1-1-2014

The Making of a Global Health Crisis: Extensively Drug-Resistant Tuberculosis and Global Science in Rural South Africa

Erica Christine Dwyer
University of Pennsylvania, ericadwyer@gmail.com

Follow this and additional works at: http://repository.upenn.edu/edissertations

Part of the African Languages and Societies Commons, African Studies Commons, History of Science, Technology, and Medicine Commons, and the Social and Cultural Anthropology Commons

Recommended Citation
http://repository.upenn.edu/edissertations/1266

This paper is posted at ScholarlyCommons. http://repository.upenn.edu/edissertations/1266
For more information, please contact libraryrepository@pobox.upenn.edu.
The Making of a Global Health Crisis: Extensively Drug-Resistant Tuberculosis and Global Science in Rural South Africa

Abstract
This dissertation is a study of the social, scientific, political and rhetorical origins of extensively drug-resistant tuberculosis (XDR-TB) and the ability of a technical medical term, in concert with local clinical and government responses, to influence global biomedical action. XDR-TB, a form of tuberculosis that is resistant to most anti-tuberculosis drugs, was first creatively named and defined in 2005 in the context of a global laboratory survey documenting increasing tuberculosis drug resistance patterns around the world. In 2006, XDR-TB attracted international attention after a deadly cluster of drug-resistant tuberculosis was discovered in the rural South African town of Tugela Ferry, KwaZulu-Natal. International media and global health workers, responding to this news, defined XDR-TB as a critical threat to global health emanating from Southern Africa. As this dissertation shows, the association of XDR-TB with South Africa shaped the global response to XDR-TB, tying it closely to HIV/AIDS and linking it to the well-known history of South African AIDS denialism and public health inaction. The careful scrutiny given to South African XDR-TB by global public health experts profoundly impacted South African government responses to XDR-TB at the national, provincial, and regional levels.

This detailed, multifaceted case study of global health knowledge in-the-making is based on nearly two years of fieldwork in South African clinical and community settings and interviews with international and South African tuberculosis researchers, policy makers, clinicians, administrators and patients. Widely circulated representations of XDR-TB are juxtaposed with the personal experience of South African nurses and local government administrators to make the case that responsibility for and control of successful global health interventions is more broadly distributed than common conceptions of global health research imply. In addition, this research uses published documents, unpublished policy literature, and promotional materials to trace how medical, public, and political understandings of XDR-TB in South Africa changed over time and across geographical space. This research changes our understanding of the politics and practices of health interventions in Africa by linking together activities ranging from the crafting of scientific publication, to global policy decision making, local public resource allocation and in-home nursing care.

Degree Type
Dissertation

Degree Name
Doctor of Philosophy (PhD)

Graduate Group
History and Sociology of Science

First Advisor
Steven Feierman

This dissertation is available at ScholarlyCommons: http://repository.upenn.edu/edissertations/1266
Keywords
Drug Resistance, Global Health, South Africa, Tuberculosis, Tugela Ferry, XDR-TB

Subject Categories
African Languages and Societies | African Studies | History of Science, Technology, and Medicine | Social and Cultural Anthropology
THE MAKING OF A GLOBAL HEALTH CRISIS: EXTENSIVELY DRUG-RESISTANT
TUBERCULOSIS AND GLOBAL SCIENCE IN RURAL SOUTH AFRICA

Erica Christine Dwyer

A DISSERTATION

in

History and Sociology of Science

Presented to the Faculties of the University of Pennsylvania

in

Partial Fulfillment of the Requirements for the

Degree of Doctor of Philosophy

2014

Supervisor of Dissertation

_______________________________

Steven Feierman

Professor Emeritus, History and Sociology of Science

Graduate Group Chairperson

_______________________________

John Tresch, Associate Professor, History and Sociology of Science

Dissertation Committee

Adriana Petryna, Edmund J. and Louise W. Kahn Term Professor in Anthropology

Robert Aronowitz, Professor, History and Sociology of Science
THE MAKING OF A GLOBAL HEALTH CRISIS: EXTENSIVELY DRUG-RESISTANT TUBERCULOSIS AND GLOBAL SCIENCE IN RURAL SOUTH AFRICA

COPYRIGHT

2014

Erica Christine Dwyer
I dedicate this thesis to my mother, Helen Anne Dwyer, who has read every word of this dissertation (and many words that never made it to these final pages) more than once, and who moved across the country to help take care of my baby daughter – first while I finished the first draft, then while I returned to the busy clinical schedule of medical school. Mine is not the first dissertation she has supported – by my count, she has played a part in the successful completion of at least five doctoral degrees. Here I give her credit and thanks for the substantial love, dedication, intellectual, and physical work that she contributed to this one.
ACKNOWLEDGEMENTS

Over the course of writing this dissertation I have benefited greatly from the contributions and support of numerous friends, colleagues, teachers, and mentors, as well as scores of other people whose paths have crossed with mine along the way. The Department of History and Sociology of Science has been a phenomenal presence in my life for more than eight years now, and its faculty, staff and students have shaped me in more ways than I can account for. Steven Feierman has been my prime advisor and mentor since before I officially entered the department, and I have been fortunate to enjoy his seemingly unconditional support and encouragement, as well as a willingness to engage rigorously and seriously with any text I put in front of him. Often he knew before I did what the core issue was that I was trying to get at, and I found that my thoughts benefitted from being reflected back at me by his lens. He stoically bore the ups and downs of mentoring an MD/PhD student with many commitments, and heroically guided me by email and phone when I was “in the field” (or simply living in another city). He introduced me to the fields of African Studies and the African History of Medicine and this background permeates this dissertation, even though the subject matter is more transnational and more contemporary than such training might suggest. Robert Aronowitz has been a model and a resource for me since the day I came to his office to discuss a transition from laboratory science to the history of science. I have shared with him a fascination for curious ironies and unexpected twists in historical scholarship, as well an apparently compulsive need to open up the black boxes of medical categories. I thank him also for “knowing” what medical training is like and for the many forward-looking conversations about how to turn my “double life” into a career. Adriana Petryna has been my inspiration for pursuing contemporary problems and has supported my efforts to become a scholar conversant in anthropology and science and
technology studies. Working with her opened up new worlds of analysis. I also thank her for her generous introductions to colleagues working in the field of medical anthropology, human rights, and photography.

Other faculty and teachers in the History and Sociology of Science have profoundly shaped my understanding of the world, including Robert Kohler, whose first-year course in environmental history was probably the most mind-bending course I took. David Barnes introduced me to the History of Medicine and laid the groundwork for much of my work on tuberculosis. The experience of TA-ing HSOC 10 with him (and then with Kent Bream) was both fun and challenging, and helped me think about global health as an object of critical historical and anthropological study. Ruth Schwartz Cohen made sure that I was exposed to the fundamentals in the history of technology and held me to a high standard, encouraging me to pay high attention to detail – something which has served me well. Riki Kucklick was always a presence in the department, and we were never at a loss for interesting things to talk about, ranging from the sociology of African academia to the discomfiting shared understanding of German and Yiddish words to the best online shopping sites. Her presence has been missed. Mark Adams, I am sure, loved to torture me, but I thank him for teaching me most of what I know about the history of science. Beth Linker was often available for a friendly (or ascerbic) conversation and I admire her dedication to mentorship. The arrival of John Tresch during my early years in the department means that I now only have myself to blame if I don’t have a nuanced understanding of the social history of knowledge. He also provided insightful responses to my early musings about the morally ambiguous nature of global health. Projit Mukharji’s breadth and depth of knowledge in colonial medicine is an inspiration and I regret not taking more opportunities to learn from him, though he has always been willing and open to share. Kate Mason encouraged me to keep going, and gave me the opportunity to lecture in her classes. I have seen Andi Johnson’s path from brilliant
graduate student to first class lecturer and it has always been a great privilege to be her junior colleague. I plan to emulate her teaching style. Over the years I have had fascinating conversations with Susan Lindee about global health research, ethics, social responsibility and careers, and she provided me with critical insights for one of my grant proposals. She was also the teacher of my year’s gateway introductory survey class into the History and Sociology of Science. As such she had a formative influence on my entire cohort – including Meggie Crnic and Jason Schwartz. Them I thank for being friends and colleagues through times of exhilaration as well as stress. We took a strange pride in the fact that all three of our last names translate to “black.”

The graduate students past and present in the History and Sociology of Science (and elsewhere) who have provided good company, new insights, and opportunities for commiseration over the years include (though this is not an exhaustive list): Joanna Radin, Kristoffer Whitney, Jessica Martucci, Agyeman Boateng, Emily Pauley, Dominique Tobell, Corrina Schlombs, Josh Berson, Roger Turner, Matthew Hersch, Eric Hintz, Chris Jones, Damian Yarnell, Perrin Selcer, Joy Rohde, Liyong Xing, Ian Petrie, Andrea Johnson, Deanna Day, Jon Milde, Peter Collopy, Sam Muka, Marissa Mika, Rachel Elder, Tamar Novick, Jason Oakes, Lisa Ruth Rand, Elaine Lafay, Allegra Giovine, Mary Mitchell, Whitney Laemml, Gavin Steingo, Cathy van der Ruit, and many others who have gone before and come after. Maxwell Rogoski and Luke Messac as well as Nick Iacobi and Utpal Sandesra are fellow quirky MD/PhDs and I am glad for our community. Elise Carpenter has been my close friend and my older academic twin throughout my training. Josh Berson provided me with the initial nudge to start this project when he forwarded me a New York Times article about a new strain of drug-resistant tuberculosis in rural KwaZulu-Natal. Joanna Radin deserves a special shout-out for being my writing buddy. Her background in communications and STS as well as her commitment to both anthropology and history in many ways made her the
perfect reader of my early work. Matt Hersch was my friend and lunch companion for many years and I thank him deeply for his readiness to solve all problems with cookies. Joao Rangel-Almeida, with whom I first crossed paths when he was working as a visiting scholar in HSS, has been a good friend and an effective online cheerleader.

In South Africa, more than anywhere else, I have benefited from the generosity of strangers, many of whom are now my friends and colleagues. In Durban I found an academic home at the University of KwaZulu-Natal and was welcomed by Julie Parle, Catherine Burns, Keith Breckenridge, Jeff Guy, and several of their colleagues. Catherine Burns, especially, has been a node in South African – American transatlantic research, and I thank her for fascinating conversations and helpful pointers while sitting at her and Keith’s kitchen table. Gail Robbins shared her work with me over tea at the University and pointed me in several useful directions. At the Medical Research Council in Durban, I would like to thank Roxana Rustomjee and Paul Ngcobo for providing me with insights and resources (including transport to Tugela Ferry). At King George V Hospital Iqbal Master showed me around, welcomed me to meetings, and shared his perspective on research in South Africa. Janet Giddy has been a mentor and friend from the time we met at McCord Hospital in 2003 and I thank her for incorporating me into her household when I needed it. Thanks also to Marian Loveday for explaining local networks in TB research and for providing a bed to stay in Pietermaritzburg.

Over the course of my training and research several families have let me into their homes to teach me Zulu language and culture, and to provide a base within the communities I was working in. From deep in my heart I would like to thank Lunga Mkhize and her family in Maqongqo, who made it their mission to teach me Zulu even as they were suffering death and loss. Near Durban, I thank Tilly Mazibuko, Nozipho Mazibuko, Granny and Abulele in Molweni for welcoming me into their family and sharing the daily commute from the almost
rural homestead to the hospital in the city. I thank Nozipho for letting me in to her social life as a young adult, and Abulele for bringing light into my day whenever I was home. I also thank Michelle and Kevin Gordon with their children Alex and Gigi in Austerville for being wonderful, steadfast friends and for taking me in when I needed to be closer to town or wanted to hear about life in the medical school. Thank you Siva Danaviah for restorative meals and conversations. In Tugela Ferry Isah and Thobani T. Buthelezi graciously welcomed me into their home, where I also got to know their beautiful daughters, Zipporah, S’thokozile and Ruth. Thobani’s brother Mdumiseni (Bafana) also helped me navigate life in Tugela Ferry. Thank you for letting me in with open arms and for incorporating me into your family.

At the Church of Scotland Hospital and at the Philanjalo Care organisation in Tugela Ferry my research was made possible with help and guidance from numerous people, especially Dr. Tony Moll and Dr. Gerald Friedland, who agreed to take on the risk of having an outsider study their activities and ask questions about it. CEO Hans Human and Matron Dube also facilitated my presence. Others who welcomed and assisted me as colleagues and at times as friends included Dr. Sheela Shenoi, Dr. Sheila Bamber, Dr. Theo van der Merwe, Dr. Francois Eksteen, Dr. Claudio Marra, Dr. Nuala Hale, Dr. Jim Periselneris, Sister Msomi, Sister Madi, and the entire staff of the TB DOTS office, Mdu Mntambo, Nelisiwe Nhlangothi, Mxolisi Myeza, Hlengiwe Myende, Cebile Fuse, Njabulo Malembe, Thobeka Majola, and all the other research staff at Philanjalo, Eugene Meyers, Ralph Brooks, Nqobizwe Ngubane, Lungi Zondi, Vi Buthelezi, Goodness Zuma, Michelle and Chuck Possin, and many, many others. I thank you all and apologize to those who have not been mentioned – may the list be more complete when I publish the edited version of the book. Nomnikelo Mvelase deserves a special mention as a research assistant, translator, and transcriber who, mostly with good humor and spirit, took on the job of being my companion and cultural mediator.
and helped me navigate some of the difficult cultural and political terrain of TB in Tugela Ferry. I appreciated her efforts greatly, and without her I would not have been able to complete this dissertation. I would like to thank all the many people who shared their stories with me, patiently answered my questions, and whose willingness to engage with me was the foundation for this dissertation.

