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The everyday labor of global health – fighting drug resistant Tuberculosis in Tugela Ferry, KwaZulu Natal.

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August 2006, XVI International AIDS Conference, Toronto.

On August 17 2006, Dr. Neel Gandhi, a young physician from Yale University, gave a late-breaker presentation to a packed room, filled with thousands of people. In his talk, titled "High Prevalence and Mortality from Extensively Drug-Resistant (XDR) TB in TB/HIV Coinfected patients in Rural South Africa"[1] he explained that a district hospital in Tugela Ferry, KwaZulu Natal had, over the course of a year, identified 221 cases of multi-drug resistant tuberculosis (MDR-TB), including 53 cases of extensively drug-resistant tuberculosis (XDR-TB.) By contrast, the US had seen only 128 cases of MDR-TB in 2004, and a global survey of XDR-TB cases had only identified 347 cases of XDR worldwide. Fifty-two of the 53 cases of XDR-TB in Tugela Ferry had died.

Neel Gandhi was confident that he had just presented important news to the international HIV/AIDS community. When he sat down however, he wasn't sure what people's reaction would be.[2] As is often the case with conference presentations, the program was running behind schedule, and there was no time for questions.[3]

The international community's response soon became apparent. The next day, the New York Times and American National Public Radio (among others) ran stories about a

[1] Neel Gandhi, et al. XVI International AIDS Conference, Toronto, August 2006.
[2] Sarita Shah, interview by author, March 30, 2007.
[3] Transcript of Oral Abstract Session: Late Breaker Track B. XVI International AIDS Conference, August 17, 2006. Downloaded from kaisernetwork.org.

powerful and resistant tuberculosis strain striking South Africans with HIV,[4] as did South African media outlets. Those who didn't pick up on it immediately, followed suit by September 7, when the South African Medical Research Council (MRC) and the US Centers for Disease Control and Prevention (CDC) held an expert consultation meeting in Johannesburg to discuss strategies to deal with the threat of XDR-TB in Southern Africa. As Karin Weyer, one of the conveners of the meeting put it: "the press conference was in a small room organized for 12 journalists that we were expecting, for half an hour. And eventually, it turned into a one and a half hour conference with all the major international press also being there: CNN and BBC and others. And more than 40 journalists if I remember correctly."[5]

People in the Umzinyathi health district[6] (which includes Tugela Ferry) soon experienced a media siege, of sorts: "the story just blew out of proportion. The news, the papers. And as a district office we were the worst... we were frustrated because we were receiving calls from all over. All the radio stations. […]You attend a meeting; in no time there are people around, up and down with cameras."[7]

It wasn't just the media that were impressed: Graeme Meintjes, a TB expert from Cape Town, explained that "myself and anybody working in a developing world situation

[4] All Things Considered, August 18, 2006, NPR "Resistant TB Strikes South Africans with HIV". The New York Times, August 18, 2006, "Doctors Warn of Powerful and Resistant Tuberculosis Strain"
[5] Karin Weyer, interview by author, July 8, 2010.
[6] Tugela Ferry is a small trade town within the Municipality of Msinga. Msinga is also a subdistrict of the Umzinyathi health district. The Church of Scotland Hospital (COSH) is a district hospital located in Tugela Ferry, and is the only hospital in Msinga.
[7] Fikile Ngema, interview with author, October 13, 2010, Tugela Ferry.

working with TB knew that this was a staggering finding, and essentially it was like uncovering the tip of an iceberg."[8]

Six years later, there is a consensus among TB/HIV researchers and clinicians that the announcement of XDR-TB was a crucial moment in the fight against TB/HIV in South Africa and elsewhere, leading to increased international and local funding and interest in combating tuberculosis. [9] For my PhD dissertation in the History and Sociology of Science, I have been studying events that led up this moment, and how the story of XDR-TB has played out since then. I have spent the past year in KwaZulu Natal investigating the South African side of XDR-TB.[10] As part of this work, I have been living in Tugela Ferry for the past eight months, working on an ethnography of the TB program at Tugela Ferry's Church of Scotland Hospital (COSH), and of the research programs of Philanjalo, an NGO affiliated with COSH.

