent and comprehensive records in nothing more than flimsy notebooks, such a system will be greatly useful.

Challenges: Changing Attitudes and Limits on Power and Authority

One of the goals of our original project was to encourage people to seek out professional treatment when sick, and the phones as a diagnostic tool did bring a sense of legitimacy and excitement in visiting the clinic. But we had to ensure that we did not overwhelm the clinic staff with an excess number of unnecessary referrals, since consultation at the clinic was free. Therefore, one of the biggest problems we faced initially involved patients falsely claiming to have symptoms. Moreover, since the output from the algorithm was only as good as the data input given, there were many problems that arose from incorrect self-reporting by the patients to the CHWs.

We attributed this phenomenon to a number of possible reasons. There might have been a communication problem many of the rural inhabitants spoke only Kono, the language of the Kono tribe in that district. As stated earlier, the concept of time, particularly in questions such as "how much time ago," was difficult to translate. Additionally, since we were visibly foreigners, we were confronted with the expectation of aid. The calls of "white man, white man!" as well as kids asking for money follow ed us wherever we went. We were seen as the white man handing out free referrals indiscriminately (ironically, there was not a single Caucasian male in our group). Nevertheless, the novelty of technology brought in by the "white man" can be harnessed to change villagers' mindsets towards going to the clinic.

To counter these obstacles, we suggested CHWs to actively use their hands-on first aid training, such as feeling for fevers, and clarifying that mild symptoms were not just a result of the normal tear and wear of working in the fields. Two successful methods for obtaining accurate information were to ask follow-up questions and to build rapport when asking sensitive questions. One of the younger CHWs found it useful to ask, in a more joking, off-hand manner, about the number of boyfriends and girlfriends one had, during the HIV testing protocol. Another CHW took on the role of a matronly protector to gain a young girl's confidence in finding out more about condom use.

Since CHWs are not doctors, one issue we tackled was

preventing the intentional or unintentional misuse of power. Unveiling ceremonies were performed in each community to introduce the CHWs as a trained authority in triage and referrals. This also served to set the limits of what CHWs can and cannot do. When initiating dialogue in screening, the language used is always centered around "helping"—and never "curing " or "treating"—the person being screened, because the latter is the domain of doctors.

Since cellphones were seen as a wealth and status symbol, CHWs and patients could have attributed a false sense of authority to them. Seen as a coveted personal item, many cellphones had elaborate phone covers, and some youths even carried around fake iPhones as mere showpieces. On one hand, this generated excitement and enthusiasm for clinic visits referred by a smartphone. On the other hand, technical or human errors that occurred in the field could have been amplified by placing blind trust in the phones. We discovered a need to place more emphasis on the human component in CHW use of the technology.

Sustainability and Future of the Project

In order to ensure the sustainability of our project, the security of the phones was crucial. Due to the prestige that comes with phone ownership and the financial gains of selling phones on the black market, we needed a system to ensure that the phones did not get stolen. To deter people from stealing the phones, we also used only phones that were incompatible for use with African SIM cards. Anti-theft strategy is still an aspect of the project that we are working on.

There are still issues with bringing smartphones into such an infrastructure-poor country, but the clinic has its own electrical generators, which was ideal for phone charging. Although power surges are common, surge protectors and other devices protect the phones.

In addition to integrating HIV, malaria and TB screening for reaching sick patients in rural communities early, we also plan on implementing a treatment follow-up protocol especially for treatments that consist of pill regimens that last for multiple months (TB) or treatments that have potential side effects (HIV). Additionally, due to the high rate of maternal mortality, prenatal and postnatal screenings will be added.

Currently, an electronic record system is being created at the clinic, which can be linked to our smartphones to upload patient histories from house visits. There is potential for GPS and cellular data usage in the future, since even in remote areas, newly built cell towers are everywhere. The running joke was that reception in rural Sierra Leone is better than it is in the U.S. Activating cellular data would allow for immediate doctor feedback and consultations; this is certainly a direction that this project may eventually take.

Reference

Government of Sierra Leone Ministry of Health and Sanitation. National Health Policy. (2009)