I shared my time in Tugela Ferry and Durban with many other itinerant and visiting researchers and medical workers, and shared housing with several of them, as well. I will not mention all of them here, but would like to highlight a few: Sara Sani, Zahir Kanjee, Krisda Chayachati, Elizabeth Wahl, David Carel, Lindsay Ryan. Many others were also a pleasure to spend time with. Thank you for sharing Tugela Ferry with me, for sharing good meals and touristy weekend trips, for engaging in deep conversations about the meaning of XDR-TB research in Tugela Ferry, for sharing your own experiences and research, and for your friendship.

This project would not have been possible without generous support from the University of Pennsylvania School of Medicine Combined Degree Program and the University of Pennsylvania’s School of Arts and Sciences (SAS). SAS funding included a Benjamin Franklin Fellowship, a Penfield Dissertation Research Fellowship, the Samuel H. Preston Presidential Prize Summer Research Fellowship and the Helfand Fund for History and Sociology of Science. In addition, fieldwork in South Africa was supported by the Social Science Research (SSRC) Council International Dissertation Research Fellowship, the Fulbright-Hays Doctoral Dissertation Research Abroad Fellowship and the Social Science Research Council Dissertation Proposal Development Fellowship. Both SSRC grants also gave me wonderful opportunities to connect with colleagues in my field and to engage in intellectual conversation with an amazing group of smart people immersed in their research. It was a privilege to share this stage of research development. Zulu language
training in South Africa was supported by the Fulbright-Hays Intensive Intermediate-Advanced Zulu Group Project Abroad program directed by Audrey Nonhlanhla Mbeje. This program not only improved my isiZulu skills but also put me in touch with a sassy group of people with an interest in South Africa, many of them talented scholars. Early experiences with South African AIDS science and research were supported by Williams College and the Robert G. Wilmers, 1990, Memorial Fellowship in 2002, and a 2003 Fulbright Fellowship to South Africa.

Thank you to my fellow travelers in the Penn MD/PhD program for being friends and colleagues on a long journey. Soon our class will be complete. Maggie Krall, Skip Brass, Maureen Kirsch and Mary Tiedeman have all worked hard to ensure our successful training and graduation. I thank Maggie for her regular “check-ins,” efficient problem-solving, and friendship. She was in fact the first person to read the entire dissertation from start to finish, and I am honored by that. I thank Skip for continuing to believe in the mission of training MD/PhDs in the social sciences and for remaining flexible, welcoming, and supportive as I carved my own path. At the medical school I would also like to thank “Suite 100,” specifically Helene Weinberg and Barbara Wagner for working with me as my combined schedule became increasingly complex and was made more so by my moving to Boston and my increasing loss of hearing. Thank you for never doubting that things can be worked out.

Last, but not least, I would like to thank my family. My parents, Helen Dwyer and James Dwyer have supported me emotionally and intellectually throughout my studies, and both have read and commented on significant portions of my work. My sister, Anne Dwyer, has been an inspiration for many years. Whenever I have difficulty writing or working out a problem, she is the person I go to first for conceptual and organizational help. My brother, Paul Dwyer, brings music into our lives, and his energy, incentive, and perseverance are a
model for me. It has been a joy seeing him often in the past year. My husband, Amar Majmundar, takes great pride in my work and actively gives me the space to pursue it, even as our combined career choices more often than not render our lives chaotic and difficult. I love him for that and look forward to juggling hard choices for many years to come. I thank my mother-in-law, Visharda Majmundar, for helping us juggle things by helping with our household in recent months and being a steady supporter. Finally, I thank our daughter, Ramona, for being a bright light in our lives, whose wondrous discoveries and growing capabilities continue to amaze us.
ABSTRACT

THE MAKING OF A GLOBAL HEALTH CRISIS: EXTENSIVELY DRUG-RESISTANT TUBERCULOSIS AND GLOBAL SCIENCE IN RURAL SOUTH AFRICA

Erica Christine Dwyer
Steven Feierman

This dissertation is a study of the social, scientific, political and rhetorical origins of extensively drug-resistant tuberculosis (XDR-TB) and the ability of a technical medical term, in concert with local clinical and government responses, to influence global biomedical action. XDR-TB, a form of tuberculosis that is resistant to most anti-tuberculosis drugs, was first creatively named and defined in 2005 in the context of a global laboratory survey documenting increasing tuberculosis drug resistance patterns around the world. In 2006, XDR-TB attracted international attention after a deadly cluster of drug-resistant tuberculosis was discovered in the rural South African town of Tugela Ferry, KwaZulu-Natal. International media and global health workers, responding to this news, defined XDR-TB as a critical threat to global health emanating from Southern Africa. As this dissertation shows, the association of XDR-TB with South Africa shaped the global response to XDR-TB, tying it closely to HIV/AIDS and linking it to the well-known history of South African AIDS denialism and public health inaction. The careful scrutiny given to South African XDR-TB by global public health experts profoundly impacted South African government responses to XDR-TB at the national, provincial, and regional levels.

This detailed, multifaceted case study of global health knowledge in-the-making is based on nearly two years of fieldwork in South African clinical and community settings and interviews with international and South African tuberculosis researchers, policy makers,
clinicians, administrators and patients. Widely circulated representations of XDR-TB are juxtaposed with the personal experience of South African nurses and local government administrators to make the case that responsibility for and control of successful global health interventions is more broadly distributed than common conceptions of global health research imply. In addition, this research uses published documents, unpublished policy literature, and promotional materials to trace how medical, public, and political understandings of XDR-TB in South Africa changed over time and across geographical space. This research changes our understanding of the politics and practices of health interventions in Africa by linking together activities ranging from the crafting of scientific publication, to global policy decision making, local public resource allocation and in-home nursing care.
# Table of Contents

**DEDICATION** ...................................................................................................................... iii

**ACKNOWLEDGEMENTS** .......................................................................................................... iv

**ABSTRACT** ............................................................................................................................... xii

**INTRODUCTION: Engaging Global Health** ........................................................................... 1
- Engaging global health.............................................................................................................. 6
- Dealing with absences and presences – where is health global? ........................................... 13
- A global health site.................................................................................................................... 17
- Local outbreak as global phenomenon ................................................................................... 19
- How to study this multi-headed beast .................................................................................... 21
- Historical overview of tuberculosis ....................................................................................... 26
- Outline of the dissertation ....................................................................................................... 35
- Methods ...................................................................................................................................... 38

**CHAPTER 1: Extensively Drug-Resistant Tuberculosis in South Africa – The Making of a Global Health Disease** ........................................................................... 43
- Inevitable Microbiology or Therapeutic Anarchy? ................................................................. 45
- A new cycle ............................................................................................................................... 55
- Keeping the momentum going – the origins of XDR-TB ....................................................... 57
- Documenting drug resistance worse than MDR-TB .............................................................. 58
- What’s in a name? The uses of the letter X ............................................................................ 63
- The importance of an moderate, yet extreme, definition ...................................................... 66

**CHAPTER 2: How XDR-TB Became South African** ............................................................... 74
- South African tuberculosis and the world ................................................................................. 78
- Tuberculosis before the time of AIDS ...................................................................................... 85
- Complexities of Co-Infection .................................................................................................... 92
- Managing TB/HIV coinfection in Tugela Ferry ....................................................................... 95
- The Sizonqoba Study ................................................................................................................ 98
- The power of treatment and the disappointment of treatment failure ..................................... 100
- Death despite conquering AIDS – MDR-TB was a surprising killer .................................... 100
- What was the appropriate response? ...................................................................................... 111

**CHAPTER 3: XDR-TB: A Global Threat Emerging from Africa** ........................................... 116
- Spreading the Word .................................................................................................................. 116
- Emergency expert consultation meeting .................................................................................. 132
- The WHO task-force on XDR-TB ......................................................................................... 139
- The definition of XDR-TB – once again, a problem ............................................................... 141

**CHAPTER 4: Dealing with a Time Bomb – At the Interface Between**
- Government Health Departments and Global Health Research .......................................... 151
- The tip of a deadly iceberg? .................................................................................................... 155
- The risk of infection .................................................................................................................. 164
Getting people into care: introducing community-based management of MDR-TB ............................................................................................................. 169
Why Tugela Ferry? ............................................................................................................. 179
From Tugela Ferry to Greytown and back ........................................................................... 188
The presence and absence of government in global health – a South African perspective ............................................................................................................ 195
From worst-case scenario to best practice ............................................................................. 199

CHAPTER 5: Finding Data in a Global Landscape ................................................................. 201
Controlling an Epidemic with Paperwork ............................................................................ 204
Foraging for information: The essential role of data managers ........................................ 210
Assessing the community-based treatment of MDR-TB (from outside the community) ........................................................................................................... 211
Improving the data ............................................................................................................ 215
Traversing the landscape: the banal nature of heroic and innovative work ................. 218
Going “out into the community” ....................................................................................... 220
Moments of tenderness, care, and concern ......................................................................... 222
Enrolling the global patient, locally .................................................................................. 225
Memory: Clinically useful, ineffective for research .......................................................... 227
Nursing work in a global community context ...................................................................... 230
Fundamental building block or donkey work? ................................................................. 231
In the field ......................................................................................................................... 233
The “first” ride-along ........................................................................................................ 238
Finding the real Africa ......................................................................................................... 241

POSTLUDE: An Ongoing Crisis and the Tyranny of Koch ............................................... 254
Escalation is inevitable ...................................................................................................... 256
INTRODUCTION: Engaging Global Health

“I have been a witness, and these pictures are my testimony.”-James Nachtwey, photographer.

On October 3rd 2008 well-renowned war photographer James Nachtwey, with help of the TED Prize and corporate sponsors, launched the website [www.xdrtb.org](http://www.xdrtb.org). The link directed viewers to a video slide show of black and white photographs Nachtwey had taken in South Africa, Cambodia, Swaziland, Thailand, Siberia, Lesotho and India. The images depicted gaunt, ill-appearing, grimacing patients being handled by doctors and nurses with gloved hands, looked upon by masked faces, and being injected with long needles. Between images terse, all-caps declarations in yellow and white lettering on a black background asked: “Tuberculosis: the next pandemic?” The text called attention to “XDR-TB” or “extreme drug resistant tuberculosis,” for which “there is no reliable cure,” and from which “patients often die within weeks of diagnosis.” The slides declared that “XDR-TB is a critical threat to global health” and called for action against the “extremely preventable” disease. The viewer needed to “Spread the story. Stop the disease,” and “Go to xdrtb.org now” since “We are the treatment.” The website provided links to sign a petition and to donate funds towards the fight against XDR-TB.

---

Nachtwey’s campaign was not limited to the website – he contributed photos and essays to magazines and blogs, and his photographs of tuberculosis-related suffering were displayed in small-scale and larger than life formats in fifty cities worldwide, including a projection on PR Newswire’s Reuters sign in New York's Times Square. His stated goal was to “create a critical mass of awareness that stimulates action.”

XDR-TB – which officially stands for extensively (not extreme) drug-resistant tuberculosis – was a new name coined in 2006 to describe a form of tuberculosis that was resistant to most tuberculosis drugs. The absence of potent drugs to treat it made it more life-threatening than “regular” tuberculosis. While the name and definition were new, such cases of highly drug-resistant tuberculosis had been documented at least as early as 1997 and had previously been included under the name multi-drug resistant tuberculosis (or MDR-TB), a form of tuberculosis resistant to at least the two most powerful anti-TB drugs (isoniazid and rifampin). Work around MDR-TB had gained significant attention and funding from public and private sources in the late 1990s and early 2000s, but compared to some infectious diseases funding remained limited, and attention in the media and in professional circles waxed and waned. Research funding for TB-specific programs increased from a few million dollars a year in the 1980s to $400 million in 2005, of which $158 million

---

4 Nachtwey, “Raising awareness about TB.”
came from the American National Institutes of Health (NIH). By comparison, in 2005 the NIH alone spent $2,921 million on HIV/AIDS research and allocated $187 and $183 million, respectively, to smallpox and anthrax.

This dissertation is about the discovery and naming of XDR-TB, how it came to be understood as a “critical threat to global health,” and how medical, public and political concepts of XDR-TB changed over time and across geographical space. It is also about the ways nurses, regional government agencies and global health researchers experienced first-hand a disease that was widely represented as a global phenomenon. I specifically look at the ways XDR-TB came to be associated with one particular town in South Africa and how the response to XDR-TB played out there. This response in turn shaped global understandings of XDR-TB as a deadly disease.

When Nachtwey’s xdrtb.org website was launched in 2008 I was already documenting the efforts of researchers and public health experts in the US and South Africa to create and promote this new category of extensively drug-resistant tuberculosis. XDR-TB had received substantial media coverage as a deadly scourge in the years leading up to Nachtwey’s efforts to place it “on the radar screen in terms of public awareness.”

A global survey that identified 374 XDR-TB isolates from reference laboratories on six continents was first published by the American Centers for Disease Control and Prevention (CDC) in March 2006. Later that same year, international science and lay media coverage focused on one outbreak of XDR-TB in Tugela Ferry, a small town in rural South Africa, where a group of researchers had uncovered a cluster of 52 deaths from XDR-TB. One notable New York

---


8 Nachtwey, “Raising Awareness About TB.”
"Virulent TB in South Africa May Imperil Millions." In 2007, the case of an American lawyer who traveled to Europe for his wedding despite warnings from the CDC that he had XDR-TB, thus possibly putting air travelers at risk, made US headlines.

