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Effectively Filling Gaps in Care: A Comparative Study of Models of Government Partnerships with Community Health Organizations in KwaZulu-Natal, South Africa

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Effectively Filling Gaps in Care: A Comparative Study of Models of Government Partnerships with Community Health Organizations in KwaZulu-Natal, South Africa

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Abstract

This study conducted Amatkiulu, Impendle, and Durban, KwaZulu-Natal, South Africa, utilizes three case studies to form a comparative analysis of the effectiveness of different models of public-private partnerships. Two expert interviews, three informal interviews, and many hours of observation inform this analysis of community health worker organizations employed through government clinics, tuberculosis tracer teams hired by government clinics, and independent non-governmental organizations heavily subsidized by the government. Subjective analysis found that the partnership between the Department of Health and a primary healthcare NGO, providing a wide range of comprehensive services, operated with the best efficiency and quality of care.

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Introduction

South Africa has continually struggles to meet the standards set forth by the Millennium Development Goals—especially in those goals relating to health and quality of life. In recent decades, South Africa’s greatest health dilemma has centered on the HIV/AIDS epidemic. This human immunodeficiency virus (HIV), spread through direct contact with infected body fluids (blood, semen, vaginal secretions, and breast milk), attacks the white blood cells of the infected person, causing immunodeficiency that allow opportunistic infections to eventually overtake the body. Though HIV/AIDS was first considered a “homosexual disease” in 1980’s, after years of widespread denial and inactivity, the virus has infected millions throughout South African and much of the developing world. In 2009, the national HIV prevalence of South Africa was estimated to be about 10.6% of the entire population. The prevalence of HIV in pregnant women, as reported by antenatal clinics, averaged to about 29.1%, but the results displayed huge disparities between provinces. While the Western Cape reported a 16.1% prevalence, KwaZulu-Natal, where this study took place, reported a 38.7% HIV prevalence rate in pregnant women.¹ Though prevention of mother-to-child transmission has made significant advancements, only 30% of male youth and 27% of female youth between the ages of 15-24 years old are estimated to possess sufficient understanding of the disease, including modes of transmission and prevention methods².

The “twin epidemics”, Tuberculosis (TB) and HIV, have also become the most significant factor influencing the high prevalence of TB in South Africa. Tuberculosis,

¹South Africa: Country Situation Analysis. (2009). *UNAIDS*. Retrieved from http://www.unaids.org/ctrysa/AFRZAF_en.pdf.

² Ibid

once referred to as “consumption” and brought to South Africa by colonizers around 1800, is a highly contagious airborne disease that severely compromises the lungs of the infected. While the disease was once considered to only affect the mining population and their contacts due to overcrowded living and working conditions with poor ventilation, tuberculosis has now become a widespread epidemic throughout South Africa.

Urbanization also played a major role in the rise of TB as people sought employment in cities. This massive population shift from rural to urban settings created overcrowded slums, increasing rates of transmission. Again poor diet and general health, coupled with a severe lack of access to care for much of the population living in these conditions due to apartheid policies, led to widespread transmission. Though the incidence continued to rise, the World Health Organization (WHO) initiated DOTS (directly observed treatment short-course) program began implementation in 1995, thus improving cure rates drastically.³ Yet as of 2009, South Africa ranked fifth on the list of 22 high burden countries for tuberculosis prevalence⁴.

In 2008, the incidence of tuberculosis cases in South Africa was 960 per 100,000 people with 58% of cases also infected with HIV⁵. It is estimated that one-third of the world’s population is infected with dormant TB as a healthy immune system can easily “wall off” the TB bacilli⁶. However, the immunosuppressed HIV positive population is

³Health Systems Trust. (2000). *Tuberculosis in South Africa*. Retrieved from <http://www.hst.org.za/uploads/files/upd56.pdf>.

⁴USAID. (May 2009). *Infectious Diseases: South Africa*. Retrieved from http://www.usaid.gov/our_work/global_health/id/tuberculosis/countries/africa/safrica_profile.html.

⁵UNAIDS. (2009). *AIDS Info South Africa*. Retrieved from <http://www.unaids.org/en/regionscountries/countries/southafrica/>.

⁶WHO. (2011). *Tuberculosis*. Retrieved from <http://www.who.int/mediacentre/factsheets/fs104/en/>.

much more likely to become infected with TB and much less likely to be cured. TB is, therefore, the leading cause of death in HIV-positive patients. With an estimated 5,600,000 people in South Africa living with HIV and 114,500 TB patients also infected with HIV, the integration of these treatment sectors will play a major role in the controlling both epidemics.⁷

While the South African government and Department of Health has long focused on the implementation of Community Health Worker (CHW) Programs and coordination with non-governmental organizations (NGO) as a means of combatting these twin epidemics, some of these partner organizations have expanded their beyond this specialization to provide services for many health issues affecting their target population.

Problem Statement

In order for healthcare to be effective, care must extend beyond the clinic or hospital walls. This care must address all the external factors that influence a patient's ability to present at a public healthcare facility when affected by a disease or infection and to remain compliant with a prescribed treatment regimen. In theory, CHW's, TB tracer teams, health educators, support groups, and home-based care providers provide exactly that follow-up care. Yet, the best model for such an extension of care, measured in both efficiency and quality, is highly debated.

⁷South Africa: Country Situation Analysis. (2009). *UNAIDS*. Retrieved from http://www.unaids.org/ctrysa/AFRZAF_en.pdf.

Methodologies

This learnership was conducted in three sites: Amatikulu, Gomane Clinic in Impendle, and Bekimpilo Trust based in Durban. The learner employed methods of observation, informal conversation, formal interviews, and secondary research to gain a comprehensive understanding of three approaches to community-based care.

In gathering primary data, the learner first shadowed a Community Health Worker (CHW) employed by the government in Amatikulu. The learner observed CHW-patient interactions and asked questions through informal conversation with the CHW. Second, the learner observed and conducted a formal interview with a tuberculosis tracer employed by the government-run Gomane Clinic in Impendle. The learner also engaged the nursing staff of the TB Clinic in informal conversation. Finally, the learner shadowed and informally interviewed the staff of Bekimpilo Trust, including administrators, nurses, tracers, and health educators.

All secondary research included in this study was found on the Google Scholar database and on the Howard Tilton Memorial Library Database by searching with keywords, including “tuberculosis”, “tracing”, “community health worker”, “NGO”, “DOTS”, “HIV/AIDS”, “diabetes”, “public-private partnership”, “PNP”, and “South Africa”. Journal articles and Department of Health publications allowed the learner to understand the multidimensionality of tuberculosis, HIV/AIDS, and other relevant infections as medical and social diseases and to understand the role of community-based support organizations and systems in their treatment. The learner retained a critical eye in usage of these publications as the sources can contain an understandable bias.

Published, peer-reviewed studies and articles allow the learner to understand the researched effectiveness of community health workers, tracer teams, and non-governmental organizations in South Africa and other geographic locations.

Literature Review

Tuberculosis Strategic Plan for South Africa 2007-2011

This document provides the overarching Department of Health plan to combat tuberculosis. It not only details implementation of DOTS nationwide, but focuses on the key challenges faced. The standards and policies provided in this document describe a clear, cohesive, and comprehensive TB support system from local to national participation. However, the learner will seek to understand the reality of the implementation of this plan in a rural, resource-poor setting.

Quality of Tuberculosis Care Provided in Different Models of Public-Private Partnerships in South Africa

This study compares the quality of patient care in three models of tuberculosis care in South Africa: public-private workplace partnership (PWP), public-private non-governmental organization partnership (PNP), and purely public healthcare system. In this study, PWP's between mining companies and the public system and PNP's between NGO's providing CHW supervision and coordination and the public system were assessed. Ratings were given on structure, process, and outcome to two samples in each model. Although both PWP's and PNP's were found to possess high quality of care than the general public system, comparative analysis found that PWP's are most successful in

providing the highest quality of care due to increased access resources and increased incentive for treatment compliance (job security). However, this study also confirmed the success of NGO's in providing increased access to DOT and increased cure rates. Further, this study confirmed NGO's unique success in tracing defaulters.

Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes

This comprehensive study of Community Health Worker programs throughout South Africa seeks to identify key demographics and qualities of an effective model. The article explains the shift in CHW's from preventative educators to treatment providers. The study cites key factors in the success of CHW programs as sustainable funding sources, good governance, comprehensive training of staff, and well-established supervision.

Reminder systems and late patient tracers in the diagnosis and management of tuberculosis

In this paper, nine trials assessing the importance of tracing and reminding and involving 5257 participants were reviewed. Though confounding factors may have been present, all of the studies proposed a link between defaulter rates and multi-drug resistant TB. Further, the overarching conclusions were that reminders and late patient tracers are effective and necessary to improve treatment progress and outcome. However, it is important to account for the societal differences between communities that may affect the utility of late patient tracers. Therefore, studies must continue in various societies to

prove the effectiveness. Also, cost-effectiveness was not considered in the review of studies.