The excitement and cutting edge nature of XDR-TB is clear from many of the interviews I have conducted with US and South African researchers who were involved in uncovering and explaining Tugela Ferry's outbreak. From the American perspective, the research in Tugela Ferry became an exciting example of the rising field of "global health."[11] Dr. Neel Gandhi (with whom I opened this article) and others have been

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[8] Graeme Meintjes, interview with author, May 14, 2010, Cape Town.
[9] For example, the K-RITH TB research institute, currently being built on UKZN's medical school campus, was funded by the US-based Howard Hughes Medical Institute and is a direct result of events related to the XDR-TB announcement.
[10] I started this project in 2007, when I wrote a masters paper on the making of XDR-TB; looking closely at the origins of the name and definition of XDR-TB.
[11] The concept of "global health" is poorly defined, perhaps essentially American and possibly not legible in the South African context. But it is certainly an energized, exciting field that has been expanding in US academia.

building promising careers around their research on TB in South Africa. A succession of international (mostly American) medical students and physicians has come through Tugela Ferry and Durban to work on HIV/TB. Even 6 years later, there is still plenty of innovative and stimulating work to be done; though activities have moved from trying to determine "what happened" to understanding "what to do about it" and expanding the knowledge gained in Tugela Ferry to the rest of the province and the rest of South Africa.[12]

In this paper, I now turn away from these international visitors to consider what "global health" looks like from a local perspective. Specifically, I look closely at the TB office at the Church of Scotland Hospital and consider the engagement of two groups of staff: injection nurses and tracer teams. Their activities are essential to the management of drug-resistant TB (and thus the global health enterprise), yet these workers do not directly receive the advantages of being included in a global endeavor.

Community-based Management of MDR and XDR-TB

Since 2007, the centerpiece of Tugela Ferry's strategy to combat the high prevalence of drug resistant tuberculosis has been decentralized, community-based management. This innovative (and somewhat controversial) program means that MDR and XDR patients who are stable are not hospitalized for the duration of their treatment (which takes at least a year). Instead, they come to MDR clinic (in Greytown) or XDR-

[12] Philanjalo, the NGO officially housing most of the TB research activities in Tugela Ferry, has recently received a grant from URC (University Research Corporation) to implement community-based treatment of MDR-TB in all provinces.

clinic (in Durban) once a month, and take their treatment at home (ideally with the help of a treatment supporter). MDR and XDR patients are required to receive injections several times a week (in addition to pills), and these are administered at their homes, where injection nurses come to find them.

At the 2010 South African TB conference, several sessions highlighted the advantages of community-based management of MDR-TB, citing excellent treatment outcomes in pilot studies in Msinga and Khayelitsha, in the Western Cape. A video presentation from Khayelitsha showed a young, outspoken community worker visiting grannies in their urban shacks. Pictures from Msinga emphasized the rugged landscape and the traditionally dressed women and children who were being served in their own remote community. The viewer might imagine the heroic field-worker relating closely to her patients – perhaps psychosocial support and side-effects monitoring would work well in this setting.

The Injection Team – community treatment and support, or too many needles?

In fact, the work of an injection nurse rarely conforms to this romantic notion. Nurses often express how exhausting and tedious injection trips can be. I have accompanied several injection nurses on their rounds through the community and describe some of my impressions below.

One day in August, I met the injection nurse OG at the transport office at the back of Church of Scotland Hospital around 9 am. By the end of the day, I understood why OG had kept telling me just how difficult her job was, 10 days on, 4 days off.[13]

It had taken her an hour to organize the battered yellow bakkie she was to drive for the rest of the day.[14] Our first joint task was to wait in the chaotic Tugela Ferry petrol station to fill up. On our way, we stopped by a small shop to buy a meal of coke and chips.