What were the particular circumstances that allowed XDR-TB to become the important and compelling threat of those particular moments? Some diseases attract ample attention and funds, while other apparently worthy diseases are neglected, and the causes are not obvious. Suffering and death due to hunger, war, AIDS, cholera or national disasters often make their way to our inboxes, browsers and television screens – yet they are not always (or even usually) coded in terms of “XDR-TB.” Nachtwey's photographs do not tell us who gave XDR-TB its name or who allowed it to be understood as a new and dangerous manifestation of an already well-known disease.

As this dissertation will show, public health researchers, physicians, policy makers, journal editors, PR specialists, journalists and photographers, among others, employed exciting language, flexible scientific categories, and powerful emotional associations to create a sense of urgency and importance around XDR-TB. This allowed them to argue for attention and funds both in front of experts and the lay public. This process was not straightforward or part of a well-executed master plan. Nor was the process dishonest or devious – thousands of people were, in fact, dying of potentially preventable and curable illness. As we will see, the current understanding of XDR-TB came together and solidified over a period of several years. Between 2005 and 2007 the name, abbreviation, definition and primary location associated with XDR-TB all changed. The instability of the XDR-TB

---

concept was part of what gave it power, however, as different groups of tuberculosis researchers, clinicians, funders and activists reshaped XDR-TB into an entity which could draw attention to the particular challenges around tuberculosis that they wanted to highlight.

Nachtwey’s xdrtb.org website was a rather explicit attempt to harness the power of the internet and its capacity to broadly distribute images to promote awareness of XDR-TB. With his gut-wrenching images of suffering in poor places, Nachtwey sought to provide the local “human face” to a global, devastating disease that had mostly been described in terms of numbers. For Nachtwey, tuberculosis was a “merciless, man-eating predator lurking in the shadows” needing to be exposed, and he argued for the importance of the public’s attention to XDR-TB: “Maybe because TB is a disease of the poor - located for the most part in the developing world - it gets overlooked. When any critical issue becomes part of our mass consciousness, solutions become facilitated. Funding, research, new initiatives - are all necessary and happen much more quickly once a problem emerges from the shadows.”

Intriguingly, the language used by the photographer was not so different from that of the public health specialists who published the first studies on XDR-TB. As Dr. Sarita Shah, the CDC officer who compiled the first study on XDR-TB, explained to me, the CDC and the World Health Organization (WHO) first started documenting extensively drug-resistant tuberculosis in 2005 in order to “bring attention and funds” to the escalating potential of drug resistance to tuberculosis. She and her colleagues often discussed the strategies they might use to do so more effectively. Experts and scientists at the CDC and the WHO put their heads together to determine the most effective ways to study, frame, and propagate

---

13 Nachtwey, "Raising Awareness About TB."
14 Nachtwey, "Raising Awareness About TB."
information about drug-resistant tuberculosis. Faced with the very real deaths from
difficult-to-treat tuberculosis they self-consciously used the tools at their disposal to seek
resources to improve the response to the deadly disease.

**Engaging global health**

The public health experts collecting health statistics on drug-resistant tuberculosis
and the documentary photographer presenting the plight of the sick in dispersed locations
were both engaged in what has come to be called “global health,” a field that has grown
dramatically over the past 15 years. Global health can be seen as a field of academic
research, a branch of philanthropy, a market for private enterprise, a domain of policy
engagement, and a frame through which to consider national security threats. In an attempt
to define the unwieldy thing that is “global health” Koplan *et al.* have suggested that “global
health is an area for study, research, and practice that places a priority on improving health
and achieving equity in health for all people worldwide. Global health emphasizes
transnational health issues, determinants, and solutions; involves many disciplines within
and beyond the health sciences and promotes interdisciplinary collaboration; and is a
synthesis of population-based prevention with individual-level clinical care.” Others have
invoked a simpler definition of global health that primarily emphasizes a desire to travel in
order to help poor people. For Dr. Patrick Lee, founding director of the Global Primary Care
Program at Massachusetts General Hospital, global health is about a cohort of optimistic
young professionals who are enthusiastic about “making a difference” in the lives of people
less fortunate than themselves, no matter where they are located. Anthropologist Betsey

---

Brada, in contrast, has articulately warned that “global health” is less a “thing-in-the-world” than a set of arguments about the spatial and temporal configurations of power and the claims to expertise and moral action that these enable.19 These moral arguments then are broadly put into practice, as many academic institutions across North America have recently made it their mission to attract and train enthusiastic individuals and facilitate global health experiences for them.20 At Harvard University a group of global health practitioners has engaged in self-conscious discipline building, providing trainees with case studies and a foundation in social theory applied to the new global health presented in the form of a textbook.21

Successful global health promoters present a world that is both divided and interconnected. Abandoned, poor, sick people in peripheries require medical humanitarian assistance, and healthy people in the metropolis are drafted to the task of providing it through money, political pressure, and individual action. While Nachtwey relies on the emotional power of photography and the pulling of heartstrings to get this message across, others, such as Columbia economist Jeffrey Sachs, have made quantitative arguments that a financial investment in health will not only save lives but enable economic gains worldwide.22 Medical journalist Laurie Garrett scares her readers into action by warning of the security risks potentially caused by crumbling public health systems.23 New York Times Columnist Nicholas Kristof tells compelling human interest stories of destitute people in far-

---

away places who are empowered and healed through "the right" humanitarian assistance (and provides links to places his readers can donate). Global health advocate, physician and anthropologist Paul Farmer makes his argument based on political economy and social theory, as well as compelling personal vignettes. He argues that the structural violence expressed in the economic power structures on which the world is based makes his wealthy, educated readers in America and Europe directly liable and morally responsible for alleviating the suffering of the global poor and sick.

Global health is no straightforward humanitarian endeavor, but denotes a wide range of activities at the intersection between research, humanitarianism and economic development. The necessary flow of action and resources is not as unidirectional as these types of representations of global health might make it seem. When global health activities take the form of research and training, trainees from developed countries (especially the US) cut their teeth in under-developed settings and benefit from the wealth of clinical material available for study and practice. Science studies scholar Johanna Crane argues that, in fact, the “awkward relationship between science, aid, and development is [...] a defining characteristic of global health research.” Nachtwey's photographs on xdrtb.org provide important insight into the power dynamics that are at play when talking about XDR-TB as a global health issue. “Global health” – or rather, global disease – is experienced primarily by the poor in developing countries, and witnessed by donors-to-be and powerful policy makers who are located in developed countries. The exploitative gaze mediated by the photographer is evident in images that expose the skin and bones of people who are clearly

ill. Many of his photographic subjects are shown experiencing the agony of medical procedures at the very moment the picture is taken. For some of them the act of breathing itself has become agonizing due to disease. Though the photographer employs this material to advocate for medical help, I wonder what choice patients had to remove their bodies from this particular exposé of global suffering and plea for medical intervention. Similarly, researchers and medical professionals engaged in global health activities often find themselves in a morally ambiguous zone, somewhere between extractors (of clinical material) and ambivalent saviors (of desperate lives).

Nachtwey’s photographs depicting tuberculosis do not only highlight the vulnerable position of dying patients, but also raise questions about the health workers (including home carers, nurses, doctors, and priests) he shows treating and caring for people with tuberculosis. They are present in almost every image, often represented by gloved hands, their faces out of frame, covered by a mask, or otherwise obscured. Who are these sometimes faceless global health workers? It is not clear if they are courageous fighters against a global scourge or merely curators of suffering; props for the photographer, demarking the absence of medical resources by their presence.

Global health workers at all levels (from lay community health workers, to fully trained nurses, to internationally renowned academic physicians, to world policy makers, with many steps in between) are crucial to allowing any kind of global health intervention to occur. Throughout this dissertation we encounter many of the different day-to-day practices that contribute to global health work. In the case of XDR-TB in South Africa, for example, nurses who make home visits to their patients in order to give them regular injections of medication don’t only serve a crucial clinical function, but form the front line of American research on the success of community-based tuberculosis treatment strategies. These nurses report their activities in tuberculosis registers and adverse event report forms
that make their way both to government public health agencies and academic research offices. These nurses also constitute an innovative stop-gap measure for a provincial tuberculosis program whose central tuberculosis hospital was completely overwhelmed by the number of drug-resistant tuberculosis cases in Tugela Ferry.

By what process do these nurses’ and others’ clinical and administrative experiences shape global health decisions? In what form is the pain, suffering, and death of a patient mediated to decision makers in halls of power? Vice versa, how does the priority setting and hand wringing over global health emergencies in Atlanta, Geneva or Seattle manifest itself “on the ground,” in places like Tugela Ferry, South Africa, where patients seek and experience care and treatment? Critics of global health projects have correctly pointed out that an important weakness of many global health programs is a lack of feedback between on the ground providers and higher level administrators that can lead to the insistent implementation of ineffective or even damaging programs that defy local common sense. Existing grant-funding structures can lead organizations to veer away from the needs they find most urgent in order to fulfill the needs that they can receive funding for. Similarly, a focus on global standards without taking into account locally relevant information about diseases and medical practices can dramatically hamper programs.27

In addition, Laurie Garrett and others have convincingly warned of the perils of implementing top-down, single-disease, time-limited global health projects that undercut local and national public health structures by syphoning off resources and personnel from other health programs – “stove piping,” as Garrett called it.28 Thus a sudden, exclusive focus

on TB and HIV specific interventions could potentially have unintended negative consequences for a health system as a whole.

Even global health programs that explicitly pride themselves in working together with their academic and government partners in recipient countries find themselves at risk of undermining them. Crane describes American institutions going to great lengths to circumvent local bureaucratic structures in order to efficiently handle transnational financial transfers, local hiring, and tax issues, and argues that the building of outside structures in global health is common practice, because local structures are seen as "too difficult" to deal with.\(^\text{29}\) This avoidance of bureaucratic barriers is no neutral work-around, however. To quote Elise Carpenter's work on HIV treatment in Botswana: "Barriers are called bureaucracy, success is called partnership. This effectively negates the contributions of [Batswana] government bureaucrats."\(^\text{30}\) This also assumes that bureaucratic blockages have no possible merit, but are at best mechanical or technocratic, arising from disorganization or provincial outlook, rather than a legitimate attempt on the part of recipient countries to regulate global health activities. At worst, local governments are accused of blatant mismanagement, nepotism, obstructionism, ignorance, and unhelpful efforts to avoid embarrassment when they do not rapidly facilitate global health engagement. Again, Nachtwey's xdrtb.org photo series is informative: Nachtwey apparently kept the true nature of his project secret from the governments whose citizens he photographed until the launch of xdrtb.org in order to side-step potential government objections to bringing the images of tuberculosis patients directly to potential donors.\(^\text{31}\)

\(^{29}\) Crane, *Scrambling for Africa*, 164.

\(^{30}\) Elise Carpenter, quoted in Crane, *Scrambling for Africa*, 164.

As we will see, the government of South Africa, in particular, has been heavily and appropriately criticized by international global health experts and South African civil society for its active opposition to attempts to bring treatment for HIV/AIDS to South Africa before 2003. Thus, when an outbreak of XDR-TB among South African HIV/AIDS patients in rural Tugela Ferry was first reported in 2006, a readily available narrative was that international researchers and policy makers, with the help of South African partners, were doing their best to contain this outbreak, despite the indifference or blockage of South African government health agencies. This was not just the narrative constructed by outside journalists. When I first interviewed South African TB clinicians and researchers in 2007, they expressed profound frustration about their government’s slow response to the XDR-TB problem, and were concerned that the international contributions to XDR-TB research and management would not be enough. As events unfolded, however, it became increasingly clear that South African authorities, especially regional and provincial health administrators, engaged extensively with the XDR-TB problem and contributed in positive ways to the management of drug-resistant tuberculosis by providing funds, material resources, human resources, and policy support, sometimes pre-empting international recommendations or the needs of international researchers. This did not mean, however, that South African government bureaucrats always aligned themselves with international XDR-TB researchers or outside health policy consultants. Just how to best respond to XDR-TB in South Africa was an open question, and from the perspective of South African government employees it was not clear that the expertise in this regard lay entirely with the outside experts. As we will see in the second half of this dissertation, local public health

33 See for example Wines, “Virulent TB in South Africa May Imperil Millions.”
authorities were not exclusively obstructionist, but often sought creative, though at times stubborn ways to interact with outside researchers and authorities that could simultaneously push forward efforts to fight XDR-TB and help them assert their authority over and independence from the regime of global health experts.

**Dealing with absences and presences – where is health global?**

Global health research is often described in terms of absences and limitations. A key “problem” of global health research is how to provide good medicine and how to conduct good research in “resource-limited,” or “resource-poor” settings. These and related terms are frequently used in scientific papers, policy reports, and promotional materials to denote the places of lack where “global health” is done. A place completely devoid of medical, intellectual, and infrastructural resources, however, is not a site where global health knowledge can be generated. Biomedical scientists need laboratory infrastructure; epidemiologists require trained technicians who can conduct surveys and compile data; doctors need nurses, pharmacists (with stocked pharmacies), laboratory specialists and clerical staff to function effectively.

While some global health projects have attempted to build most of the infrastructure and logistics required for their research and activities from scratch, most have not, as this is an expensive, time-consuming undertaking which requires expertise and influence. Instead, global health researchers tend to place their studies in areas where they already have personal and professional connections and that already have key resources in place, though these may need to be substantially expanded. Often, internationally funded research projects cluster around academic institutions in mostly urban locations that have invested in laboratory infrastructure. Over time, crowded researchers may start looking to
more remote locations, but they often still rely on the connections and infrastructure of the city.34

When international AIDS funding expanded towards the end of the 20th century, American biomedical researchers built on past relationships with established institutions in countries across Africa to initiate new HIV/AIDS research. South Africa was a particularly convenient country for global health work by Americans and Europeans because it combines high rates of HIV/AIDS and poverty with well-developed infrastructure for higher education and medical services, including modern laboratories, and a relatively large educated elite that can hold its own in international settings. Although South Africa has eleven official languages, English is the most commonly used language in the country, and local doctors, nurses and biomedical researchers are proficient in English, even if their patients are not. Visitors to South Africa do not need to suffer major deprivations, as basic infrastructure (such as clean water, electricity, rental cars, hotels, etc.) is available in the cities, and is usually within reach even in more remote areas.