The Implementation of the National Tuberculosis Control Programme (NTCP) at a regional/district Hospital and Three of its Feeder Clinics: A Case Study (November 2007)

The extremely high rates of TB co-infection with HIV has a very significant impact on the treatment and support of TB patients in rural South Africa. Tracer teams often battle the stigma associated with HIV, which not only causes patients to default on treatment but also makes TB harder to diagnose in the first place. The variability of training and education of nurses also poses a serious problem to effective TB treatment. It is also extremely important that tracer teams have a clearly defined role in the TB support system to provide a continuity of care with individual patients and between all TB patients. If, as the report summarizes, the majority of TB defaulters did not understand that they needed more treatment, it seems that tracer teams are a necessary and effective way to manage that misunderstanding.

Emergence of Increased Resistance and Extensively Drug-Resistant Tuberculosis Despite Treatment Adherence, South Africa (2007)

While many studies have detailed the link between defaulting on treatment and the emergence of drug resistant disease, this study on a mining population of about 3,000 exhibited increased drug resistance despite treatment adherence. These studies must be analyzed and further researched to identify gaps in the DOTS system of care beyond lack of adherence, such as failures in the prescribed treatment regimens.

High Treatment Failure and Default Rates for Patients with MDR-TB in KwaZulu-Natal, South Africa, 2000-2003

This article discusses the extreme difficulty that KwaZulu-Natal has faced in the treatment of MDR-TB as compared to other provinces. The article suggests increased individualized treatment, decentralization of treatment, and integration with HIV treatment. Tracer teams will play a part in this decentralized, community-based solution.

Findings and Analysis

History of Government Coordination with Community Initiatives

Like many other countries, the South African healthcare system is segregated between public and private sectors. However, as HIV/AIDS became increasingly prevalent throughout the 1980's and 90's, so did the presence of a whole populace of “lay health workers”, working with and amongst both public and private health professionals. During this same time, many of these organizations and “lay health workers”, who began as DOTS supporters, health educators, and peer counselors, became financially dependent on international donors. However, after the democratic transition in 1994, many international donors withdrew financial support, assuming the government's competency to assume the financial burden⁸. With a life expectancy of just 52.8 years⁹, the South

⁸Friedman, I., Ramalepe, M., Matjuis, F., Bhengu, L., Lloyd, B., Mafuleka, A., Ndaba, L., and Boloyi, B. (September 2007). *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes*. Health Systems Trust. Retrieved from http://www.hst.org.za/uploads/files/chws_bestpractice.pdf.

⁹ United Nations. (2011). *International Human Development Indicators: South Africa*. Retrieved from <http://hdrstats.undp.org/en/countries/profiles/ZAF.html>.

African government has come to recognize community-based organizations and larger NGO's as an integral part of the solution to the rise of infectious disease and to the sub-standard health indicators. In 2001, the Department of Health published the National Guidelines for Community and Home Based Care, yet the purpose, quality, and organization of these care providers remained fragmented. By 2004, there were estimated to be 40,000 "lay workers", practicing HIV counseling, DOTS support, home based care, and much more. This number was no far cry from the 43,660 professional nurses employed by the public sector in 2004¹⁰. In 2004, the Department of Health labeled all of these lay workers providing community-based general health promotion, disease prevention, and health-resource networking with an overarching term "Community Health Worker (CHW)". At the launch of the government supported CHW program, the Minister of Health, Dr. Manto Tshabalala-Msimang, explained the goals of the program:

The President's articulation of a people's contract to create work and fight poverty, and the government's commitment to improve service delivery, the national human resource and skills development strategies, [and to address] the increasing complexity of the burden of diseases and poverty-related challenges, [and] the increasing need for health promotion activities, community and home based care."¹¹

¹⁰ Schneider, H., Hlophe, H., and Van Rensburg, D. (4 March 2008). *Community Health Workers and the Response to HIV/AIDS in South Africa: Tensions and Prospects*. Oxford Journals: Health Policy and Planning. 23(3), 17-187. Retrieved from <http://heapol.oxfordjournals.org/content/23/3/179.full>.

¹¹Department of Health. (26 February 2004). *Speech by the Minister of Health, Dr. Manto Tshabalala-Msimang at the Launch of the Community Health Worker Programme*. Retrieved from <http://www.doh.gov.za/show.php?id=864>.

In the same speech, Dr. Tshabalala-Msimang asserted the Department of Health's (DOH) intention to form partnerships with NGO's employing CHW's. The CHW's would then be "employed by organisations in civil society and will not be government employees." The role of these CHW's, though somewhat refined in recent years, remains highly debated. For the purposes of this paper, the learner will define CHW's as Schneider et al. does, "local inhabitants given a limited amount of training to provide specific basic health and nutrition services to the members of their surrounding communities. They are expected to remain in their home village or neighbourhood and usually work part-time as health workers. They may be volunteers or receive a salary. They are generally not, however, civil servants or professional employees of the Ministry of Health."¹²In theory, CHW's should be "agents of social change for communities...community mouthpiece to fight against inequities and advocate community rights and needs to government structures."¹³(See Appendix B).The role of CHW's differs from that of home-based care givers. Home care can be defined as "the provision of health services by formal and informal caregivers in the home in order to promote, restore, and maintain a person's maximum level of comfort, function, and health including care towards a dignified death."¹⁴Recent studies of 300 organizations in partnership with the DOH have found that 87% of CHW's are women, 57% are

¹² Schneider, H., Hlophe, H., and Van Rensburg, D. (4 March 2008). *Community Health Workers and the Response to HIV/AIDS in South Africa: Tensions and Prospects*. Oxford Journals: Health Policy and Planning. 23(3), 17-187. Retrieved from <http://heapol.oxfordjournals.org/content/23/3/179.full>.

¹³ Lehmann, U and Sanders, D. *Lay and Community Health Workers and the Response to HIV – Are We Learning from the Past?* School of Public Health, University of the Western Cape. http://www.who.int/hrh/documents/community_health_workers.pdf

¹⁴South African Department of Public Health. (2001). *National Guidelines on Home Based Care and Community Based Care*. Retrieved from <http://doh.gov.za/docs/factsheets/guidelines/homecare/>.

unemployed, and 65% are without matric education status.¹⁵ This same study determined characteristics of successful CHW programs to have strong governing bodies, substantial and sustainable funding, constant support and on-going training, and high levels of supervision.¹⁶

While some cadres of CHW's are in fact employed directly by the Department of Health or their clinics, the department has also formed vast numbers of public-private initiatives (PPI). These PPI's allow the private sector to provide health services to the general population, while financed by the public sector. This private sector refers to all non-governmental health providers, including private for-profit hospitals and non-profit NGO's. One of the benefits of utilizing community-based NGO's has been a greater ownership in the results of the program by CHW's. This result is in direct opposition to the lack of ownership displayed by individuals working in programs where CHW responsibilities that have been tacked on to existing health systems¹⁷. Further, services can be tailored to specific communities instead of following top-down protocol. Critics, however, believe that these partnerships bequeath excessive accolades upon the private sector and perpetuate mistrust of the public sector. Between 2005 and 2006, the Department of Health increased the national budget allocated for NGO's working with HIV/AIDS and TB patients, many of whom employ and utilize CHW's, from R49

¹⁵Department of Health. (26 February 2004). *Speech by the Minister of Health, Dr. Manto Tshabalala-Msimang at the Launch of the Community Health Worker Programme*. Retrieved from <http://www.doh.gov.za/show.php?id=864>.

¹⁶ Lehmann, U and Sanders, D. *Lay and Community Health Workers and the Response to HIV – Are We Learning from the Past?* School of Public Health, University of the Western Cape. http://www.who.int/hrh/documents/community_health_workers.pdf

¹⁷ Ibid

million to R56million¹⁸. The services rendered by these organizations vary greatly, as some specialize and others provide comprehensive primary care. In a study conducted by Health Systems Trust in 2007, researchers found a trend in community health organizations, indicating emergence as a specialized service providers and a gradual process of generalization as staff becomes more experienced and the organization realizes the “multi-dimensionality of community problems.”¹⁹ (See Appendix A) In addition, funding may be greater for specialized programs in the short term, but donor fatigue often lessens support if programs fail to expand.²⁰ Many models of community-based healthcare provision exist. Here, the learner has sought to compare three, very different models in an effort to document the advantages and disadvantages of each.

Case Study: Amatikulu

Amatikulu, KwaZulu-Natal

Amatikulu is an extremely rural area located just 120 km north of Durban. The area is just one part of the Uthungulu health district that encompasses nearly 973,000 people and is home to two regional hospitals, six district hospitals, 57 fixed clinics, one community health center, and 14 mobile clinics.²¹ Amatikulu’s fixed clinic has become a training center for CHW’s in the past decade.

Community Health Workers

¹⁸Department of Health. (2006). *More Funding for AIDS and TB NGO’s*. Retrieved from <http://www.doh.gov.za/show.php?id=439>.