Our yellow DoH vehicle apparently had no suspension to speak of, and after we had spent a day driving on rocky, rocky roads through the Msinga countryside I was completely exhausted. The next day, my back was aching and my shoulders were stiff, though I had recovered from the headache that had set in the day before.

We spent hours driving through a hilly, dry, winter landscape, to places without any obvious nearby water source or easy access to food. In some places there was evidence of significant agricultural activity and small-scale gardening, but in most places I couldn't help imagining that isolated huts had been dropped on vast fields of rocks and thorns.

For an outsider like myself, this harsh landscape was at times stunningly beautiful – different shades of brown and black; empty riverbeds which seemed to be flowing with red rocks. The stark, blue, cloudless sky created brilliant light-effects. When OG and I

[13] I confess that even now I occasionally wonder how hard a job can really be that involves driving in circles for several hours a day. Then I do another ride-along and remember that my body suffers dramatically every time.
[14] On another day I would watch the process of fetching the vehicle, which includes waiting for the mobile clinics of other departments, which park in front of the TB vehicles, to be moved.

had been driving for about 4 hours, we parked on the top of a hill under a tree to eat our lunch, and I pointed out how beautiful the scenery was. She looked at me and shrugged: "the people here live like animals. They don't even have any shops, nothing."

One client we visited appeared to be squatting in an abandoned compound surrounded by nothing but dust – a cluster of several decaying rondavels with brittle walls and absent roofs, situated around a former cattle enclosure which was missing most of its wooden beams. Only her own room was covered.

Over the course of the day, we managed to visit 8 patients in about 5 or 6 hours (on other trips we saw around 15 in a day). In some cases we drove straight to the patient's house, waited a few seconds to be invited in, and then entered the patient's room, where she handed OG her treatment card, and then lowered her pants for the injection. OG would tick off the date on the treatment card, while the patient rubbed the injection site with a swab. In other cases, we would ride up to an area and then dramatically honk the car's horn.[15] We would wait a few minutes, and eventually a gaunt figure would emerge in the distance. He would come up to the car, and wait by the door while OG drew up the injection. Only partially hidden from view, he would then receive the injection in the middle of the road. One clearing, where we met a gogo and her TB-patient husband, was littered with several dozen alcohol swabs – the evidence of weeks and months of injections. Others would meet the car under pre-designated trees, not too close to home, away from neighbors who might see the DoH vehicle and assume their neighbor was HIV positive.

[15] Or, since this is South Africa, we hooted.

Sometimes, we didn't find our patients. One patient had given up waiting for OG and had gone to the shops in the next town. No matter, OG would find her tomorrow. When we arrived at our last patient's house only his mother was there, saying that she had received a call from the hospital, claiming that her son was dead. OG had only spoken to this patient the day before, and promised the mother she would look into it when she got back to the hospital.

Overall, the encounters were brief. They did provide the patients with an opportunity to report problems if they arose, and since these patients saw OG several times a week, there perhaps wasn't much to discuss. There was a friendly conversation here, a moment of support there, but as the day got longer, the goal seemed to be to get back to home base soon. Why get out of the vehicle if that is not, strictly speaking, required? Why walk to the house if the patient can walk to you? Sometimes it felt like we were racing from house to house across surprising distances to then simply have the patient drop her pants, so that we could then move on. While the task of the day was achieved – injections were provided for TB patients who needed them – I couldn't help wondering if these trips into the community might be an opportunity for a more substantial engagement with community health and welfare. Perhaps the conference presentations had oversold something that is not more than a injection service.

Moments of tenderness, care, and concern.

This is not to say that all was rushed business as usual. One day, I watched another nurse – NC - carefully touch the left butt-cheek of an XDR-patient who had been

receiving injections for well over a year. She was feeling for a place that wasn't already sore and swollen. Eventually, NC and her patient agreed on a location. The patient closed her eyes and grimaced as NC tried to be as gentle as she could be.