The locally specific process through which research sites have arisen means that certain types of global health knowledge have become associated with certain places and certain research networks and institutional sponsors. The location most closely associated with XDR-TB on the global health map is the Church of Scotland Hospital (COSH) in the rural town of Tugela Ferry, South Africa, which made international headlines in 2006 as the center of a deadly outbreak of XDR-TB. When researchers affiliated with Yale University presented news of Tugela Ferry’s XDR-TB outbreak at the 2006 International AIDS

---

34 This claim is based primarily on the author’s long-term experience conducting and studying HIV/AIDS research in South Africa. Similar examples in Ugandan HIV/AIDS research are described by Johanna Crane, whose subject (and employer) Jason Biehl moves from city to countryside to escape a crowded research landscape (Crane, Scrambling for Africa). In addition, Betsy Brada describes a type of global health one-upmanship which leads global health trainees to push “out into smaller hospitals, clinics, villages, and homes [...] to make reality match fantasy” of remote, destitute, resource poor locations, no matter what the danger (Brada, “Not Here,” 307).
Conference, it created a minor media frenzy, with public health experts wondering out loud what this meant for the continental and global spread of an apparently aggressive and highly deadly strain of seemingly untreatable tuberculosis. In the aftermath, anti-tuberculosis efforts in Tugela Ferry and the surrounding region were reassessed and revamped. Tuberculosis programs in other countries looked to South Africa, both as a warning for what could go wrong, and as a model for addressing XDR-TB once it had made itself known. The first scientific reports of XDR-TB had not mentioned South Africa at all.\textsuperscript{35} Now, XDR-TB came to be popularly (though incorrectly) understood as a deadly South African disease that had specifically emerged from the small town of Tugela Ferry.\textsuperscript{36} For public health experts Tugela Ferry became synonymous with XDR-TB, and some scientific and news articles incorrectly referred to Tugela Ferry as the original source of XDR-TB. Not surprisingly, it is one of the places featured in Nachtwey's 2008 photo-series on XDR-TB. It is also one of the main locations featured in this dissertation.

The central importance of Tugela Ferry to the story of XDR-TB cannot be taken for granted. Throughout this dissertation I consider the scientific, political and epidemiological processes that put Tugela Ferry in the frame as the epicenter for XDR-TB. I also consider Tugela Ferry as an ideal global health location that is simultaneously poor and remote, as well as well-resourced and well-connected. Tugela Ferry is located in the administrative district of Msinga, one of the poorest districts in South Africa, and is notable for poor basic infrastructure, high illiteracy and unemployment rates, as well as a history of violence related to faction-fighting and crime. According to the Statistics South Africa 2007 community survey, only an estimated 2.2% of the population in the district in which Tugela


Ferry is located has access to piped water in their dwellings or yards, and about 50% get water from open rivers or streams. (It is estimated that less than 10% of the population has access to consistently clean, potable water.) Similarly, 48.9% of households have no provision for sanitation, while 38.8% have either pit latrines or dry toilet facilities. Only 12.8% of the population has access to electricity, and there is no formal system for refuse removal. In addition, adult illiteracy in the region is high at 68%. The housing stock in the region is poor, leading to overcrowding in inadequate housing, and there is an acute shortage of rental housing in Tugela Ferry for people who come to the town from outlying areas for work.37 At the same time, the Church of Scotland Hospital, which is the district hospital located in Tugela Ferry, provides basic medical services around the clock, in addition to referrals to a network of higher-level hospitals that in some instances are able to provide high-technology “first-world” medicine. The area is less than two hours drive from the provincial capital of Pietermaritzburg, and less than 3 hours drive from Durban, which is arguably the third-largest city of South Africa, and center to many laboratories and internationally renowned academic resources around HIV/AIDS and tuberculosis.

Tugela Ferry is often neglected on South African maps, which have historically under-charted the areas where black South Africans lived. A Zulu outreach worker at a Christian mission in Tugela Ferry once told me how proud she was to host numerous missionaries each year from other parts of South Africa as well as from overseas (including several from Germany, the Netherlands and the US). She was delighted because even though Tugela Ferry was so small that it wasn’t on her physical map, the visitors knew how to find her because Tugela Ferry was on God’s map.

Tugela Ferry has also been a location on the *global health map* for some time, even before the discovery of XDR-TB. In fact, international (non-South African) medical professionals (especially medical missionaries) have been instrumental in assessing and treating patients at the Church of Scotland Hospital since its founding as a mission hospital in the 1920s.\(^{30}\) Since the early 2000s, however, the influx of a mostly secular international presence has accelerated, as dozens of Americans and other non-South African citizens have come through Tugela Ferry for periods lasting from days to years in order to in some way be part of the research and care endeavor around HIV and TB which has developed in Tugela Ferry.

**A global health site**

Photographer James Nachtwey first visited Tugela Ferry in 2000 (8 years before returning to photograph XDR-TB) to take photographs of AIDS in Africa for *Time* magazine. He delivered devastating images of people who were close to death. The accompanying article by Johanna Mcgeary, which was dramatically titled “Death stalks a Continent,” painted a depressing picture of deprivation, despair, disease and ignorance across the continent, including in Tugela Ferry. She also featured the hopeful work of Tugela Ferry based physician Dr. Anthony Moll, who had started a home based care program and hospice to help the many people in the region who were dying of AIDS.\(^{39}\)

The article had a broad audience, and Dr. Moll anonymously came to stand in for all frustrated health workers in Africa when the *Time* article was quoted by American President George Bush in his 2003 State of the Union address: “A doctor in rural South Africa describes his frustration. He says, “We have no medicines, many hospitals tell people,

---

\(^{30}\) It has been a government hospital, not affiliated with any church, since the 1970s.

‘You’ve got AIDS. We can't help you. Go home and die.’”40 President Bush went on to state that “In an age of miraculous medicines, no person should have to hear those words,”41 and announced his Presidential Emergency Plan for AIDS Relief (PEPFAR), which would provide billions of dollars for AIDS programs in fifteen countries, including South Africa.42

Dr. Moll’s compassionate, clinical, and scientific work is heavily featured in this dissertation. A white Southern African who had studied medicine in Stellenbosch, he had moved to Tugela Ferry in the 1980s in order to do God’s work with other Christian colleagues, serving the rural Zulu population of the KwaZulu homeland. When AIDS hit the region in the 1990s he stepped up to the plate for his patients and sought help from programs in Durban and elsewhere. Through these efforts, Dr. Moll became connected to national and international biomedical research networks. By 2003, he was collaborating with American physician and researcher Dr. Gerald Friedland from Yale University in order to provide life-saving medication to a subset of his AIDS and tuberculosis patients in Tugela Ferry. Eventually, patients in Tugela Ferry and the region would in fact benefit from American PEPFAR funding, as well. Dr. Moll was one of the first physicians in the region to treat a cohort of patients from a public hospital with HIV medications, and people sometimes came from afar to see his ground-breaking program in action. I myself first met Dr. Moll in 2004 when I was spending a year after my BA degree in Durban, South Africa as a Fulbright scholar working at another pioneering HIV treatment program in the city. I joined two English medical students to travel to Tugela Ferry for a day to see what a rural South African hospital looked like. Dr. Moll was generous with his time and allowed me to shadow him as he saw HIV patients, and he showed me the room where patients sat

42 Ibid.
together making calendars for the coming month, stapling packets of daily pill doses to a paper calendar in order to help them remember when to take their medicines. The lively chatter and active participation of patients, nurses, and HIV counselors in this new and life-saving program was inspiring to me. At that time, any effort to provide rural South Africans with HIV medications could be seen as revolutionary. Later, it was through this ongoing program and Dr. Moll’s collaboration with Dr. Friedland that high rates of tuberculosis drug resistance in Tugela Ferry eventually came to be discovered in 2005 and internationally known in 2006, featured at conferences and publications as a deadly disease with global significance.

Local outbreak as global phenomenon

In Tugela Ferry, XDR-TB was simultaneously experienced as a local outbreak and personal tragedy as well as a global phenomenon whose significance went well beyond the lives of the people in the region immediately affected by the disease. This dissertation traces how a particular disease – extensively drug-resistant tuberculosis – in a particular place – Tugela Ferry, South Africa – was converted from a non-entity to a local health problem and then to an emergent global health problem. How should we understand the relationship between transnational global health expertise (CDC/WHO), American academia (Yale), provincial public health programs (South Africa) and the patients who came to the hospital in Tugela Ferry for care and ended up as a data point in globally distributed statistics?

While the first half of this dissertation outlines the role of global experts in creating XDR-TB as a new entity, the second half focuses on the role that the small town of Tugela Ferry played in bringing tuberculosis to global attention. I highlight the role of South African doctors, nurses, and government officials in generating and enabling responses, both locally and globally, to XDR-TB, often in concert with an expansive group of “international” health
workers (many of whom were American) who came to Tugela Ferry as researchers, clinicians, and trainees.

XDR-TB as global health phenomenon is a multi-headed beast located everywhere and nowhere at once. The power to name, define and promote XDR-TB as an important policy issue did not lie with any one person or agency, and tuberculosis experts were not unanimous about the new disease name's significance or usefulness. Similarly, the power to act against XDR-TB in Tugela Ferry was unevenly but broadly distributed. Many narratives about XDR-TB in South Africa emphasize the role of American doctors and researchers fighting a deadly disease against the odds of poor health infrastructure and languishing bureaucracy, or highlight the role of heroic South African individuals such as Dr. Moll who continued to heal the sick despite poverty and a lack of resources. I partially echo such narratives as I tell the origin story of XDR-TB research in Tugela Ferry based on accounts of American and South African researchers who were directly involved in it.

At the same time, I try to tell a more nuanced story that acknowledges that the locus of control and action is not always where it seems. XDR-TB came to light in the context of a AIDS research collaboration whose funds initially came from American charitable and research sources, as did the expertise required to administer and study life-saving AIDS medications. Many of the resources used to discover and treat XDR-TB in Tugela Ferry, however, were provided directly or indirectly from South African government sources. This included medications and laboratory tests for tuberculosis, physical government clinic and hospital facilities where patients were seen and recruited, as well as some of the nurses and vehicles used for visiting patients in their homes. Similarly, while international researchers provided much of the intellectual motivation for work on XDR-TB they relied on the significant expertise, hands-on work, and emotional investment of nurses, community health workers, public school teachers, and local authorities to help identify and treat XDR-
TB patients. By drawing on interviews with nurses, tuberculosis research assistants, local government administrators and bureaucrats, as well as my experiences living and researching in Tugela Ferry and Durban I expand that global health narrative to include people who are not as actively involved in publication and promotion.

The relatively small group of academics conducting work from abroad was not in the position to put in place an entire health system for people in the Tugela Ferry region suffering from these infectious diseases, nor did they intend to. The region already had a (flawed) public tuberculosis diagnosis and treatment infrastructure in place, and it was this infrastructure which was built upon and expanded, under the authority of regional and provincial government, with expert input of visiting Americans, but also with considerable South African expert and administrative involvement. American researchers continued to study and support new strategies tuberculosis management in Tugela Ferry and the surrounding region, but new tuberculosis treatment programs had to be actively supported by government bureaucrats and coffers to be successful.

Local government agencies rightly wondered how to reassert administrative and programmatic control over hospital clinicians who were using South African government resources not only for clinical care but also for American-driven research. Tuberculosis researchers and practitioners found different ways to come to terms with these conflicting narratives as they sought to understand the origins and meaning of XDR-TB in South Africa and globally.

**How to study this multi-headed beast**

In recent years anthropologists, historians, and science studies scholars have written nuanced accounts of global health in action from multiple perspectives, including
those of patients, doctors and nurses, scientists, research assistants, program directors and policy makers, clinical trial participants, health activists, and medical students among others. Taken together, these accounts go well beyond simplistic donor–recipient narratives favored in some popular understandings of global health intervention. They reveal that diseases, treatments, and the populations to be intervened upon in global health cannot be taken as givens, and that relationships among the various actors in global health are extremely complex. Adriana Petryna, Vinh-Kim Nguyen, Joao Biehl and others have argued that new types of citizenship and governance are constituted through the process of global health intervention, as the quest for health and the fight against death and disease (especially in the form of pharmaceutical intervention) becomes a legitimate way of staking claims on national and international assistance in settings where more “conventional” methods of claims-making are ineffective. The process of framing social inequality in terms of health may provide politically active language with which to achieve political goals of state representation and care by claiming biological citizenship. Yet biological citizenship does not offer the full complement of rights and responsibilities.