¹⁹Friedman, I., Ramalepe, M., Matjuis, F., Bhengu, L., Lloyd, B., Mafuleka, A., Ndaba, L., and Boloyi, B. (September 2007). *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes*. Health Systems Trust. Retrieved from http://www.hst.org.za/uploads/files/chws_bestpractice.pdf.

²⁰ Ibid

²¹ Uthungulu Health District. (2011). *South African Department of Health*. Retrieved from <http://www.kznhealth.gov.za/uthungulu.htm>.

Unlike NGO driven models of community healthcare, the CHW's operating throughout Amatikulu are employed directly by the municipality health system, removing some aspects of community control in the program. CHW's were selected from community members, in an effort to spark community participation and acceptance, while ensuring each CHW's contextual understanding. The women were trained in a year-long course and assigned approximately 60 families in one catchment area. The male supervisor of the CHW's expect the women to visit a minimum of three patients per day, but the learner was informed by one CHW that three patients is the maximum number of visits in reality.²²

Though many CHW programs have evolved to focus on provision of care in addition to education, the CHW program in Amatikulu almost solely provides health education. The learner observed education be given at two households on tuberculosis symptoms and treatment and at one household on HIV/AIDS prevention, symptoms, and treatment. At each of these houses, the CHW also provided ongoing mentoring on techniques for the family's vegetable garden, which she had helped them to create. During the learner's two days of shadowing, the CHW also visited a bedridden tuberculosis patient, an 87 year old diabetic amputee, and a fourteen year old orphan cared for by her gogo and described as "paralyzed." In fact, this fourteen year old was epileptic and severely mentally handicapped, but still maintained physical mobility despite extreme wasting and fatigue. Each of these patients was advised to visit the clinic, yet each household was located far from the clinic. With transportation costing over one hundred Rand, the CHW admitted the unlikelihood that the patients would

²² Confidential Informant A. CHW. Personal Comm. Amatikulu. 26 October 2011.

present to the clinic in the near future.²³ Despite this knowledge, the CHW did not make any effort to coordinate transportation. The CHW also displayed a clear lack of medical knowledge as she explained the 87 year old diabetic's amputation as a result of cancer caused by hiding money in the shoe and in contact with the foot, instead of a necrotic sore as his clinic records indicate.

Effectiveness of Community Health Workers as Direct Government Employees Model

Though health education and awareness was certainly promoted by this model of CHW involvement, this particular program proved inefficient. The CHW's provide comprehensive education on symptoms of TB and HIV and provide valuable information on the importance of home gardens. However, inadequate selection, training, and supervision significantly impaired the success of the program. Many CHW's fail to visit more than three families per day and provide little coordination with the the government health facilities for the families that are visited. While monthly reports are given to the district and infectious diseases are documented, CHW's in this model fail to provide any real healthcare services as an extension of the employing clinic. Medication is not brought to patients unable to travel to clinics. With increased training on both medical knowledge and government coordination tactics and with intensified supervision, the CHW program directly funded and run by the municipality in Amatikulu could become an extremely effective part of the greater public health system.

²³ Confidential Informant A. CHW. Personal Comm. Amatikulu. 26 October 2011.

Case Study: Gomane Clinic's Tracer and Outreach Nurse

TB Tracing

Because tuberculosis is a highly contagious, airborne disease passed from person-to-person, international standards on treatment protocol have been detailed extensively. One such protocol has been the implementation of TB tracer teams, used to track potential new patients and patients defaulting on treatment. Effectiveness of TB tracing has become widely acknowledged in recent years. In fact, in a recent study with nine trials and 5257 participants published by the Cochrane Review, the importance of tracing and reminding was again underlined. Though confounding factors may have been present, all of the trials proposed a link between defaulter rates and multi-drug resistant TB. Further, the overarching conclusions were that reminders and late patient tracers are effective and even necessary to improve treatment progress and outcome.²⁴ In 2008, South Africa allocated 33 million Rand to fund the initiation of tuberculosis tracer teams countrywide.²⁵ If patients fail to present at a clinic or hospital for a scheduled appointment and have defaulted on their prescribed treatment regimen, teams are dispatched to track the patient or patients in question. TB tracing is not only important in terms of providing the best quality of care for individuals and for preserving the public health, but also in preventing the emergence of drug resistant strains of tuberculosis. If treatment isn't taken

²⁴Liu, Q., Abba, K., Alejandria, M., Balanag, V., Berba, R., and Lansang, M. (8 October 2008). *Reminder Systems and Late Patient Tracers in the Diagnosis and Management of Tuberculosis*. Cochrane Library. Retrieved from <http://summaries.cochrane.org/CD006594/reminder-systems-and-late-patient-tracers-in-the-diagnosis-and-management-of-tuberculosis>.

²⁵Punitha, Hannah. (2008 March). *S. Africa Launches TB Tracer Teams*. MedIndia. Retrieved from <http://www.medindia.net/news/SAfrica-Launches-TB-Tracer-Teams-34776-1.htm>.

as prescribed, the small, infrequent doses of medication allow tuberculosis bacteria to mutate and develop resistance to first-line drugs instead of being killed by the full, proper dosage of medication. It is absolutely vital, therefore, that healthcare providers and support systems control patient defaulting to prevent a curable disease from morphing into an incurable one.

Gomane Clinic, Impendle, KwaZulu-Natal

The learner shadowed a TB tracer employed by one of the two government clinics located in Impendle in the uMgungundlovu District of KwaZulu-Natal. The district has high numbers of risk factors affecting the general health of the population, including high rates of poverty and unemployment, alcohol and substance abuse, crime rates, HIV/AIDS and STI prevalence, as well as a lack of basic infrastructure in many rural areas. The rural town of Impendle is located 150 km west of Durban and is home to a population of 32, 676 people, as reported by the 2005 uMgungundlovu District Brochure. While this population only comprises 4% of the total district population (995, 303), Impendle is serviced by two clinics, Gomane and Nxamalala, out of the total 43 district clinics (plus 4 satellite and 14 mobile clinics).²⁶ Gomane Clinic is open 24 hours a day and offers primary health services, including voluntary HIV counseling and testing (VCT), anti-retroviral therapy for HIV/AIDS (ART), antenatal checkups, prevention of mother to child HIV transmission counseling (PMTCT), and tuberculosis treatment.²⁷

Gomane's TB clinic boasts a 0% defaulting rate, with high cure rates though some patients are terminal. The TB clinic is staffed by two full-time nurses—one based in the

²⁶ uMgungundlovu Health District. (2005). *UMgungundlovu Health District*. Retrieved from <http://www.kznhealth.gov.za/umgungundlovu/brochure.pdf>.

²⁷ Confidential Informant B. Nurse. Personal Comm. Gomane Clinic. 2 November 2011.

clinic and one outreach nurse—and one tracer to attend to the close to 100 tuberculosis patients currently seeking treatment.²⁸ The full-time nurse working within the facility explained the process by which new tuberculosis patients are identified and treated, as decreed by the Department of Health.

Tuberculosis Diagnosis and Treatment

When a new patient presents to the clinic, complaining of a variety of symptoms including persistent, productive cough, night sweats, fever, weight loss, chest pain, loss of appetite, and fatigue, a sputum sample (mucus produced by coughing) is taken. This sputum sample is then taken to a lab for a smear (rapid results) and culture (results take two to three weeks). However, sputum samples often test negative for HIV co-infected individuals with active TB. If an HIV positive individual presents with symptoms of TB, he or she may be initiated on treatment without a sputum sample and then referred to a district hospital for a chest x-ray for confirmation of the infection.²⁹

Once a patient has been identified to be infected with active pulmonary tuberculosis, the patient is initiated on the intensive phase of treatment, consisting of two months of once-a-day ingestion of a drug called Rifafour, along with Bactrim (an antibiotic), Vitamin B supplements, and Pyridoxine (to replace pyridoxine depleted by Rifampicin and Isoniazid). Rifafour is an oral tablet containing Rifampicin, Isoniazid, Pyrazinamide, and Ethambutol. Patients experiencing extreme weightloss will also be given high-protein porridge supplements to aid in weight gain. During the seventh week of intensive treatment, the patient resubmits a sputum sample for testing. If the sample tests positive for acid-fast TB bacilli (AFB), the patient remains on the intensive drug

²⁸Confidential Informant B. Nurse. Personal Comm. Gomane Clinic. 2 November 2011.