Another nurse, RB, came across a patient with terrible eye-pain and shingles in his face – and she expressed grave concern for his well-being. She mentioned his case in the nurses' meeting the next morning, but the doctor had already ordered eye-drops the week before, so it was unclear what to do next.

On another occasion, OG found her patient lying on a dirty mattress in a very untidy room that had not been cleaned recently. OG called in the patient's sister in law and informed her in no uncertain terms that it is her responsibility to keep the patient's room clean. She implied that if the patient didn't get better, it might be her fault for not giving the medication a chance to work.

Interactions with the family could be incredibly frustrating – when LX (another nurse), my research assistant and I approached one patient's home we realized that we had entered in the middle of a loud fight. The patient's mother was accusing the patient of being an abusive alcoholic and was desperately asking us for help. We suggested that she needed to go to the social worker, or, if he was violent, to call the police. We politely listened to the dramatic exchanges for quite some time, but we eventually moved on, leaving this family's problems completely unresolved.

Thus even when injection nurses tried to help their patients beyond the injections themselves, it was not always clear what the next step would be. Other resources (like social workers and home based care workers) were available, but not always satisfactory.

TB Careers?

There is a global market in data coming out of Tugela Ferry. The research-evaluation of the community-based management of MDR-TB is ongoing, and preliminary studies have been presented at conferences by several different groups. Yet most of the injection nurses are not fully aware of the fact that their activities are an object of great interest. They are strongly aware of certain every-day challenges that make their lives difficult – including the poor vehicles they drive, the absence of spare tires, the poor roads, and the poor conditions their patients live in, independent of their TB diagnoses.

They are also aware of a certain amount of HIV/TB tourism – requests for ride-alongs with the injection teams are not infrequent, and the visitor's purpose is not always explained too clearly. Visitors over the past 8 months have included an American public health historian, an American photojournalist, an American visiting doctor and her husband, and a delegation of TB program managers from Mpumalanga, among others. I myself am the odd-ball who keeps coming back. Recently, one of the TB nurses finally asked a question that had been bothering her: "Erica, why is it that you guys come from overseas to work on TB and HIV? Don't you have TB in America?" Unfortunately, the answer is truly devastating: "No, we don't. Not to this extent." One person explained to me that this is yet another piece of evidence for what she has always suspected – that black people are cursed by God.

While injection teams perform necessary – even *interesting* work, there is little glory in chasing down patients and giving them injections. Injection nurses are witnesses to the process of going through MDR-TB treatment, but they are not attending conferences or workshops where they can put their work on display to be admired, nor do they generally provide input into the work that is presented there. They have relationships with patients, but these relationships are tenuous, since they are negotiated primarily through the inflicting of pain in the form of an unwanted, but perhaps life-saving injection. Injection nurses rarely get to follow their patients to the very end of their treatment and potential cure, since the injections are stopped before the patient is fully recovered.

In fact, one administrator argued that despite the fact that TB treatment is almost entirely nurse-driven, it was never COSH nurses who provided significant intellectual input into how to manage the MDR-TB outbreak. Rather, TB nurses did the routine "donkey work" of discharging, transporting and transferring TB patients, while and it was researchers from outside who had truly made an impact on programs for MDR-TB in Msinga.[16]

Yet, it is these nurses (and others) who maintain contact with the patients and ensure that they remain within the research programs, able to contribute to the research data. They would actually know if there was some sort of pragmatic problem with how the public health or research program was designed. But generally, nobody asks them. This became blatantly clear, when the department of health district manager, in an

[16] Interview with author, January 2011.

exception to this rule, decided to interview several of the injection teams as part of a small evaluation of the community-based management of MDR-TB. He asked them what the biggest challenges were. Most of them mentioned logistics and infrastructure, such as the state of their vehicles, or the complexities of caring for patients who came to Tugela Ferry despite living in a different health district. In addition it emerged, however, that none of them had ever received training regarding the fact that they were now doing "community management of MDR-TB" – despite the fact that this is a much discussed topic at TB conferences. Several nurses expressed to me that they were absolutely elated about being able to communicate with the district manager about their work (for the first time), and that they hoped there would soon be improvements.