45 Crane, Scrambling for Africa.
granted a modern citizen of a wealthy nation. In Giorgio Agamben’s terms, biological citizens are granted "bare life" absent of intrinsic human rights.\textsuperscript{52} Applying these concepts to AIDS in South Africa, Jean Comaroff has asked why "the biomedical definition of life [has] become so central a site of contestation where other kinds of populist politics – the politics of labor movements, for instance – seem to be eroding." She argues that we are at risk of reducing the analysis of political economic structures of inequality to access to medicines, “rather than, say, jobs, clean air, or freedom from war."\textsuperscript{53}

Not only citizens but also diseases and epidemiologic and biological categories are newly constituted through the power dynamics of global health activities – concepts like “treatable” and “untreatable,” “adherent” and “non-adherent,” even HIV and AIDS, and, as we shall see, MDR-TB and XDR-TB are contested on the international battle ground of global health policy and treatment. Arthur Kleinman, a Harvard-based anthropologist who has been engaged in teaching global health courses together with leading global health hero Paul Farmer for many years, succinctly summarized the leading theoretical frameworks that underlie much of the current scholarship in global health in 2010.\textsuperscript{54} He selected four themes: Merton’s unintended consequences of social action; the social construction of reality (conceived originally by Berger and Luckman); the theory of social suffering (whereby suffering and ill-health is not an individual experience with individual causes, but rather is a social experience caused by socioeconomic and sociopolitical forces and social institutions); and Foucault’s biopower and its more recent theoretical expression, biological citizenship. I build upon these well-established fundamentals, taking as a starting condition the fact that even the most solid biomedical “facts” are socially constructed and contingent upon time and space. I reapply the fact that who is sick and who is healthy is a matter of

\textsuperscript{52} Giorgio Agamben. \textit{Homo Sacer: Sovereign Power and Bare Life} (Stanford University Press, 1998).
definition, and that scientific definitions are negotiated entities, as has been effectively argued by Ian Hacking and Robert Aronowitz, among others. 55

Global health operates at many spatial levels and different levels of authority, across continents, across hierarchies of governmental order, and across hierarchies of expert study and practice. As will emerge from the chapters of this dissertation, these many layers of global health action are interconnected, depend on each other and operate simultaneously. Yet their diverse locations and access points make them difficult, if not impossible, to capture in a single study. Accounts that eliminate local governments from the story, for example, miss the work done by bureaucratic absences and presences that provide the space for non-governmental global health players to act. Insufficient attention to the science and policy workings of transnational and international players like the WHO and CDC, meanwhile, means missing important global cues for action. The scientists and epidemiologists who produce, compile, and package the data that justify policy action also hold power that is often overlooked. 56

In this dissertation I use XDR-TB as a lens through which to consider these different levels of geography, expertise, and authority. I attempt to bridge localities, perspectives and disciplines in order to weave together a multi-sited, multi-level story from multiple points of view. I pay particular attention to the different ways knowledge around XDR-TB is generated, as well as to the relationships between different types of experts and their professional networks. In order for a global health project to come together, information (mostly in the form of “data”) needs to flow between sites of clinical activity, like Tugela Ferry, and sites of academic production, like New Haven, with many steps in between.

Global health actors at all levels contribute to the blockage and flow of information, and as such hold some component of the global health system in their hands.

Thus, this is neither a story about the dangers of top-down global health implementation, nor is it a grass-roots story from below which focuses on the individual experience of patients and their families. Instead I focus on the flow of knowledge, information, and international expertise. This focus on international expertise and packaged knowledge runs a risk of being intrinsically depoliticizing, in as much as international experts often have little knowledge of local specifics, and instead apply universal templates to the world’s problems.\textsuperscript{57} For this reason, my own analysis does not ignore the “local,” but instead engages earnestly with clinical and scientific experiences and perspectives based in Tugela Ferry and Durban, South Africa. At the same time, this work does prioritize processes of scientific knowledge production over a detailed understanding of the politics of race, poverty, and wealth distribution in Tugela Ferry and South Africa. This is also a problem for the global health endeavor itself, which, while inextricably entwined with global political processes, also serves a depoliticizing function. Under the rubric of research and care, international actors gain access to contested spaces and bodies, uncover secrets, and make public the real and perceived failings of a host country’s ability to take care of its citizens. Yet global health’s conscious de-emphasis of the nation state\textsuperscript{58} and focus on individual sufferers and the microbes that ail them, which is then mediated through non-governmental organizations and institutions of learning, creates a type of anti-politics of global health, not so different from the anti-political rhetoric of the development projects of

\textsuperscript{57} James Ferguson, \textit{Anti-Politics Machine: Development, Depoliticization, and Bureaucratic Power in Lesotho} (University of Minnesota Press, 1994).

the 1980s documented by James Ferguson in Lesotho.\textsuperscript{59}

I have stated that I will be using XDR-TB in South Africa as a case that tells us something about how global health research works. As importantly, however, this dissertation contributes to our understanding of the role (drug-resistant) tuberculosis has played as a key disease that has shaped the fields of clinical medicine, public health, and global health. Thus, before turning to a chapter overview and the rest of the dissertation, I will provide a brief overview of the history of drug-resistant tuberculosis in international health.

**Historical overview of tuberculosis**

Tuberculosis is a particularly interesting disease entity with which to track the recent history of the workings of global health, as well as the much longer history of public health. Tuberculosis has been at the center of key debates about the causation and meaning of disease for several centuries.\textsuperscript{60} As geographer Matthew Gandy has argued, ‘the history of TB was marked from the outset by rival bodies of medical thought rooted in alternative explanations for the transmission of disease. The gradual acceptance of various ‘germ theories’ undermined the moralistic discourses of nineteenth-century medicine and strengthened the political salience of the public health movement. Yet by the middle decades of the twentieth century the recognition that TB was a social disease rooted in poverty and poor housing became gradually obscured by an emphasis on the success of new forms of biomedical intervention.’\textsuperscript{61} Before the medical discoveries and events that are now

\textsuperscript{59} Ferguson, *Anti-Politics Machine*.
summarized as the bacteriologic revolution, medical professionals engaged in a vigorous debate around the question of TB’s origins: Was it contagious, transmitted from person to person? Was it passed down in families? Or did it arise from unhealthy urban environments, where dirt and decay was ubiquitous and overcrowding was rampant?62

On March 24, 1882, Robert Koch convincingly demonstrated to the public that a microscopic germ could cause tuberculosis, apparently putting an end to this debate. He showed that the bug – *Mycobacterium tuberculosis* – could be transmitted from host to host, and that tuberculosis did not exist in the absence of the germ. In the same decade, a series of other disease-causing bacteria, including cholera, diphtheria and tetanus were discovered.63 For many medical professionals it became clear that the next step in the treatment of disease would be to identify specific agents that could kill these specific germs. For Koch, the discovery of the tuberculosis bacillus was merely the beginning of a long and intense preoccupation with developing a therapeutic agent effective against tuberculosis.64 Historian Sheila Rothman argued that the “new understanding of tuberculosis in the bacteriological era bred not only a fear of contagion, but also a heady optimism about the prospects for cure.”65

Not all leading physicians of the day were convinced that they should immediately discard the environment and living conditions as a cause of disease, however. Rudolf Virchow, a renowned physician and the founder of cellular pathology, actively resisted the new bacteriology. In 1847, towards the beginning of his career, he had been appointed to

---

64 Christoph Gradmann, *Laboratory Disease: Robert Koch’s Medical Bacteriology*, trans. Elberg Forster (Baltimore: The Johns Hopkins University Press, 2009), 70.
investigate a deadly typhus outbreak in Upper Silesia and was convinced that it was deplorable living conditions, including bad housing and malnutrition, which had caused workers to succumb to disease. In his report he stated that social interventions were as important as medical ones. According to Leon Eisenberg, Virchow argued that “nothing but prosperity, culture, and freedom could bring about improvement and these could only be achieved on the basis of ‘complete and unrestricted democracy.’”

Virchow continued to doubt the importance of contagious germs until the end of his career.

At the end of the nineteenth century, tuberculosis was one of the leading causes of death across the globe, including in the US and Europe, and had killed more people than any other disease up until that point. At the turn of that century, therapeutic efforts focused primarily on the institutional treatment of tuberculosis in sanatoria – institutions which focused on the salubrious characteristics of outdoor environmental conditions (such as cold mountain air), rich foods, and moderate exercise.

Tuberculosis became the focus of early public health campaigns in the US, the UK and France, as well as other countries in Europe, whereby “the threat of contagion fostered a significant expansion of public health mandates.” Authorities could demand diagnostic testing (such as X-ray screens), ban spitting in public places (in order to contain germs), and order sick people to be treated in sanatoria. The location of tuberculosis treatment in these closed institutions meant that public health authorities sometimes found it hard to

---

68 Barnes, “Historical Perspectives on the Etiology of Tuberculosis.”
distinguish between the goals of curing tuberculosis patients and confining dangerous sources of contagion.\textsuperscript{71}

With the advent of effective antibiotic therapy in the 1940s and 1950s, scientists and physicians were optimistic that the disease would be eliminated in the near future, and announced the end of tuberculosis.\textsuperscript{72} In fact, as Thomas McKeown illustrated in the 1960s, rates of tuberculosis infection had been dropping in industrialized countries for decades prior to the discovery of anti-tuberculosis drugs, most likely due to improved living conditions in the cities.\textsuperscript{73} Once the drugs were available and shown to be effective, tuberculosis saw an even more rapid decline and was less and less a problem which physicians and scientists found interesting. As Baron Lerner shows in his book \textit{Contagion and Confinement}, however, tuberculosis did not drop off the radar of American medical professionals and public health specialists immediately. Tuberculosis efforts in Seattle increasingly focused on poor, unemployed alcoholics with myriad social problems who were “recalcitrant” to long-term antibiotic therapy. By the 1970s, however, tuberculosis rates in the US had dramatically dropped, and tuberculosis programs across the country were reduced or shut down.\textsuperscript{74}

The study of tuberculosis, then, illustrates important themes in the history of medicine and society, including debates regarding the causation and transmission of disease, the importance of social conditions on the health of people, and the role of professionals and government in enforcing compliance with medical care and providing

\textsuperscript{71} \textit{Ibid}, 194.
\textsuperscript{72} For example, Selman Waksman, the discoverer of the first anti-TB drug, streptomycin, announced the “Conquest of Tuberculosis” in the title of his book: Selman A. Waksman, \textit{The Conquest of Tuberculosis} (Berkeley: University of California Press, 1964).
\textsuperscript{74} Barron H. Lerner, \textit{Contagion and Confinement: Controlling Tuberculosis Along the Skid Road} (Baltimore: Johns Hopkins University Press, 1998).
resources for the care of the indigent. The story of tuberculosis also demonstrates how global priority setting around health follows the interests and fears of wealthy countries, rather than a rational understanding of global epidemiology. Tuberculosis was essentially considered “solved” by medical elites and public health specialists by the 1970s (and for many people much earlier) in view of the fact that anti-tuberculosis drugs were known and tuberculosis rates in the US and Western Europe had reached very low levels.

Globally, however, tuberculosis had never disappeared, though interest in tuberculosis had clearly fallen.\textsuperscript{75} In the 1950s-1970s, the World Health Organization (WHO) participated in a strong push to support anti-tuberculosis campaigns focusing on prevention and treatment of tuberculosis around the world. Efforts included mass vaccination campaigns with BCG vaccine (thought to prevent tuberculosis infection), and programs to screen large parts of the population for tuberculosis by using mobile X-ray units. Researchers in India and Africa sponsored by the UK Medical Research Council and the WHO continued to investigate the best strategies for treating tuberculosis, assessing the differences between inpatient and outpatient treatment, and adjusting the length of time that was required in order for patients to be treated successfully.\textsuperscript{76} Yet the WHO’s involvement in tuberculosis-related activities eventually followed the trends seen in industrialized countries, and WHO-led anti-tuberculosis campaigns were dismantled by the 1970s. While tuberculosis was proclaimed vanquished (or at least irrelevant) by scientists in wealthier countries, most developing countries maintained moderate to high rates of


tuberculosis throughout the twentieth century, with individual governments running their own tuberculosis programs with varying levels of success.\textsuperscript{77}

It was not until tuberculosis unexpectedly resurged as a problem in the US in the late 1980s that the international public health community took up the cause of tuberculosis once again. To everyone’s great dismay, tuberculosis was on the rise again in developed countries. This was dramatically illustrated by a widely publicized tuberculosis outbreak that occurred in New York City in the late 1980s and early 1990s. The under-funded New York public health infrastructure, combined with rising numbers of people with HIV/AIDS, had enabled tuberculosis to take a firm hold, eventually necessitating drastic and expensive measures to regain control over the city's tuberculosis statistics.\textsuperscript{78}

In fact, tuberculosis rates were increasing in cities and countries across the world, and very visibly – driven by the global HIV epidemic, failing public health systems, and harsh economic conditions which were undermining the capacity of states and their citizens to cope with ill health. In his book \textit{Infections and Inequalities} Paul Farmer emphatically argues that tuberculosis never disappeared, even in wealthier nations, but that “the ‘forgotten plague’ was forgotten in large part because it ceased to bother the wealthy,” while tuberculosis continued to “hide” among poor people, only to “reemerge” by becoming dangerous to the non-poor.\textsuperscript{79} In addition, the neoliberal economic reforms that occurred in the early 1990s in the wake of the fall of the iron curtain and the Soviet Union left public

\begin{footnotesize}
\begin{itemize}
\item\textsuperscript{77} Amrith, “Plague of Poverty? The World Health Organization, Tuberculosis and International Development, C. 1945–1980.”
\end{itemize}
\end{footnotesize}
health systems in Eastern Europe and Central Asia in disarray and populations vulnerable
to diseases like tuberculosis.\textsuperscript{80}

According to WHO figures, approximately one third of the world’s population
harbors the tuberculosis bacillus. Yet most of these people do not become ill with active
tuberculosis. It is estimated that someone carrying the tuberculosis bacillus has about a
10% chance over a lifetime of progressing to active disease. Usually active tuberculosis
affects people who are particularly susceptible to it due to a weakened immune system,
poor nutrition, high stress, old age and other only partially understood predisposing factors.
In Eastern Europe, increasing rates of tuberculosis were exacerbated by prison conditions, a
failing medical system, and high rates of alcohol abuse. In other parts of the world, the rise
of tuberculosis was primarily due to its association with another “social disease” –
HIV/AIDS. Infection with HIV raises a person’s risk of going from inactive to active
tuberculosis disease from 10% in a life time to about 10% a year. In South Africa, which by
any measure has a very high burden of HIV/AIDS, tuberculosis is the most common cause of
death for people with HIV/AIDS, and 70% of tuberculosis patients in the country are
coinfected with HIV.\textsuperscript{81} To quote one review article: “In 2007, South Africa, with 0.7% of the
world’s population, had 17% of the global burden of HIV infection, and one of the world’s
worst tuberculosis epidemics.”\textsuperscript{82}

Tuberculosis’ close but distinct relationship to HIV/AIDS is also helpful for
interrogating the nature of global health. Much of today’s global health infrastructure
(especially in Africa) is built around research and care dealing with the massive global AIDS

\textsuperscript{80} Farmer, Pathologies of Power.
\textsuperscript{81} Salim S. Abdool Karim et al., “HIV Infection and Tuberculosis in South Africa: An Urgent Need to
\textsuperscript{82} Ibid., 921.
pandemic. Tuberculosis is much older than AIDS and the history of its scientific discovery and treatment is profoundly different from that of AIDS. The philosophies and strategies of the scientific and policy communities dealing with tuberculosis and AIDS also developed in very different and conflicting ways, whereby the management of tuberculosis focused on surveillance and prioritized the protection of the public from infection over the dignity of the individual patient, while the acceptable management paradigm of AIDS developed around concepts of human rights, knowledge, empowerment and individual agency (despite the potential risk to the masses). In contemporary debates, these differing philosophies are often summarized as the “public health” approach versus the “human rights” approach.