²⁹Confidential Informant B. Nurse. Personal Comm. Gomane Clinic. 2 November 2011.

regimen for another month. However, if the patient tests negative for AFB, he or she replaces Rifafour with Rifinah. Rifinah, taken once daily like Rifafour, contains just Rifampicin and Isoniazid. This continuation phase continues for four months, at which time symptoms are assessed and another sputum sample (or chest x-ray in the case of an HIV positive patient) is taken to confirm completion of treatment and “cure” of infection.³⁰

If the patient presenting to the clinic has previously been treated for pulmonary TB, the intensive phase consists of three months of once-a-day Rifafour and a daily Streptomycin injection, while the continuation phase consists of five months of once-a-day Rifinah and an additional tablet of Ethambutol. Because of the necessary Streptomycin injections, patients must come to the clinic daily to receive treatment. However, if the patient is too weak to travel or is at risk of defaulting, the outreach nurse at Gomane will visit the patient in his or her home to administer the injection.³¹

Like many bacterial infections, tuberculosis is difficult to cure if treatment is not taken correctly and as prescribed. Multi-drug resistant tuberculosis, defined by the World Health Organization as resistance to Rifampicin and Isoniazid, and XDR, defined as resistance “to any fluoroquinolone and at least one of the three injectable second-line drugs in addition to MDR-TB”³², emerge from improper treatment regimens or inadequate compliance with a correctly prescribed treatment regimen. The World Health Organization, therefore, recommends the DOTS strategy, directly observed short-course treatment, be utilized for all tuberculosis patients. This strategy mandates a DOTS

³⁰Confidential Informant B. Nurse. Personal Comm. Gomane Clinic. 2 November 2011.

³¹Confidential Informant B. Nurse. Personal Comm. Gomane Clinic. 2 November 2011.

³²World Health Organization. (2011). *Tuberculosis*. Retrieved from <http://www.who.int/tb/challenges/mdr/en/index.html>.

supporter be assigned to every TB patient and that this supporter “directly observe” the administration of each dosage of medication, in addition to providing emotional and psychological support. While some facilitators are more effective than others, a DOTS supporter can be a health professional, CHW, family member, or friend.

Tuberculosis Treatment Defaulting

The reason for which the patient has interrupted or defaulted is of course vital in determining the tracer team’s success in retrieving the patient. Many patients default due to side effects of treatment or due to lack of health education, as many believe treatment unnecessary once tuberculosis symptoms cease. One case study at a regional hospital and its three feeder clinics in South Africa conducted by Health Systems Trust in 2007 found that a majority of TB defaulters failed to understand the necessity for continued treatment. If, as this report summarizes, many individuals default due to a lack of communication between clinic staff and patient, tracer teams are a necessary and effective way to manage that misunderstanding.³³ Though the tracer at Gomane Clinic echoes the same belief in the necessity of TB tracing, he believes the greatest number of interrupters result from lack of easily accessible and affordable transport to the clinic, especially for physically handicapped and bedridden patients.³⁴ Other patients have been known to default due to the stigma of co-infection with HIV that a TB diagnosis presents. While some patients may not wish to be found, the others who do desire treatment but are constricted by external factors must receive the follow up care that tracer teams provide.

³³ Health Systems Trust. (November 2007). *The Implementation of the National Tuberculosis Control Programme (NTCP) at a Regional/District Hospital and Three of its Feeder Clinics: A Case Study*. Retrieved from <http://www.hst.org.za>.

³⁴ Siyabonga Zuma. TB Tracer. Personal Comm. Outside Gomane Clinic. 3 November 2011.

TB Patient Tracing

Contact Tracing

Whenever an individual is identified as AFB positive from a sputum smear, the “contacts”, mostly family members or inhabitants of the same homestead, must be traced and provide a sputum smear. These individuals have a greater chance of infection due to increased contact with an infected individual. When a patient tests AFB positive, he or she is phoned and notified of his or her status and asked to present the clinic the following day to initiate treatment. If the patient presents as asked, the tracer at Gomane Clinic transports the patient back to his or her residence and collects names, contact numbers, and sputum samples from each family member. If the patient fails to present to the clinic, the tracer is dispatched to locate the infected individual and collect all necessary information and sputum from contacts upon discovery of the patient’s whereabouts.

Defaulter Tracing

By Gomane Clinic’s definition, according to the WHO’s guidelines, “defaulting” on tuberculosis treatment indicates a prolonged interruption of treatment equal to or greater than two months. However, if a patient fails to present to the clinic for his or her monthly appointment date to refill medication, the patient is phoned. If the patient fails to present to the clinic for three days past the set appointment, the tracer is sent to locate the “interrupter.” Despite the necessity for this tracing because of aforementioned reasons, many difficulties arise in practice. In many rural areas and also in urban townships, residential addresses consist merely of vague descriptions in relation to landmarks as opposed to numbers and street names. Another challenge that Siyabonga Zuma, the

tracer employed by Gomane Clinic, sites as particularly frustrating is the interchangeable use of nicknames, Christian names, and traditional Zulu names.³⁵ While one name may be given at the clinic, neighbors may only know the patient in question by another name and may, therefore, misreport the patient as non-existent in a certain area. Also, due to the constant migration from rural to urban, many patients disappear all together. However, Siyabonga Zuma believes that tracing is easier in rural areas, where the main reason for default is lack of transport to the clinic, as compared to urban areas, where migration is constant and a variety of other factors affect defaulting rates. Zuma asserts that he has not encountered patients defaulting due to the stigma attached to TB diagnosis, often linked to HIV positive serostatus. He believes the population of Impendle has been educated enough to understand that TB is curable, unlike HIV/AIDS, and, thus, have detached any stigma associated with tuberculosis.³⁶ In addition to his personal knowledge of Impendle's geography from over 30 years of residence in the area, Zuma uses several outside resources when tracking patients, including shopkeepers and teachers at schools in the general location of the residence given to the clinic, who are well-known in the community, as well as a whole network of CHW's.³⁷

Effectiveness of Treatment Model

Though Gomane Clinic certainly had TB interrupters, the clinic has been able to maintain a 0% defaulter rate. According to the nurses at the clinic and the tracer himself, TB tracing has played the most significant role in maintaining this success rate.

³⁵ Siyabonga Zuma. TB Tracer. Personal Comm. Outside Gomane Clinic. 3 November 2011.

³⁶ Siyabonga Zuma. TB Tracer. Personal Comm. Outside Gomane Clinic. 3 November 2011.

³⁷ Ibid

However, the tracer is focused solely on tuberculosis treatment support. Though the tracer only has a couple of patients per day to track, the tracer is only hired to track current patients and their contacts. Any health or other social issues encountered at each residence can be referred to the CHW's, but none are addressed during these home visits. TB tracing has, thus, proved an effective specialized model of government healthcare extension into the community.

Case Study: Bekimpilo Trust

Bekimpilo Trust

Bekimpilo Trust (BT) was founded in 1987 by Dr. Elizabeth Standing with a mission to provide “ free preventative and promotive” health services to the semi-rural townships just north and south of Durban. Though a self-governing, independent non-governmental organization, Bekimpilo Trust entered a public-private partnership South African Department of Health and is now almost fully funded by the government. The trust employs a 41 person staff, 33 of who are qualified nurses, working in the eight fully functioning, primary healthcare clinics in semi-rural townships. The trust manages these clinics and utilizes mobile teams from a central office located on Umbilo Road in Durban, functioning with an Operational Manager, three nurses, a microscopist, and four other staff members.

Clinics

The trust operates four clinics to the north of Durban and four to the South, most of which are located on the grounds of primary schools. This location allows the clinics to provide the primary schools with a nursing staff for minor ailments, such as bumps, bruises, and colds, and for immunization tracking of school children. However, the

clinics treat a population much greater than the children attending each primary school. The services rendered by each of the Bekimpilo Trust clinic units are listed below.

HIV/AIDS Counseling and Testing

Each of the eight clinics provides voluntary HIV/AIDS counseling and testing services with a rapid test. However, if identified with a positive serostatus, a patient must be referred to a government clinic for a CD4 count. If identified with a CD4 count low enough to initiate ART, these drugs must be prescribed and dispensed from a government clinic. Bekimpilo Trust believes that the financial burden of employing a doctor to prescribe ART is impractical for their size, especially because the nursing staff is capable of effectively providing all other care.

Tuberculosis Diagnosis and Treatment

Each of the Bekimpilo Units diagnoses and treats tuberculosis patients daily. While Sandasonke Clinic had only 11 active TB cases and Inanda Day Clinic had only 7 active pulmonary cases in November 2011, Amatikwe Clinic was treating over 50 patients. The health team helps to increase case finding by coordinating with local CHW's in each area. Instead of outsourcing lab work, Bekimpilo's own microscopist picks up sputum samples daily and returns microscopy results within 48 hours. Though sputum cultures must be taken to King Edward, the rapid microscopy results can be used to initiate new patients on treatment immediately. While the government decreed treatment regimens utilized by Bekimpilo clinics are the same as Gomane's, there are certain differences in the care provided at Bekimpilo's units. In great contrast to Gomane's policy, patients are given appointment dates one to two weeks apart at each BT unit. The nurses use this policy to ensure treatment adherence and to prevent

interruption, especially because many patients' DOTS supporters are family and friends instead of government registered and trained DOTS supporters. The nurses also adhere strictly to calendars marking exact dates for sputum samples and treatment phase changes. The nurses utilize all government educational packets, brochures, and checklists and distribute higher quantities of high-protein porridge packets. All MDR-TB cases are referred to King George Hospital. Even if a patient is only resistant to Isoniazid, which does not qualify as MDR-TB status, the patient is referred to King George because a nurse cannot change the national treatment protocol. Only registered physicians can prescribe the necessary nine months of Rifampin. Overall, Bekimpilo has great success in TB treatment, with few defaulters and MDR cases.