The Tracing Team - Government surveillance or casual cruising?

While injection teams make sure patients get their injections on schedule once they have been put into community treatment, it is the tracing teams that find new patients, or get in touch with patients who failed to come to fetch their MDR and XDR medications. Tracers go out on assignment to find specific people, screen the relatives of MDR-TB patients for disease, and touch base with outlying clinics to see if their patients are all coming to fetch their treatments. At times, they participate in community events and encourage people to test for HIV and TB. If a positive TB result comes back from the lab (especially MDR-TB or XDR-TB), it's the job of the tracing team to find the person who the result belongs to.

This tracing process is essential to the successful conduct of research (to maximize recruitment numbers and minimize the sets of incomplete data due to patients "lost to follow-up.") At the same time, the tracing team represents an important surveillance arm of a state-sponsored public health program. Tracers themselves occasionally make comments to this effect, as they move through the Msinga landscape. As we were negotiating a narrow road hugging a mountain, tracer GT pointed to huts in the distance, at the end of the road, saying: "there didn't used to be a road here – the government built this road so that we could find these people. But they don't want to be found." Another tracer told me: "Dr. Bamber calls me the map." He explained that he knew every MDR patient from the past 6 years this side of the Tugela river, and that that means that he pretty much knows every community. "They call me by name as I drive out there – anywhere." While researchers trying to map the locations of TB patients employ GPS data, the actual tracers prefer to use their heads (as do the injection nurses who quickly memorize their patients' wherabouts).

One patient told me that she had tried to run away from the painful injections by going to stay with her husband's family in another part of Msinga. The TB team found her anyway, and convinced her to finish her treatment, letting her know that "if I run away, it's my life."

Certainly, tracers and injectors aren't the only government representation criss-crossing the Msinga roads, either. In some parts of Msinga we rarely come across another vehicle, but when we do, the plaques on the sides of the bakkies identify them as belong to the Msinga municipality, SASSA (South African Social Security Agency), the

department of education, the department of agriculture, and occasionally the police, etc. Other vehicles belong to NGOs active in Tugela Ferry, sending out social workers, nurses, community workers, etc. These services provide services and collect information – at times their presence is welcome, at times it is not.

Yet the penetration of this surveillance and service provision is in no way complete – for this reason departments like Home Affairs, SASSA, and the Department of Health are present at municipal and community events, allowing people to apply for I.D. books, apply for social grants, and screen for TB, HIV and high blood pressure at mobile sites.

Back to the tracer teams – delivering bad news.

One task of the tracer is to collect TB culture results from the TB office, and to tell those patients who had lab results indicating they had MDR-TB or XDR-TB the bad news. Weeks earlier, a patient would have coughed into a bottle either because they were feeling sick or participating in a screening event. It takes *at least* 6 weeks before the Durban-based lab sends a positive MDR-TB result back to Tugela Ferry.

One day, GT and I notified a patient who was already being seen daily by the injection team because she was a TB retreatment case[17] Just the week before I had seen her together with OG, and she had expressed joy about the fact that she only had 2 more weeks of painful injections. Thus, when GT arrived to tell her that the lab had diagnosed her with MDR-TB (and that she had at least 6 more months of painful injections ahead of

[17] Patients who have been previously treated for TB but are now again being treated for TB receive injections of streptomycin for 2 months.

her) she was visibly devastated. She switched from Zulu to English, exclaiming, "You must be joking!" and walked away from us with tears in her eyes. GT informed her that she needed to get to the hospital as soon as possible. Surprisingly, by the time we got back to COSH, she was already waiting in line at the TB office, wearing a surgical mask to prevent her TB from circulating in the air.