Yet, at the same time, as South African nurses have told me over and over, AIDS and tuberculosis are “twins” or “siblings.” In South Africa, more often than not, the two diseases occur in the same body. Tuberculosis is both a common early manifestation of AIDS (you are at increased risk for tuberculosis even before your immune system has completely collapsed), and a frequent final manifestation (tuberculosis is the most common immediate cause of death in people with HIV/AIDS). In the past, physicians who shied away from disclosing AIDS on a death certificate would write “tuberculosis” as a cause of death; and South Africans can list a litany of celebrities and politicians who unexpectedly died of TB... but not without a question mark. As poet Eddie Vulani Maluleke declared: "We died of TB / That was us / Whispering it at funerals / Because nobody ever said AIDS.” At the same time, unexpected disease courses and poor outcomes in the tuberculosis ward were

---

84 AIDS was only identified in the early 1980s, though cases have been traced back to the middle of the 20th century.
sometimes quickly attributed to overwhelming AIDS, even in the absence of a definitive HIV diagnosis, or the careful consideration of alternative explanations, such as drug resistance.

Tuberculosis also is a suitable disease through which to consider the historical and present role of the South African government in ensuring the welfare of its country’s citizens. The historiography of disease in South Africa has emphasized the features of the national political economy that have made many South Africans extremely vulnerable to ill health due to apartheid and the legal exploitation of black labor.86 Randall Packard’s study of tuberculosis in South Africa documents how segregationist policies and the interests of the mining industry not only jeopardized the health of black workers but also altered the scientific understanding of tuberculosis among South African medical professionals.87 Marks and Andersson employ tuberculosis and other diseases of poverty and deprivation to illustrate the ways in which apartheid South Africa’s political economy was detrimental to the health of its majority black population, especially in the so-called homelands or Bantustans.88 These were the undesirable parts of South Africa that were reserved for blacks by the white minority government and were divided by dubious tribal affiliations. Blacks were not given permanent residence in white South Africa, and needed permits to work there as part of an exploitative system of migrant labor.

In a very small way, this research can be seen as a study of health in the post-apartheid homeland. Tugela Ferry, my primary research site and the town that became internationally famous for harboring an XDR-TB ‘epidemic,’ used to be in KwaZulu, the

---

88 Marks and Andersson, “Issues in the Political Economy of Health in Southern Africa.”
homeland designated for Zulu people, and is now located in the hyphenated successor province of KwaZulu-Natal. Packard’s historical analysis found tuberculosis devastating the homelands, even as South African tuberculosis statistics were improving, in part due to the progressive exclusion of the homelands not just from South African citizenship, but also from statistical capture. In contrast, I was drawn to this former homeland by the internationally available and devastating tuberculosis statistics. Tuberculosis was wreaking more havoc than ever, more than a decade after the first democratic elections and the end of legal apartheid. Packard and Marks’ focus on national economy and polity is very compelling in explaining the social context of illness in apartheid South Africa. In my work, however, the crucial dynamic is one not between state and industry, but between the state and international expertise. The international community has focused on post-apartheid South Africa’s biomedical ills, discussing problems of child welfare, gender inequality and poverty in the idioms of immunodeficiency and infectious disease. This is the angle from which I approach the history of tuberculosis in South Africa.

Outline of the dissertation

In this dissertation I explore how a sad but commonplace occurrence – the death of rural South Africans from HIV and tuberculosis – was transformed into an extraordinary and dangerous event of global interest accompanied by language that was powerful enough to make claims on government agencies and to demand action from humanitarian organizations. This dissertation consists of two interconnecting parts. In Part I (Chapters 1-3), I tell the story of the rhetorical and scientific origins of extensively drug-resistant tuberculosis (XDR-TB). Setting it against the backdrop of public policy debates around multi-drug resistant tuberculosis (MDR-TB) that took place in the 1990s, I show that XDR-TB was deliberately named and defined to maximize both scientific and moral impact in the face of a truly devastating problem. Public policy experts consciously collected data on
tuberculosis drug-resistance that they hoped would have the power to call attention to the dangers of underfunded tuberculosis programs. Careful consideration was given to scientific parameters such as standardization and quality controls to maximize scientific credibility of the new XDR-TB concept. This scientific legitimacy served to mobilize moral authority, enabling demands for intervention into the lives of the sick and dying based on scientific, public health, humanitarian, and ethical arguments.

It is well established that diseases are socially constructed and are framed by the social realities in which they are embedded. Indeed, science does not exist independent of society; "science and society [are] co-produced, each underwriting the other's existence." Part I provides insights into the social construction of XDR-TB in a very literal sense, from the viewpoint of the experts who had the power to convene meetings, assemble numbers, and decide a new disease name was needed to describe an existing phenomenon; thus inventing XDR-TB was part of their work. The case of XDR-TB makes it very clear that the disease did not have to be defined just the way it was, and that it was not automatically endowed with the power to generate public health and media attention. Several sources argued, for example, that the use of the letter “X” to describe extensively drug-resistant tuberculosis was one of the reasons that XDR-TB captured the imagination of journalists and funders.

To say that XDR-TB is socially constructed, or even that policy makers and scientists “invented” XDR-TB, however, does not mean that XDR-TB is a made-up disease. Even as I lay bare the processes and negotiations that underlie the coming-to-be of extensively drug-

---


resistant tuberculosis, I am not arguing that the resources and attention given to XDR-TB were inappropriate, exaggerated or somehow the result of deception or fraud. Though I do interrogate the notion that XDR-TB is a distinct pathological disease entity independent from the experts who diagnose, study, and manage it, I also stress that extensively drug resistant tuberculosis is a contagious, fatal disease that affects thousands of people, causing significant illness and death, leading to stories of suffering in countless individuals around the globe.

This dissertation does not deal directly with this suffering, however, but instead traces how biomedical experts convert suffering into data which can be manipulated, “cleaned,” graphed, charted, and acted upon with the tools of epidemiology and public health. The early international meetings around XDR-TB used disease definitions, laboratory guidelines, statistical methods and bullet-pointed action plans as their primary tools with which to understand and intervene against drug-resistant tuberculosis.

In Part II of the dissertation (Chapters 4-5) the focus shifts away from international meetings and conferences to Tugela Ferry, South Africa, which became the town best known for the discovery of the biggest cluster of deadly XDR-TB cases. In chapter 4 I focus primarily on the role of the local department of health in making an expansion of MDR-TB services in Tugela Ferry and the surrounding region possible. The publications, international presentations, and popular retellings of the story of MDR-TB and XDR-TB in Tugela Ferry could lead to the impression that American global health workers single-handedly brought effective tuberculosis treatment to rural KwaZulu-Natal. Here I show that to a large extent American researchers relied on South African resources in order to be able to conduct their work, and even as they provided knowledge, expertise, advice, and organizational leadership, South African government officials had good reasons to attempt to rein in outside influence.
Chapter 5 considers the labor and documents that go into providing and representing Tugela Ferry’s answer to MDR-TB and XDR-TB: community-based treatment. The initiation of the community-based management of MDR-TB that occurred in the aftermath of the discovery of XDR-TGB was simultaneously a state-driven public health program and an externally funded global health research program. While the needs of research, public health and clinical care often overlap, the key products that result from these efforts – peer-reviewed journal articles, government reports, and cared-for patients, respectively – are not the same. While state-funded public health nurses spent a large part of their work-day filling out forms in order to comply with bureaucratic guidelines enforced by the department of health hierarchy (which is itself subject to international reporting needs), research-funded nurses intervened into the process of care-provision in ways that ensured the completeness of the medical record according to the needs of their bosses who hoped to publish in high-prestige biomedical journals.

**Methods**

This dissertation was researched over the period from early 2007 to late 2011. Much of the information about XDR-TB and its origins was assembled from published sources, including peer-reviewed journal articles, meeting abstracts, conference reports, press releases, web presentations, fundraising materials, etc. I also had access to some private correspondence around the early definition of XRD-TB. I attended several conferences and meetings at which drug-resistant tuberculosis was discussed, including the 2010 World Meeting of the International Union Against Tuberculosis and Lung Disease in Berlin, the 2010 South African TB Conference, and the 2011 South African AIDS Conference. I also attended a 2010 TB conference organized for staff at McCord Hospital in Durban, and a 2010 conference on TB diagnostics organized by the KwaZulu-Natal Research Institute for TB and HIV (K-RITH) in Durban. In addition, I conducted over 80 interviews with public
health experts, scientists, WHO officials, South African government employees, physicians, nurses, research workers, patients, and others. Most of these interviews I conducted in English either by phone or in person, in some cases at the conferences listed above. In South Africa I conducted some interviews together with a research assistant, Nomnikelo Mvelase. Most of those were in Zulu and English, with Mvelase translating between the two languages when needed. Mvelase also conducted a handful of interviews with tuberculosis patients independently and transcribed and translated these interviews.

I gave the people I interviewed the option to either be interviewed “on the record” or to remain anonymous. Most (though not all) international experts, academics, and physicians were willing to be on the record for most or all of their interview and allowed me to record the interview. Most (though not all) nurses, auxiliary hospital staff and patients chose to remain anonymous and preferred I only take notes, without an audio recording. As a result there is a clear imbalance in power, position, race, and language between those people who are directly quoted and those who are summarized and represented as a group (“some nurses say,” “a staff member argued”). Despite this, I use and attribute quotes from interviews when available. In some cases I do not disclose the source of a particular statement or claim. Quotes that are not attributed are anonymous. It would be impractical, however, to make this entire dissertation anonymous, in part because the location of the events I describe is well-known (and easily googled), and the leading researchers and clinicians who work there are well-known in the research community and have published extensively. In some cases they have been interviewed on the record on similar topics by other people.

In 2010, after piecing together much of the story of how XDR-TB in South Africa came to be a matter of global concern from my home base in Philadelphia, with visits to New Haven and New York, as well as a two-month stay in Durban in 2007, I based the rest
of my research in South Africa. I first spent four months in Durban, where I attended TB-related events, interviewed Durban-based scientists, and observed some of the TB-related activities at McCord Hospital. To help me gain some insights into local South African perspectives on the XDR-TB outbreak in Tugela Ferry, South Africa I then moved to Tugela Ferry itself to live there for eleven months. There I engaged in participant-observation in clinical, research and community settings. I was officially affiliated with Philanjalo, the non-governmental organization and hospice founded by Dr. Moll that provided care to people with HIV/AIDS and tuberculosis. This was also the organization through which most XDR-TB research activities were officially channeled. I spent much of my day observing the work of TB nurses, TB researchers, and clinicians. I spent work-time and off-time with nurses, doctors, research assistants and coordinators, administrators, peace corps workers, community health workers, and patients, and participated actively in hospital and community life. This was facilitated by my living situations – I first stayed with a local, middle-class Zulu family who actively participated in church and community life, and later lived on the hospital compound in housing built for visiting researchers and clinicians, with a rotating cast of American and South African short and long-term visitors.

While the professional and research language in Tugela Ferry is English, most of the local residents speak Zulu and very limited English. I had prepared for this with Zulu language instruction in the US and in South Africa and was able to engage in polite conversation in Zulu. As mentioned above, I worked together with a research assistant when interviewing people (including nurses, patients, and community members) who were more comfortable in Zulu than in English. In addition to serving as my translator and interview transcriber, she generously facilitated many social interactions in town, invited me to social functions and initiated conversations with her friends about HIV/AIDS and tuberculosis for my benefit. She and other Zulu-speaking research and hospital staff helped
me bridge the tangible divide between those who were affiliated with the hospital compound through their work and those who lived outside of it and only came there as patients, family, and visitors.

The goal of my fieldwork was to understand the significance of Tugela Ferry as a point on the global health research map, and to capture what XDR-TB signified not only to health professionals, but also to patients and community members in Msinga. More pragmatically, I was also interested in how the practice of tuberculosis care and management in Tugela Ferry had been impacted by the international and national attention that had been focused on the area due to the broad public promotion of the XDR-TB outbreak via scientific and popular media.