Baby Wellness/Immunizations

Two days per week are designated as Baby Wellness Clinic days in each of the eight units. On these days, women from the surrounding community bring newborns and infants for growth monitoring and immunizations.

The operational manager, Mabhi Ndamane, identified these Baby Wellness Clinics, as the least effective service provided by Bekimpilo Trust due to the fact that many women bring their children to several clinics and do not bring documentation from previous visits indicating immunization records or services rendered.³⁸

Family Planning and Reproductive Health

While one day per week is designated as a Family Planning Clinic day, patients present to the clinic for these services throughout the week. Many women visit the clinic

³⁸ Mabhi Ndamane. Operational Manager. Personal Comm. Bekimpilo Trust. 18 November 2011.

to receive contraception. Upon arrival, these women are individually counseled on all contraception methods and the resulting side effects. Contraceptive injections are administered at each unit, and condoms are distributed.

The nurses at Bekimpilo's units identify sexually transmitted infections (STI's) as one of the greatest problems affecting their clients. Nurses perform physical examination of the affected body part and assess symptoms before prescribing antibiotics to treat the infection. However, patients diagnosed with genital warts are referred to a government clinic for treatment prescribed by a physician.

Breast exams and pap smears are performed at all eight of the units. However, if an abnormal result is found, patients must be referred to a district or regional hospital. Yet, the extremely high volumes of patients referred to these facilities have resulted in waiting times for appointments of a minimum of 9 months. Nurses expressed frustration with these wait times, as many precancerous cells identified in pap smears or in breast examination can progress rapidly in that time. However, the nurses believe that this situation will not be rectified at any point in the near future.

While these clinics provide basic primary healthcare, the many other health services provided by this NGO are detailed below, along with disease-specific case studies as witnessed by the learner.

Community-Based Care

Tuberculosis

Throughout the communities surrounding BT's units, the health team visits the homes of tuberculosis patients. The team coordinates with clinics and CHW's assigned by another community-based NGO to certain areas in order to identify homes with

infected patients. Health education is provided to the patient and his or her family to ensure proper understanding of the treatment regimen and methods of transmission. Individuals are also further educated on nutrition and hygiene. These home visits also serve as contact tracing for new patients, as family members are educated and urged to provide sputum samples to the clinic. Beyond these educational services, the health team also traces defaulters identified by the clinic. These defaulters are counseled on the risks of defaulting and strongly advised to return to the clinic. If the patient is willing, the health team will even transport the patient to the clinic to reinitiate treatment.

Diabetes

The health team encounters many diabetics on their daily rounds. Diabetics are provided with continued mentoring on proper diet restrictions. While some of these patients are managing their diabetes fairly well and following their prescribed treatment regimen, others practice extremely poor adherence. Many of the patients visited daily are amputees or have necrotic lesions on their peripheral limbs. In these cases, the health team monitors the status of lesions or amputations and counsels the patient on proper cleaning and dressing methods.

HIV/AIDS

The health team makes routine visits to known HIV/AIDS patients, especially those with deteriorating CD4 counts. Beyond the provision of health education on nutrition and the prevention of secondary infections, the members of the health team provide emotional and psychological support to patients.

Mental and Physical Disorders/Disabilities

As opposed to the aforementioned illnesses, the role of the health team during home visits to mentally and physically disabled persons is slightly different. Instead of providing health education to the patient, the caregiver within the family is addressed. The health team helps to facilitate disability grant applications and to procure any necessary aids, such as wheel chairs or crutches.

Other–Epilepsy, Tetanus, Ringworm

A local CHW, working with a small community-based NGO, coordinates a health team home visit whenever she learns of sick neighbor. In this way, the health team discovers many cases unknown to the clinic nurses. During the learner's period of observation, she witnessed several new home visits. Several epileptics were identified and referred to a clinic for a thorough diagnosis. In addition, one case of tetanus was diagnosed, as the patient complained of muscle spasms, lockjaw, fatigue, and weight loss. The patient was referred to the clinic and a follow-up visit was conducted the next week.

The health team also visits local crèches and baby-minders to inspect children for common infections like ringworm. Antibiotic cream to treat ringworm is kept in the health team's vehicle at all times to ensure the ability to dispense treatment to any identified patients.

Community Projects/Enrichment Programs

In addition to providing healthcare both inside and outside of clinics, Bekimpilo Trust has expanded its focus to include a variety of community projects to boost the economic situation and quality of life for their clients. Throughout the north and south townships, the health team has identified ambitious individuals to begin community

garden projects. The health team then helps these individuals to gather a group to tend to the garden, educates on gardening techniques and nutrition, and provides seedlings for the first crop. These groups, primarily composed of women, are then able to support themselves financially by selling their produce and to support their families' nutritional intake. Further, these gardening groups become quasi-support groups for the women, many of whom are struggling with poverty and poor health. Bekimpilo has also sparked others small-scale projects to provide individuals with economic opportunity and independence, including livestock projects, providing a family with its first chickens, cows, or pigs, and crafting groups, providing a group of individuals with crafting training. The health team of the trust mentors and supports these community projects from inception to self-sustainability and on, visiting the sites of the projects once a month if not more. During these rounds to projects and home visits, the health team distributes free condoms to tuck shops and shebeens throughout the townships and rural areas visited.

Beyond these economic projects, Bekimpilo Trust has also coordinated support groups for those affected by similar plights. For example, one support group for “gogo’s” in the north meets weekly to provide each other with emotional and psychological support. However, the health team visits these meetings at least once a month to provide education on diseases, exercise, nutrition, and more.

Effectiveness of the Public – Non-Governmental Organization Partnership

Bekimpilo Trust operates under a model that integrates the provision of many health services, instead of specializing in just one area, as do TB tracer teams. Mabhi Ndamane, the operational manager of BT, cites home visits as the most important service

provided by the organization: “We don’t just wait for people to come to the clinics. And we don’t just treat patients, we treat their families, too.”³⁹Ndamane believes that Bekimpilo’s effective home visits is a direct consequence of the additional training, unlike government trained CHW’s, that the staff incurs. In addition, the trust is able to operate independently of government initiatives and protocol, allowing the governing body much more freedom to focus on the needs of specific communities. Though the clinics lack several key services, namely the ability to prescribe and dispense ARV’s, the trust’s independence from bureaucracy, small organization size, and pervasive management structures foster a sense of accountability and ownership in the staff members, ensuring high quality of care.

Conclusions

Not only have the services rendered by community-based caregivers and organizations evolved overtime, but their partnerships with the public government healthcare system have also drastically changed. Some community health workers are employed directly through the municipality health systems. While sufficient health education is provided by the CHW’s observed by the learner and operating under this model, several key qualities of community health worker programs are lost—especially the role of coordination between government health systems and the patient. The model observed in this learnership could benefit from increased supervision and training of CHW’s. The next model of extended care, TB tracing, provides extremely effective results for tuberculosis treatment. This model fails to take advantage of case

³⁹ Mabhi Ndamane. Operational Manager. Personal Comm. Bekimpilo Trust. 18 November 2011.

finding opportunities for the broader spectrum of health problems during home visits. However, the specialized focus of TB tracing may be necessary to ensure positive treatment outcomes due to the high volume of TB patients treated at many public health facilities. The integrated healthcare provided by the public – non-governmental organization partnership model may prove to be the most efficient, effective, and comprehensive community healthcare scheme. The NGO is able to address issues pertaining to specific communities and is able to provide a continuity of care from case-finding home visits to clinic visits to treatment to follow-up. The independent NGO also demonstrated the best governing and supervising structures, which, in turn, produced high quality care. Though all three models of community-based healthcare arguably deserve utilization in the larger public health system, the potential implications of public – non-governmental organization partnerships on general health statistics are promising.

Recommendations for Further Study

Limitations for this study included the extremely small sample size of organizations analyzed for the effectiveness of their model. Further studies should increase sample size in a comparative analysis of Public—Non-Governmental Organization Partnerships (PNP), Public—Private Partnerships, and fully public community health initiatives based out of government clinics and structures. While the learner determined that the greatest quality of care was provided by the PNP Model, cost-effectiveness studies should also be undertaken to analyze the differences between specialized models of care versus generalized, comprehensive care models.