That same day, we were looking for another patient whose MDR-TB result had arrived in the past week. We knew her name and the area she was from, but we didn't have a detailed address.[18] Once we were in the general area, we asked for directions two or three times before we found the compound. One person told us that the woman we were looking for had died a month or two before.

When we arrived, we were eventually met by the head of the household, who is also the patient's father. He came to speak to us by our bakkie. GT informed Baba that his daughter had died of TB, and in fact had died of MDR-TB, the type of TB that doesn't respond to the normal TB treatment. Baba then responded at length, explaining that he knew his daughter had been on TB treatment and that she had been at the hospital, but that he didn't understand why she had died. He had called the nurse at the hospital, but she didn't have any answers for him.

He was a traditional healer and had been taught (in a course run by hospital nurses) how to identify TB and to refer patients with TB to the clinic, because *TB is*

[18] The TB office is quite meticulous about obtaining the name of the nearest school and the name and grade of a child who might be able to direct hospital staff to the patient's house. Other hospital departments usually do not collect this information. Interestingly, school teachers always appear happy to see TB tracers, and they release children from class to direct tracers to their relatives.

curable.[19] Thus, when his daughter died of this curable disease despite treatment, he was mystified and wondered if he had made a mistake in sending her to the hospital instead of taking care of her himself. He thanked GT for letting him know that it was in fact *MDR*-TB that had killed his daughter, thus resolving his confusion.

GT then proceeded at length to ask questions about the family to help establish whether anyone else in the household was at risk for TB. He asked about the number of rooms the family slept in, the number of children in the family, the family's sources of income, the distance to water sources, type of toilets and firewood, etc. When he finished the survey, he distributed sputum-collection bottles for the family members who had been in contact with the woman who had died of MDR.

For our last visit of the day we drove quite a distance, only to find that the person we were looking for had moved to Newcastle, and thus was outside of our district. We asked the relative we found to please call her and tell her she had TB and needed to go to the hospital.

Like the injection nurses, tracers often find their jobs quite difficult and tedious. They too struggle with the extensive driving. Even more than the injection nurses – many of whom had been transferred to TB work from other wards of the hospital and considered TB work to be just another job – the tracers I spoke to expressed a certain amount of disappointment in the exact nature of the work they do. They were recruited to do "community work," but the exact nature of the work is difficult and does not

[19] TB is curable – this is the mantra of all TB-related campaigns. Even in the presence of MDR-TB and XDR-TB, the vast majority of TB in Tugela Ferry is drug-sensitive and can be cured if it is diagnosed early in its course, if patients take their drugs religiously, and if underlying problems (such as HIV/AIDS) are also managed appropriately.

provide a ready emotional connection to the community. Like the injection nurses tracers also cannot gain fulfillment through involvement in the global health aspects of their work. Even though they do actively collect household data on MDR-TB and XDR-TB patients, they are unable to name the investigators who are planning to compile that information (perhaps to say something about the relationship of poverty to TB transfer).

In conclusion

In this paper, I have attempted to contrast some of the excitement of global health research on XDR-TB with the everyday public health practices required to manage drug resistant tuberculosis in Tugela Ferry, South Africa.

In this first, preliminary attempt to engage with my field notes and interviews regarding the every day work of managing tuberculosis I have tried to paint a picture of some of the themes which emerge, hopefully providing some food for thought and discussion regarding what may seem to be an *absence* of global health activity, in tasks that are in fact crucial for the generation of the data that is the basis of global health careers. The fact that the excitement does not translate down to the ground level of public health in Tugela Ferry may turn out to be an impediment in maintaining high quality TB services over the long term, since there is little feedback between different levels of program management, and because the motivation for a tiring and repetitive job is difficult to maintain in the absence of a greater narrative convincing employees of the importance of their work.