This was not my first visit to South Africa. This research builds on more than a decade of engagement with South African HIV, TB and AIDS activism and research. I first went to South Africa in 2002 as an undergraduate intern working for the AIDS-activist Treatment Action Campaign (TAC) in Khayelitsha, a township outside of Cape Town. I was able to return to South Africa the following year, this time to Durban on a Fulbright Scholarship. I spent ten months conducting HIV related research; first in a molecular virology laboratory; later at a hospital in Durban that was running one of the first HIV treatment programs in town. After starting medical school in the US in 2004, I returned for a brief clinical elective in Mseleni, South Africa in 2006. I returned to Durban in 2007 and 2009 for short research trips and language training during my academic summers. This research was very much dependent on the colleagues and friends who facilitated my work around HIV/AIDS and tuberculosis even as my interests shifted from laboratory science to sociological, anthropological and historical questions about the conduct of HIV and TB research. Thus I was able to gain a long-term understanding of AIDS and TB research in Durban and its connection to international projects from the perspective of activist,
laboratory scientist, clinical researcher, and medical trainee. All in all, I spent nearly two years between 2006 and 2011 in the province of KwaZulu-Natal, South Africa (in Tugela Ferry, Greytown, Pietermaritzburg, and Durban) conducting interviews, collecting documents, and engaging in participant observation around different aspects of XDR-TB and HIV/AIDS research and care.
CHAPTER 1: Extensively Drug-Resistant Tuberculosis in South Africa – The Making of a Global Health Disease

In March 2006 a new disease was born. No new pathogen had been discovered; no one had visibly died with unusual symptoms or of mysterious causes. Yet on March 24, 2006, World Tuberculosis Day, the US Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) announced the emergence of a new and dangerous form of tuberculosis. It had a somewhat mysterious and potentially powerful name: XDR-TB.91

XDR-TB, which stands for extensively drug-resistant tuberculosis, refers to a form of tuberculosis that has mutated to become invulnerable to almost all anti-tuberculosis drugs. The first publication on XDR-TB was in the Morbidity and Mortality Weekly Report of the CDC (the same journal which in 1982 had documented the first cases of a new illness that later came to be known as AIDS) and warned that XDR-TB had “emerged worldwide as a threat to public health and TB control, raising concerns of a future epidemic of virtually untreatable TB.”92 Detractors wondered if whoever had determined the acronym had made a mistake. Shouldn’t extensively drug resistant be abbreviated EDR? As one Lancet Infectious Diseases commentator put it: "Were the authors trying to "sex up" their report by choosing the abbreviation XDR?"93 Also, this was no new disease – hadn’t highly drug resistant strains of tuberculosis been documented before under other names?94 Was extensively drug-resistant tuberculosis (XDR-TB) significantly different from multi-drug resistant tuberculosis (MDR-TB)?

92 Wright et al., “Emergence of Mycobacterium Tuberculosis with Extensive Resistance,” 302.
Despite these critiques, however, XDR-TB eventually captured the attention of biomedical, public health, and lay communities. By early 2007, news outlets in several countries reported about the growing threat of XDR-TB in South Africa; in mid 2007, an American traveler diagnosed with XDR-TB was the focus of a brief media frenzy in the United States. Several biomedical research funders (including the AIDS Clinical Trial Group and the Howard Hughes Medical Institute) decided to expand their research on tuberculosis, including XDR-TB. Tuberculosis programs in Peru and Russia supported by Partners in Health (PIH) reviewed their patient files to see if they had documented cases of XDR-TB and published their outcomes; researchers working for Doctors without Borders in Khayelitsha, South Africa similarly re-analyzed treatment outcomes and participated in debates about the best treatment strategies for XDR-TB. Partners in Health also started a pilot-project in Lesotho to demonstrate effective strategies for treating XDR-TB, using funding from the Soros foundation.

The publication of the first XDR-TB paper in MMWR was only one of a number of events that contributed to making a case for XDR-TB as a global health threat that required global action. Most of the interest around XDR-TB eventually focused on a particular XDR-TB outbreak in rural South Africa. This chapter, however, looks at the earlier events that led up to the first publication on XDR-TB worldwide, before the publication of the South African

---

outbreak. I pay special attention to the negotiations that preceded the naming, definition, and promotion of this new category. Among other things, the definition of the new concept of XDR-TB was carefully crafted in order to be helpful to researchers and clinicians working on different aspects of tuberculosis. XDR-TB was envisioned and understood as an amplification of multi drug-resistant tuberculosis, or MDR-TB, which itself had generated considerable media attention and funding in the preceding decade. Public health experts used conventional scientific strategies of data management as well as creative language in order to draw attention and funds to the new disease concept of XDR-TB. It gained traction as its definition was refined by scientists and was shared at meetings, and as existing networks of expertise around multi drug-resistant tuberculosis (MDR-TB) took it on as a legitimate and important new part of their work. For this reason I begin with a brief overview of the policy debates and interventions which took place around MDR-TB in the 1990s and early 2000s before I transition to XDR-TB, the core subject of this dissertation.

**Inevitable Microbiology or Therapeutic Anarchy?**

One way to tell the story of tuberculosis as an object of public and expert interest is as a story of repeated cycles of escalation followed by retreat and decline. In May 2000 the US Institute of Medicine issued a report about the state of tuberculosis in the US, in which it commended ongoing efforts to eliminate tuberculosis, but also warned that tuberculosis programs were at the mercy of “recurrent cycles of neglect followed by resurgence that have been the history of tuberculosis.” Until the 1980s American public health experts had been lulled into believing that tuberculosis (at least in the US) was a thing of the past. Yet in 1991 tuberculosis expert Lee Reichman had to report that “Tuberculosis (TB) is back with a

---

vengeance.” In New York City, in particular, the number of patients with tuberculosis nearly tripled from 1978 to 1992. In the 1990s public health experts also documented an outbreak of multi drug-resistant tuberculosis in New York City’s correctional system, as well as across the city more generally. Many of these cases were in patients with compromised immune systems – especially patients with AIDS.

The World Health Organization (WHO) and the International Union against Tuberculosis and Lung Disease (IUATLD) declared tuberculosis a “global emergency” in 1993. This was triggered in part by the tuberculosis outbreak in New York City and increasing tuberculosis rates around the world more generally, as well as the realization that globally increasing HIV/AIDS rates would lead to further increases of tuberculosis. The WHO’s Global TB Program decided to push for the global implementation of directly observed tuberculosis therapy (branded in 1995 as “DOTS,” which stands for Directly Observed Therapy, Short Course). DOTS is a standardized treatment regimen which uses the two most effective tuberculosis drugs, isoniazid (INH) and rifampin (also called rifampicin), together with two additional drugs. DOTS treatment occurs in outpatient settings (rather than in the hospital), and emphasizes the need to ensure that patients take all their medication for the full duration of treatment. In most cases standard tuberculosis treatment takes six months. The name DOTS refers to the recommendation that health workers (or lay community health workers) ”directly observe” patients as they take their

---

medication in order to guarantee their compliance – or full participation – with the program. From a public health perspective compliance is both crucial and onerous due to the long period of tuberculosis treatment. The WHO used its political weight to advocate for the introduction of DOTS in countries around the globe.\(^\text{104}\)

Wherever there is drug treatment there is the potential for drug resistance, as pathogens adapt to the medications they encounter. When a patient’s treatment course is shortened, or when patients miss a significant number of medication doses, this has two potential negative effects. On an individual level, a patient may not get better due to unsuccessful treatment of tuberculosis. On a population level, incomplete or inappropriate treatment can lead to a rise of tuberculosis that is resistant to the standard tuberculosis drugs. Sanctioned tuberculosis treatment employs at least four drugs in order to minimize the chances that treatment fails when tuberculosis becomes resistant to one (or more) of the four drugs. Despite this, over the past 65 years tuberculosis experts have repeatedly observed that every time a new anti-TB drug is introduced, “drug-resistant cases or case series are reported within months to years.”\(^\text{105}\) Thus, it was no scientific surprise when the 1990s saw the rise of multi-drug resistant tuberculosis (MDR-TB), a form of tuberculosis that is resistant to at least isoniazid and rifampin (the two most effective anti-TB drugs). MDR-TB is generally impervious to the standard TB therapy regimen, which relies on the power of these two drugs. Despite the fact that the emergence of drug-resistance was scientifically predictable, however, the difficulty of treating MDR-TB effectively, together with TB’s airborne transmission, caught the attention of the news media. Both the popular


press and public health promoters warned the public about a new kind of deadly “Ebola with wings,” and argued for increased tuberculosis control measures.\textsuperscript{106}

One thing that made the famous outbreak of tuberculosis in New York frightening was that it included many MDR-TB cases. Multiple MDR-TB "hotspots" were also documented in Peruvian slums and Russian prisons, where MDR-TB was spreading even among people who had never been exposed to tuberculosis medications before. This meant that drug-resistant TB was being transmitted from person to person and not just arising in patients who did not take their medications very well. This added a new dimension to tuberculosis, a disease that was previously considered beatable because it was relatively straightforward to treat and cure.\textsuperscript{107} In the period following the fall of the Soviet Union, the rise of drug-resistant tuberculosis in places like Russia, Georgia, Latvia and Uzbekistan was of particular concern to public health campaigners and scientists and garnered significant media attention. While the definition of MDR-TB only required strains to be resistant to isoniazid and rifampin, strains that were resistant to even more anti-TB drugs were known from the very beginning of documenting drug resistance. At least as early as 1997 scientists called a strain of MDR-TB which was common in New York “extremely drug-resistant” due to the fact that it was resistant to five important tuberculosis drugs, including all four first-line drugs and one second-line drug.\textsuperscript{108} Pan-resistant tuberculosis that was resistant to all first and second-line drugs in use at the time was also documented in 1997 and was especially alarming.\textsuperscript{109}

\textsuperscript{106} Richard Baumgarner, quoted in Reichman, \textit{Timebomb}, 1.
\textsuperscript{108} Moss et al., “A City-wide Outbreak of a Multiple-drug-resistant Strain of Mycobacterium Tuberculosis in New York.”
Interestingly, while the gradual rise of drug-resistance can be considered an inevitable microbiological outcome, global public health experts have simultaneously read the rise of drug-resistant tuberculosis as an indicator of programmatic public health failure. As the authors of the 1997 WHO and IUATLD report “Anti-TB Drug Resistance in the World” stated: “a high prevalence of MDR-TB is the result of therapeutic anarchy” and the rate of MDR-TB should be considered a "good 'summary' indicator of the performance of NTPs [National Tuberculosis Programs].”

While this report squarely blamed national tuberculosis programs for failing to contain drug-resistant tuberculosis, others held international structures of governance and economics accountable. MDR-TB gained an increased profile among people interested in public health and social justice when Paul Farmer, global health advocate, physician, medical anthropologist, and co-founder of the organization Partners in Health, publicly accused of the WHO of allowing poor people to die of drug-resistant tuberculosis. The standardized DOTS approach, supported by the WHO, focused on infectious cases of drug-susceptible tuberculosis while ignoring those cases that did not respond to the standard drug-regimen. In practice, this meant that the WHO explicitly advocated for the continuation of a one-regimen-fits-all first-line standard drug-regimen even once patients had documented MDR-TB that was known to be resistant to the two most important first-line drugs. Christopher Murray and other health economists at the World Bank had declared DOTS for drug-susceptible tuberculosis one of the most cost-effective interventions in human health, but considered MDR-TB untreatable, claiming that second-line drugs were

---

too expensive, and thus not cost-effective. As Paul Nunn, TB/HIV and drug resistance coordinator for the WHO, explained in 2010 the WHO preferred to single-mindedly pursue DOTS as their “one strong idea,” and had significant success in encouraging countries to implement their standardized tuberculosis program. Even as the problem of MDR-TB grew, the WHO felt justified in neglecting drug-resistant tuberculosis because it was still in the process of convincing countries around the globe to implement DOTS, and because in the WHO’s view, MDR-TB indicated a public health failure on the part of the implementing country. If national tuberculosis programs managed to properly implement the new DOTS strategy for drug-susceptible tuberculosis – so the WHO reasoning went – then MDR-TB would be a rare occurrence (which could now be blamed on individual patient non-compliance rather than health system failure), and ignoring these few cases (essentially allowing them to die without receiving appropriate treatment) would make sense on a broader public health scale.