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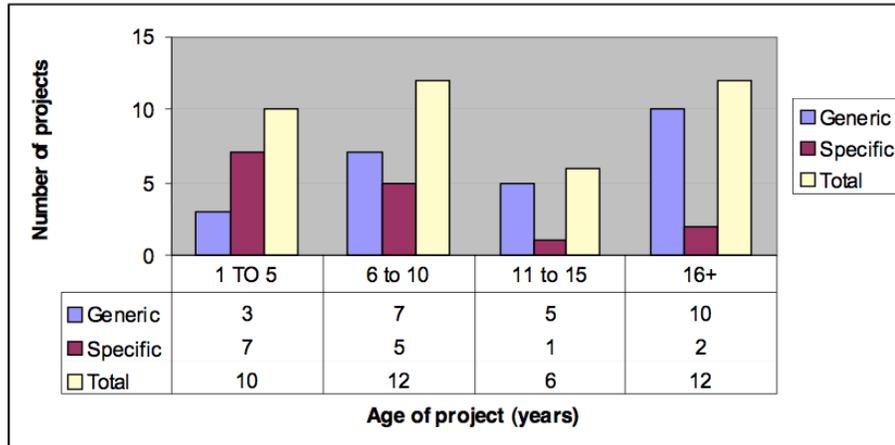
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Appendices

Appendix A – NGO Service Progression from Specialized to Generalized With Age

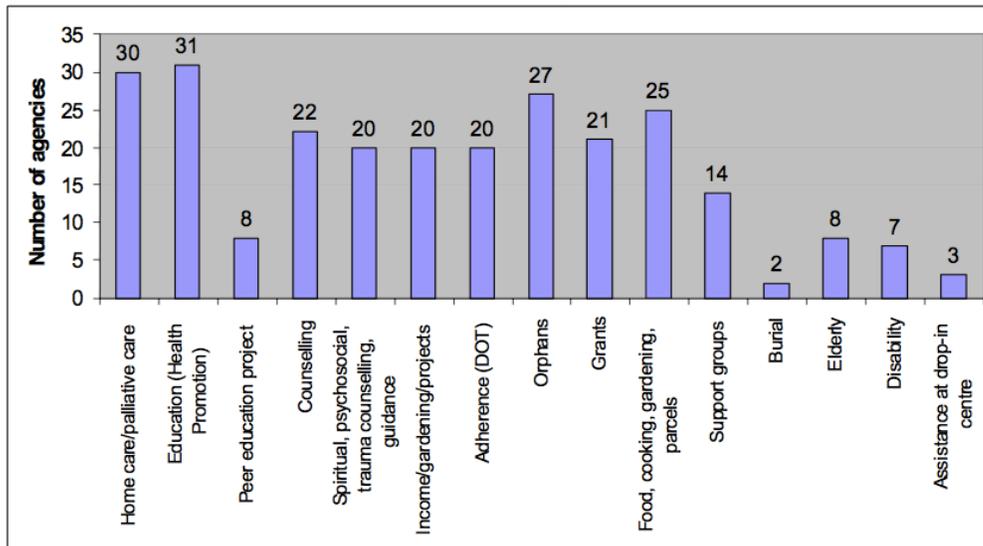
Fig. 1: Focus of CHW Projects by age of project



Friedman, I., Ramalepe, M., Matjuis, F., Bhengu, L., Lloyd, B., Mafuleka, A., Ndaba, L., and Boloji, B. (September 2007). *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes*. Health Systems Trust. Retrieved from http://www.hst.org.za/uploads/files/chws_bestpractice.pdf.

Appendix B – CHW Tasks

Fig. 8.: Types of activities in which CHW agencies are involved



Friedman, I., Ramalepe, M., Matjuis, F., Bhengu, L., Lloyd, B., Mafuleka, A., Ndaba, L., and Boloji, B. (September 2007). *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes*. Health Systems Trust. Retrieved from http://www.hst.org.za/uploads/files/chws_bestpractice.pdf.

Appendix C—Log of Hours

Monday, October 31st

Transport to Impendle

Tuesday, November 1st

7:30 to 11:00 – Introduction to Gomane staff and introduction to treatment protocol by TB nurse

11:00 to 15:00 – TB tracing with Siyabonga Zuma

Wednesday, November 2nd

7:30 to 9:00 – Refilled and organized stock room for TB clinic

9:00 to 14:00 – Completed TB patient charts and collected “interrupter” data

Thursday, November 3rd

7:30 to 9:00 – Interview with Siyabonga Zuma and informal conversation with TB nurse

Transport back to Durban

Friday, November 4th

Meeting with Zandile Wanda and Zed McGladdery to discuss ISP placement

Monday, November 7th

8:30 to 9:00 – Introductions to staff

9:00 to 15:30 – Home visits and patient tracing with health team

Patients: Severely mentally and physically handicapped 23 year old, diabetic amputee, diabetic with necrotic sore, TB defaulter

Tuesday, November 8th

8:30 to 15:30 – Rounds at clinics in the north with Eunice

Amatikwe, Hlengimpilo, Inanda Day, and Sandasonke Clinics

Wednesday, November 9th

8:30 to 15:30 – TB patient treatment at Amatikwe Clinic

Thursday, November 10th

8:30 to 14:45 – Rounds to garden and livestock projects, condom distribution with health team

Monday, November 14th

8:30 to 15:30 – Home visits with the health team in the south

Patients: Diabetic with necrotic sore, TB defaulter, tetanus case, two new TB case, diabetic amputee, AIDS patient, cellulitis patient

Tuesday, November 15th

8:30 to 15:00 – Home visits with the health team in the south

Patients: New TB patient, elderly diabetic amputee living with young alcoholic in utter poverty, 96 year old man caring for one son with AIDS and one mentally disabled, epileptic son

Wednesday, November 16th

8:30 to 14:30 – Gogo support group and garden rounds with health team

Thursday, November 17th

8:30 to 15:30 – Crèche visits and TB tracing in the north

Friday, November 18th

8:30 to 12:30 – Interview with Mabhi and record review in office

Total Number of Hours: 73 hours and 15 minutes of work on site

(Note: No lunch or tea breaks were taken at either site)

Appendix D—Ethical Clearance Forms

Learnership Access Contract I

1. I understand that I have been granted access to conduct a learnership at Gomane Clinic
2. I understand that NO RESEARCH may be conducted.
3. I place myself at the disposal of the medical manager/ facility manager, Siyabonga Zuma, to do whatever work that is within my capacity that can be conducted without risk to myself or patients.
4. I will undertake a negotiation with the abovementioned manager or his appointee so as to learn skills and knowledge about TB tracer teams and the TB support system
5. I recognize my responsibility as a learner to ensure no harm comes to myself, patients, staff or the institution.
6. I agree to Indemnify and hold harmless the South African Department of Health, all staff and any who I come into contact with at the abovementioned facility. I acknowledge the high risk of infection with HIV, Tuberculosis, Hepatitis and other infectious diseases, in this context. I undertake to take all necessary precautions to protect myself and will not enter such spaces without protective clothing and masks. I recognize that the above precautions are not 100% effective and thus voluntarily assume the risk inherent in entering this learnership site.

Student Signature
Madeline Ross

date
October 24, 2011

Learnership Access Contract II

1. I understand that I have been granted access to conduct a learnership at Bekimpilo Trust
2. I understand that NO RESEARCH may be conducted.
3. I place myself at the disposal of the medical manager/ facility manager, Mabhi Ndamane, to do whatever work that is within my capacity that can be conducted without risk to myself or patients.
4. I will undertake a negotiation with the abovementioned manager or his appointee so as to learn skills and knowledge about the provision of medical care on a community level
5. I recognize my responsibility as a learner to ensure no harm comes to myself, patients, staff or the institution.
6. I agree to Indemnify and hold harmless the South African Department of Health, all staff and any who I come into contact with at the abovementioned facility. I acknowledge the high risk of infection with HIV, Tuberculosis, Hepatitis and other infectious diseases, in this context. I undertake to take all necessary precautions to protect myself and will not enter such spaces without protective clothing and masks. I recognize that the above precautions are not 100% effective and thus voluntarily assume the risk inherent in entering this learnership site.

Student Signature
Madeline Ross

date
October 24, 2011

Learnship Site Approval

Student Name: Madeline Ross



Learnship Site Information

Reminder: During the Learnship, we need to know how to get in touch with you **at all times**.

This document needs to be approved by the AD before you will be permitted to begin your Learnship. In addition, you may not travel to any destination other than what is listed below without getting permission from the AD first. Please also indicate the places you will be staying, contact names, phone numbers, addresses or PO Box numbers, email addresses, and fax numbers (if applicable) during Learnship.

Longer distance Travel date(s)	Destination	Mode of travel: bus, train, airline (with flights, times)	Contact Information (phone, email, travel companion, people you are staying with)
October 31	Impendle	Thula Mobile	Mobile: 083 700 1388
November 3	Durban	Thula Mobile	Mobile: 083 700 1388

And Brief description of daily travel from accommodation site to the facility.

Daily travel to (site name)	Describe modes and distances of transp	Daily Departure and Return Times
Gomane Clinic	Walk	7:30am-2:30pm
Bekimpilo Trust	Sdu/Thula Mobile	8am-3:30pm

CALL-IN DATES:

Every Monday and Thursday students must text the words, “I’m safe and my Learnship going fine” to Thula by 5pm

- Note that the Thula will be awaiting your calls on the designated call-in dates and will be concerned for you if no call is received.
- A reminder: Certain activities deemed potentially dangerous to individual safety and program integrity are not permitted and are grounds for dismissal. These include, but are not limited to, motorcycling, hitchhiking, driving, parachuting, bungee-jumping, hang-gliding, riding in private airplanes, rock climbing, white water rafting, and scuba diving. Nor are you permitted to leave the country.

Dated: October 24, 2011

Madeline Ross

Student Signature

Any changes to this travel form must be agreed by the AD before travel

SIT Study Abroad Statement on Ethics

(Adapted from the American Anthropological Association)

This document must be read, signed, and submitted to the AD prior to the ILP.

In the course of field study, complex relationships, misunderstandings, conflicts, and the need to make choices among apparently incompatible values are constantly generated. The fundamental responsibility of students is to anticipate such difficulties to the best of their ability and to resolve them in ways that are compatible with the principles stated here. If a student feels such resolution is impossible, or is unsure how to proceed, s/he should consult as immediately as possible with the Project Advisor and/or AD and discontinue the field study until some resolution has been achieved. Failure to consult in cases which, in the opinion of the AD and Project Advisor, could clearly have been anticipated, can result in disciplinary action as delineated in the “failure to comply” section of this document. Students must respect, protect, and promote the rights and the welfare of all those affected by their work. The following general principles and guidelines are fundamental to ethical field study:

I. Responsibility to people whose lives and cultures are studied

Students' first responsibility is to those whose lives and cultures they study. Should conflicts of interest arise, the interests of these people take precedence over other considerations, including the success of the Independent Learnership Project (ISP) itself, for if the ILP has negative repercussions for any members of the target culture, the project can hardly be called a success. Students must do everything in their power to protect the dignity and privacy of the people with whom they conduct field study.

The rights, interests, safety, and sensitivities of those who entrust information to students must be safeguarded. The right of those providing information to students either to remain anonymous or to receive recognition is to be respected and defended. It is the responsibility of students to make every effort to determine the preferences of those providing information and to comply with their wishes. It should be made clear to anyone providing information that despite the students' best intentions and efforts anonymity may be compromised or recognition fail to materialize.

Students should not reveal the identity of groups or persons whose anonymity is protected through the use of pseudonyms.

Students must be candid from the outset in the communities where they work that they are students. The aims of their Independent Learnership Projects should be clearly communicated to those among whom they work.

Students must acknowledge the help and services they receive. They must recognize their obligation to reciprocate in appropriate ways.

To the best of their ability, students have an obligation to assess both the positive and negative consequences of their field study. They should inform individuals and groups likely to be affected of any possible consequences relevant to them that they anticipate.

Students must take into account and, where relevant and to the best of their ability, make explicit the extent to which their own personal and cultural values affect their field study.

Students must not represent as their own work, either in speaking or writing, materials or ideas directly taken from other sources. They must give full credit in speaking or writing to all those who have contributed to their work.

II. Responsibilities to Hosts

Students should be honest and candid in all dealings with their own institutions and with host institutions. They should ascertain that they will not be required to compromise either their responsibilities or ethics as a condition of permission to engage in field study. They will return a copy of their study to the institution sponsoring them and to the community that hosted them at the discretion of the institution(s) and/or community involved.

III. Failure to comply

When the AD(s) feel that the student has violated this statement of ethics, the student will be placed on probation.

In the case of egregious violations, students can be subject to immediate dismissal under the conditions of the SIT STUDY ABROAD dismissal guidelines.

I, Madeline Ross, have read the above Statement of Ethics and agree to make every effort to comply with its provisions. Date: October 24, 2011

ILP Application for Review of Research with Human Subjects
Fall Semester 2011
School for International Training - Study Abroad
South Africa: Community Health, Program

ILP Details

1. Student's Name: **Madeline Ross**
2. Student Phone and/or E-mail: **083-700-1388, mross4@tulane.edu**
3. Title of ILP: **Effectively Filling Gaps in Care: A Comparative Study of Models of Government Partnerships with Community Health Organizations in KwaZulu-Natal, South Africa**
4. ILP Advisor Name, Title, and Contact Telephone: **Zandile Wanda**
Human Subjects Review

1. Brief description of procedures relating to human subjects' participation:

- a. Indicate proposed number of persons that may be participating per set
Experts (Staff Members) – 5+ (Tracer team members, nurses, doctors)
Academics – 0
Minors – 0
Other – 0
- b. Provide details of any cooperative institution? What is it, who is the contact, and how was their permission obtained?
Gomane Clinic. Impendle, KwaZulu-Natal
Mr. Siyabonga Zuma, 072 218 8686 (Head of the Tracer Team)
Permission was obtained through Zandile Wanda.

Bekimpilo Trust, Durban, KwaZulu Natal
Mabhi Ndamane, 083 759 9016 (Operational Manager)
Permission was obtained through Zandile Wanda.
- c. What will participants be asked to do, or what information will be gathered? (Append copies of interview guides, instructions, survey instruments, etc. where applicable).

Participants at Gomane Clinic will be asked questions, as seen below:

Doctors/Nurses:

1. Do you think that the community you treat understands TB and has an adequate understanding of how it is treated?
2. What is the most important part of the support system for TB patients beyond the clinic walls?

3. Do you think that TB tracer teams are a necessary part of the TB support system?
4. Do you think that TB tracer teams are effective in improving the quality of patient care?
5. Do you think that TB tracer teams are effective in preventing the emergence of drug resistant strains?

Tracer Teams:

1. Do you think that TB tracer teams are a necessary part of the TB support system?
2. Do you think that TB tracer teams are effective in improving the quality of patient care?
3. Do you think that TB tracer teams are effective in preventing the emergence of drug resistant strains?
4. What are the biggest challenges you face in tracking patients?
5. What methods do you utilize in tracking patients?

Patients/Members of the Community:

1. What is TB?
2. What effect does TB have on you? Your family? Your community?
3. How do most people treat TB in your community?
4. Was the TB treatment prescribed fully described to you at the clinic or hospital?
5. What did you have to do to treat your TB?
6. Why didn't you come to the clinic on ___day?
7. What happens if you stop taking your medication or don't come for a check up at the clinic?
8. Do you know why the TB tracer team has come to your house?
9. Do you think TB tracer teams are helpful or hurtful?
10. Do you think that the government has a right to trace you?

Participants at Bekimpilo Trust will be asked questions, as seen below:

Staff:

1. How important are NGO's, like Bekimpilo Trust, to public health in South Africa?
2. What gaps in primary healthcare does Bekimpilo Trust fill?
3. What existing governmental or non-governmental structures does Bekimpilo coordinate with?
4. To what extent is Bekimpilo independent from the Department of Health despite almost total governmental funding?
5. Which services (in clinics/communities) are lacking as a result of limited funding?
6. What is the most successful or effective service provided by Bekimpilo Trust?
7. What is the least successful or effective service provided by Bekimpilo?

8. Which diseases or health problems most affect the semi-rural townships in which Bekimpilo works?
9. Do you believe TB is a bigger problem in these semi-rural townships or in more remote rural areas?
10. Do you think CHW's coordinated by government clinics provide adequate follow-up care for patients outside clinics?
11. Is TB tracing an important service to provide?

All other components of the learnership will be completed through observation and informal conversation, as well as through research from secondary sources.

- d. Reciprocity – what is being given back to each participant?

Though it is arrogant to think that an undergraduate student's evaluation of the effectiveness of community-based healthcare schemes based solely upon experiences with three organizations will have resounding effects, the individuals contacted in the study will be given the chance to disclose feedback on the existing system, empowering each individual's voice. Further, the learner hopes to aid the tracer team, CHW, or health team in increasing efficiency and decreasing individual work load.

2. Protection of human subjects. Before completing this section, you must read and agree to comply with the SIT Study Abroad Statement of Ethics. Even if no research is being done it is incumbent on any person volunteering or learning to ensure no harm might be done.

- a. Have you read and do you agree to comply with the World Learning Ethics Statement noted above?

Yes.

- c. Identify and indicate whether any participants risk any stress or harm by participating in this Learnership Project? If there is even a slight possibility, should this research go ahead? Why? How will these issues be addressed? What safeguards will minimize the risks? (*Even if you do not anticipate any risks, explain why*)

It is very unlikely that participants in this learnership will be harmed in any way. The tracer teams, CHW's, and health teams all visit patients to their homes, which, in many ways, does infringe on the patient's privacy and may cause social harm due to the stigma attached to TB, HIV, and other diseases. However, my participation in tracking and observation during home visits will not exacerbate any of these stresses. Extreme discretion will be observed outside of the actual visits to ensure privacy and confidentiality.

- d. Who might you need written consent from?

The learner will need written consent from all individuals partaking in interviews, in order to use the material in the written study.

- e. Indicate whether any participants are minors or not likely to understand consequences of participation? If there are, how will they be protected, and who will ensure their rights are protected?

While no minors will participate in this learnership, individuals unable to speak or comprehend English sufficiently must be provided with a written explanation of the consequences and their rights in their first language.

- f. Will you ask questions of any persons who may appear unable to negotiate freely? How will you protect them from feeling coerced?

While most of the questions asked in formal and informal interviews with experts and academics should be free from confounding factors like coercion, the answers to questions posed to patients and community members may be twisted, depending on the audience listening. The learner will do her best to ensure privacy when questions are asked and will use discretion in halting an interview if the participant seems uncomfortable in the situation.

3. Human Subject Protection Essay:

Describe who you will be interviewing and how you will ensure that the following will be protected.

- a. Privacy (protecting information about participants): Refers to an individual and their investment in controlling access to information about themselves.

Individuals reserve the right to withhold any information unless the withheld information directly affects the safety of another individual. For this reason, the learner recognizes her inability to presume cooperation and full disclosure from every participant questioned. The learner hopes to obtain personal anecdotes, opinions, and general information concerning tuberculosis tracer teams, CHW's, and NGO's. However, the learner will not seek any information from healthcare professionals that breaches doctor-patient confidentiality. The only records the learner hopes to utilize are clinics' general records pertaining to number of tuberculosis patients and number of defaulters. Also, all information gathered from conversations in the clinic will be excluded.

- b. Anonymity (protecting names and other unique identifiers of participants): Whose names should not be attached to the data, unless subject chooses to be identified?

Throughout this learnership, anonymity will be the default protocol. All participants interviewed or spoken with in passing will remain anonymous, unless they explicitly ask to be named. All observations made during home visits, tracking, and the entirety of any treatment process will remain general to the serviced area in Impendle or semi-rural township, without any geographic or specific demographic identifiers. Academics consulted

in personal communication and through lectures given through SIT will be named, though each will be given the option to remain anonymous.

- c. Confidentiality (protecting data about participants): How is access to data limited? Researcher will consider how coding will be kept separate from information obtained; how data will be stored and when will it be destroyed; whether data will be used in the future and, if so, how permission for further use will be obtained.

While any data collected through interviews and conversation will only be utilized upon the receipt of explicit, written consent to publish, anonymity will be strictly observed by keeping data records confidential. Also, records of observations will only include general identifiers, so as not to pinpoint any specific location or individual. These data records will not accompany the learner on site visits, so as to ensure they are not lost or taken. Upon completion of the learnership, the learner will dispose of any records of participant information lacking consent the accompanying consent forms. However, contact details will be kept for named participants to be used in the case of future publication or usage.

- d. Organizational integrity. If the ISP is to be read by the organization, what types of information should be excluded from the report.

If this ISP is to be read by my host organizations, Gomane clinic or Bekimpilo Trust, all criticism of the work of individuals shadowed will be excluded. While general critiques of the overarching community-based healthcare system may be made, any criticism specific to Gomane Clinic or Bekimpilo Trust's efforts will be excluded.

4. Participant observation situations; Declaration:

When participating in an organization or community I will:

- a. Undertake a bilateral negotiation with the group I am participating with.
- b. Work with gatekeepers to assist in that negotiation and draw up a contract with that gatekeeper, defining roles and conditions of access.
- c. Work with the gatekeeper to communicate that contract with the group.
- d. Refrain from criticizing and intervening unless invited by the gatekeeper in consultation with the group, and even then with due tact and caution.

By signing below I certify that all of the above information is true and correct to the best of my knowledge, and that I agree to fully comply with all of the program's ethical guidelines as noted above and as presented in the program and/or discussed elsewhere in program materials. I further acknowledge that I will not engage in ILP activities until such a time that both my ILP proposal as well as my Human Subjects Participation application are successful and I have been notified by my Academic Director(s) to this effect.

Student's name (signature)

Date: October 24th, 2011

Madeline Ross

Student's name (printed)

Consent Form For Adult Respondents in English FORM A

I can read English. (If not, but can read Zulu or Afrikaans, please supply). If participant cannot read, the onus is on the researcher to ensure that the quality of consent is nonetheless without reproach.

I have read the information about this learnership project and had it explained to me, and I fully understand what it says. I understand that this learnership is trying to find out how tracer teams help support tuberculosis patients and treatment in rural KwaZulu-Natal.

I understand that my participation is voluntary and that I have a right to withdraw my consent to participate at any time without penalty.

I understand and am willing for you to ask me questions about :

Tuberculosis infection and transmission
The role of tracer teams
Personalized TB care and follow up
Multi-drug resistance

I **do/ do not** require that my **identity (and name)** be kept secret. I understand that, if requested, my name will not be written on any questionnaire and that no one will be able to link my name to the answers I give. If requested, my individual privacy will be maintained in all published and written data resulting from this learnership project.

I **do/ do not** give permission for a **photograph** of me to be used in the writeup of this learnership or for future publication. I understand that the learnerer will not use or provide any photographs for commercial purposes or publication without my permission.

I understand that I will receive **no gift** or direct benefit for participating in the learnership.

I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (18 Alton Road, Glenmore, Durban).
I know that if I have any questions or complaints about this learnership that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982).

I agree to participate in this learnership project.

Signature: Siyabonga Zuma (Signature Held) Date: 03/11/11

Signature Madeline Ross Date: 03/11/11

FORM B

I can read English. (If not, but can read Zulu or Afrikaans, please supply). If participant cannot read, the onus is on the researcher to ensure that the quality of consent is nonetheless without reproach.

I have read the information about this learnership project and had it explained to me, and I fully understand what it says. I understand that this learnership is trying to find out how NGO's and community based organizations fill gaps in necessary primary healthcare provision in South Africa.

I understand that my participation is voluntary and that I have a right to withdraw my consent to participate at any timewithout penalty.

I understand and am willing for you to ask me questions about :

Public-Private Partnerships
Non-Governmental Organization
Experience at/with Bekimpilo Trust
Community Health Workers
TB Tracer Teams
Primary Heathcare Provision

I **do/ do not** require that my **identity (and name)** be kept secret. I understand that, if requested, my name will not be written on any questionnaire and that no one will be able to link my name to the answers I give. If requested, my individual privacy will be maintained in all published and written data resulting from this learnership project.

I **do/ do not** give permission for a **photograph** of me to be used in the writeup of this learnership or for future publication. I understand that the learnerer will not use or provide any photographs for commercial purposes or publication without my permission.

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I know that if I have any questions or complaints about this learnership that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982).

I agree to participate in this learnership project.

Signature _____Mabhi Ndamane (Signature Held)____ Date: _____18/11/11_____

Signature _____Madeline Ross_____ Date: _____18/11/11_____

Confidential Section

Gomane Clinic

While Gomane Clinic boasts a 0% defaulter rate, the learner's analysis of patient records proved somewhat contradictory to this assertion. The learner was asked to assist the TB Clinic in completion of subsections of patient files left blank, as there was to be an inspection by the Department of Health the following week. Though the TB nurse wrote notes after each patient visit, she did not complete the calendar of dosages included in every TB file (as mandated by the Department of Health). On this calendar, the nurse should mark the treatment initiation date and every following appointment or date upon which the patient presents to the clinic without an appointment. The nurse is responsible for counting the number of days between appointment dates and dispensing an equal number of treatment dosages. However, the nurse at Gomane TB Clinic dispensed 28 dosages to every single patient that presented to the clinic and scheduled an appointment date that ranged from 25 to 45 days away. Therefore, 28 dosages were given each time, completely disregarding the time to the next appointment day. Upon review of every patient file and completion of the calendar (using the nurse's notes from patient visits), the learner was shocked to find that more than two thirds of Gomane's active TB patients were "interrupting" treatment *each* month. Streptomycin injections for retreatment patients were even more haphazardly documented. In fact, many retreatment cases were incorrectly documented as new TB patients on paper, despite treatment regimens correctly prescribed for retreatment cases. Though the clinic's definition of "defaulters" only includes patients that have failed to take TB treatment for over two months, the issue of such large numbers of "interrupters" cannot be ignored. It is just this sort of

inadequate treatment administration that leads to the emergence of drug resistance.

However, patients cannot be held entirely at fault if the clinic itself fails to properly calculate the dosages necessary for distribution before the next appointment date.

Bekimpilo Trust

Overall, Bekimpilo Trust displayed a much higher quality of care provided in their clinics and during home visits. However, the staff did demonstrate a clear lack of knowledge and training on some fronts. The health team possessed little knowledge of nutrition and wound care. In one instance, a nurse's discretion was questioned as she strongly discouraged an 18 year old female to refrain from sexual intercourse until age 21 in front of a full waiting room, publicly shaming the girl. Yet this one instance proved an exception from the norm.