Paul Farmer and others made the moral, political and microbiological argument, however, that the continued inflexible and futile provision of standard DOTS treatment in light of resistant strains would not only kill those (supposedly few) individuals denied effective drugs, but would quickly amplify the presence of MDR-TB as partially resistant

---

113 Paul Nunn, interview by author, 27 May 2010, Durban, South Africa.
115 I hesitate to claim that the WHO as an entity “thought” or “claimed” anything, yet this is how my sources speak about the WHO. Questions regarding who the individual people are through whom the WHO’s actions manifest themselves rarely led to a specific answer.
tuberculosis strains become increasingly resistant, leading to the uncontrollable spread of difficult-to-treat MDR-TB, and worse, around the world.\textsuperscript{116}

Paul Farmer had first encountered the devastating effects of MDR-TB in Peru, a country that had been praised by the WHO for its strong DOTS program. By using expensive resources available to him due to his position as a physician affiliated with Harvard University and thanks to his particular skill at fundraising, Farmer and his organization, Partners in Health, demonstrated that it was indeed possible (and in his view imperative) to save lives in poor countries by treating MDR-TB. Farmer also called attention to the plight of prisoners in the former Soviet Union who were being kept in overcrowded conditions. Crumbling prison and health infrastructure contributed to the spread of MDR-TB, leading to situations where prisoners returned home from their prison terms only to suffer and die from drug-resistant tuberculosis, putting their families and communities at risk for infection in the process. Of course the disease was not limited to the prisons, and there was no reason to believe that an air-borne illness would restrict itself to the former Soviet Union, either. At a time when the effects of structural adjustment programs and harsh post-communist market transitions were becoming increasingly clear, the rapid rise of MDR-TB in the former Soviet Union served as a metaphor for the global abandonment of the needy at a time of increased global mobility. In a twist of retributive justice, that abandonment was turning out to have potentially dangerous consequences for the first world.\textsuperscript{117}


The debate around the treatability or untreatability of MDR-TB demarcated a number of institutional and generational shifts that were taking place in the international public health world. As described in the introduction, the problem of tuberculosis was mostly considered solved by the middle of the twentieth century, as improved living conditions contributed to declining rates of tuberculosis in wealthier countries and effective antibiotic therapy seemed to promise the possibility of tuberculosis elimination world wide. Research projects around tuberculosis were mostly limited to operational questions around the proper administration of known drugs, and few young biomedical practitioners made their careers as tuberculosis specialists. The WHO's focus on directly observed treatment of tuberculosis reflected a public health stance which emphasized enforcing compliance to an approved drug regimen in order to protect the health of populations over the rights of individuals.

In the 1990s, eager young professionals like Paul Farmer represented the moral energy and zeal of a new generation of physicians and public health experts who had been trained during the rise of HIV/AIDS. This new generation became involved in international public health in the context of AIDS activism and the struggles of people living with AIDS fighting for their rights to determine how they would come to terms with a deadly and highly stigmatizing disease. Many health professionals trained at this time were less comfortable than old-guard tuberculosis experts with coercing people to take treatment for the sake of the common good, and instead argued for health as a human right for all citizens of the world. This imperative for health underpinned activists’ demands for access to expensive antiretroviral treatments for people with HIV even if economic analyses deemed this as not cost-effective in poor countries. Thus, according to some, the debate around the appropriate management of MDR-TB in poor countries also reflected a generational battle
between old guard public health bureaucrats and a new generation of campaigners who saw themselves as fighting for the lives of the poor and disenfranchised.\textsuperscript{118}

The WHO eventually acknowledged the necessity to identify people with MDR-TB and to treat them with additional second-line drugs beyond the standard four-drug DOTS treatment course. In 1999, WHO guidelines endorsed “DOTS-Plus,” which called for the use of second-line drugs to treat MDR-TB in appropriate settings. Large partnerships were created and funded with large grants from donors such as the Bill and Melinda Gates foundation to facilitate a new drive to develop and study well-managed pilot programs to deal with MDR-TB. In 2000 the WHO created the Green Light Committee (GLC) to oversee the distribution of concession-priced second-line anti-TB drugs, as well as training and support, to eligible tuberculosis control programs.\textsuperscript{119} The Green Light Committee was conceived not as an agency of the WHO, but as a public-private partnership made up of “academic institutions, civil society organizations, bilateral donors, governments of resource-limited countries, and a specialized United Nations agency”\textsuperscript{120} which would facilitate the global expansion of MDR-TB treatment programs.\textsuperscript{121}

During this time period, the provision of long-term medical therapy to poor people with infectious diseases was becoming increasingly politically acceptable (even imperative), in large part through the work of AIDS treatment activists as well as organizations like Partners in Health and others who managed to frame health as a human right, rather than as a good to be acquired with a set pool of limited resources that could only be distributed unfairly. At the same time a vocal and global network of AIDS activists convincingly argued

\textsuperscript{118} Claire Wingfield, interview by author, 2010; Gregg Gonsalves, interview by author, 5 March 2010, New York, NY.

\textsuperscript{119} WHO, “DOTS-Plus and the Green Light Committee” (World Health Organization, 2000).

\textsuperscript{120} Rajesh Gupta et al., “Increasing Transparency in Partnerships for Health – Introducing the Green Light Committee,” \textit{Tropical Medicine & International Health} 7, no. 11 (2002): 970.

that prevention messages and sympathy would not suffice in a world where almost forty million people were already living with HIV/AIDS and suffering from its accompanying infections – including tuberculosis.

In New York the immediate threat of tuberculosis, including drug-resistant tuberculosis, was averted in the 1990s through intense treatment and infection-control activities led by New York City’s public health department.\(^{122}\) This led to a dramatic decline of overall tuberculosis rates in New York. The cost was high, however: the shock of the resurgence of an almost-forgotten airborne disease in a less treatable form meant that an estimated $1 billion were spent on containing tuberculosis in New York City alone.\(^{123}\)

Over the course of the next several years, pilot programs for the treatment and management of drug-resistant tuberculosis were also put in place in “hotspots” like the slums of Peru (by Partners in Health, working with Harvard University and public health officials in Peru), in Latvia (by the Latvian government and supported by the American CDC and the US Agency for International Development - USAID), and in prisons in Siberia (supported by Partners in Health and Doctors without Borders (MSF)), among others.\(^{124}\) The Green Light Committee (together with funding from the Global Fund to fight AIDS, TB and Malaria) put within reach affordable MDR-TB treatment programs for middle- and low-income countries. With the New York outbreak contained, and international MDR-TB outbreaks managed, drug-resistant tuberculosis slipped into the background of public concern and was no longer featured frequently in the news.\(^{125}\)

---

\(^{122}\) Frieden et al., “Tuberculosis in New York City—Turning the Tide.”

\(^{123}\) Kenneth Castro, interview by author, phone interview, 23 February 2010.


\(^{125}\) It is worth noting that in current tuberculosis and public health lore, Partners in Health (PIH) has reached superstar status, a large following, and significant moral weight. However, some activists stress that PIH was not the first organization to demand action on tuberculosis, and that other
A new cycle

This, then, is where the story of XDR-TB, and thus the story of this dissertation begins. The shock brought on in the 1980s by AIDS – a new and fatal disease – and tuberculosis – an unexpectedly resurgent and increasingly untreatable disease – had passed. AIDS continued to have a huge cultural impact in public health circles as well as on the broader public, while tuberculosis mostly retreated into the background. Between 2000 and 2005, occasional reporting on tuberculosis did occur as the media continued to report on the hottest infectious disease threats of a given season, be it anthrax, SARS, Dengue fever, West Nile Virus, bird flu, super-resistant staphylococcus or, for that matter, New York’s bedbug epidemic. Experts did not stop working on drug-resistant tuberculosis, of course. Dr. Peter Cegielski, the Team Leader for Drug-resistant Tuberculosis at the CDC took exception to my characterization of the early 2000s as a quiet time for tuberculosis. Cegielski remembered the period as a very active time, when international agencies finally supported the idea that resources should be used to treat MDR-TB and programs were put in place, accordingly. Yet it was also clear to Cegielski “that the suddenness of the outbreaks of MDR-TB in the early 90s was starting to fade a little bit from people’s memory.” As Dr. Sarita Shah, a young physician working for the CDC in 2005 perceived it, broad interest in tuberculosis had waned “since MDR-TB came under control in the US following

---

127 Peter Cegielski, interview by author, phone interview, 2 February 2010.
implementation of strong policies and programs.” She felt that by the time she was involved, a relatively small group of people was working on the problem of global tuberculosis compared to the burden of the disease and the scope of the problem worldwide.128

Thus, by 2005, MDR-TB no longer felt like an overwhelming crisis in public health circles. Yet away from the headlines, MDR-TB continued to spread and continued to kill people, despite efforts by various agencies and countries to contain it. Programs running under the auspices of the Green Light Committee covered only a small percentage of those at risk for drug resistant tuberculosis. Though the Green Light Committee had approved 37 pilot projects for almost 13,000 MDR-TB patients in 31 countries, this barely put a dent in the approximately 460,000 MDR-TB cases that were estimated to occur every year. Only 8 of the 22 WHO-designated high burden countries addressed MDR-TB as part of their national TB treatment programs in 2005.129 Even when second-line drugs were used effectively to treat MDR-TB, mortality rates were still disappointingly high, at over 20%, even in model programs.130 In fact, most people around the world who were dying of tuberculosis were still dying of perfectly drug-susceptible (non-resistant) strains of tuberculosis, which would respond to standard drug regimens if they were made available.131

The rest of this chapter describes the efforts of a core group of tuberculosis experts to keep tuberculosis, and drug-resistant tuberculosis, in particular, in the public eye. Just as the under-treatment of drug-resistant tuberculosis was known to further amplify drug

resistance, members of the tuberculosis community found they had to amplify their descriptions of tuberculosis in order to keep the interest of funders, scientists, governments, and the public.

**Keeping the momentum going – the origins of XDR-TB**

In 2000, at a time when treating MDR-TB seemed urgent, Partners in Health, together with Harvard, the CDC, the Peruvian Department of Health, and the Taskforce for Child Survival and Development received a $4.7 million 5-year grant from the Bill and Melinda Gates Foundation to help lead global policy development for MDR-TB, which, among other things, funded the activities of the Green Light Committee (GLC) described above.\(^\text{132}\)

By 2004, the Green Light Committee was nearing the end of this funding cycle and it was unclear who would provide future funding.\(^\text{133}\) Public interest in MDR-TB had waned following successful anti-MDR-TB programs in the US, and unlike for HIV/AIDS, there was no strong tuberculosis lobby or activist movement working to leverage increased funding for the Green Light Committee. Global statistics compiled by the WHO clearly demonstrated that MDR-TB was still a global concern that was far from being solved, but experts felt there was a need to raise public awareness about drug resistant tuberculosis to ensure future funding and attention.\(^\text{134}\)

Green Light Committee chair Dr. Peter Cegielski, who represented the CDC in the Green Light Committee, often had the opportunity to visit national MDR-TB programs around the world as part of his work.\(^\text{135}\) When visiting program sites, he would usually be shown the most complicated cases and he would hear stories about tuberculosis patients

---

\(^{132}\) Cegielski, interview by author, 2010.
\(^{133}\) Shah, interview by author, 2007.
\(^{134}\) *Ibid*.
\(^{135}\) Peter Cegielski was chairman of the Green Light Committee from 2004-2006.
whose tuberculosis strains were so resistant to drugs that they were not responding even to the second-line drugs used to treat MDR-TB because first-line drugs no longer were effective. As mentioned earlier, such resistance to second-line drugs had in fact been documented previously and was considered almost inevitable in view of the biology of drug-resistance. Yet its increasing prevalence was still a disturbing unintended consequence of expanding access to second-line tuberculosis drugs to treat MDR-TB. By 2004 Dr. Cegielski had the impression that the reports of severe drug-resistance were becoming more frequent, leading him to believe (as he put it) that “wow, this is an emerging epidemic.” After consulting with some laboratory-based tuberculosis experts who agreed that they, too, were seeing this trend, Cegielski decided it would be fruitful to get a global, numerical sense of the extent of second-line resistance. He believed that compiling the data in a quantitative way would demonstrate that increasing levels of drug-resistant tuberculosis continued to be a threat and would highlight the importance of well-managed second-line tuberculosis treatment programs that do all in their power to prevent the rise of further drug-resistance. The goal, in part, was to generate a new wave of excitement about tuberculosis and render the tuberculosis funding climate more favorable. 

**Documenting drug resistance worse than MDR-TB**

Cegielski assigned the task of documenting these highly resistant tuberculosis strains in a systematic fashion to Dr. Sarita Shah, who had recently joined the CDC’s Epidemic Intelligence Service (EIS) in August 2004. As an EIS officer, she belonged to the fabled “disease detective corps” that has a reputation for attracting people who are “young, highly trained, and fiercely committed” to their work. Descriptions of EIS work often

---

focus on heroic adventures that involve hunting down deadly diseases in remote places.\textsuperscript{139} This assignment, however, hinged on assembling and analyzing statistical data generated around the world and could be completed from Atlanta (where Shah was based) or any other location with a computer and an internet connection. Together with Dr. Cegielski and her immediate CDC supervisor, Dr. Kayla Laserson, Dr. Shah created a data-collection instrument with which to capture the state of highly drug resistant tuberculosis around the world. They decided that a survey of the Global Supranational TB Reference Laboratory (SRL) Network would be the most efficient way to generate credible and powerful global data.

The SRL Network consists of “25 reference laboratories on six continents that collaborate with national reference laboratories to increase culture and drug-susceptibility testing capacity and provide quality control for global surveys to assess anti-TB drug resistance.”\textsuperscript{140} These laboratories were originally identified in the mid 1990s when concern about MDR-TB was growing but only limited information about MDR-TB’s global scope was available. The WHO sought high quality laboratories that could help the WHO administer global tuberculosis drug resistance surveys and use standardized measures to assess the presence of tuberculosis strains resistant to first-line anti-tuberculosis drugs (specifically isoniazid and rifampin).

The Secondary Reference Laboratories that were selected to conduct these surveys have good reputations for performing high quality, reliable work relating to tuberculosis diagnostics. Not only are they globally distributed and receive clinical samples from many


countries, but they also participate in a centralized quality assurance program to ensure accuracy and consistency of their first-line drug resistance data. The good reputation of the labs was especially important to Dr. Shah’s study of highly drug resistant tuberculosis because testing of resistance to second-line tuberculosis drugs (which are used to treat MDR-TB) is not routinely done by most labs, and has not been universally standardized.

The SRLs are not centrally managed or administered, however, and while they may be inclined to participate in collaborative research and surveillance projects beyond the regular WHO drug resistance surveillance surveys (which are financed by the WHO), they are under no obligation to do so.\textsuperscript{141} In addition, the labs are not distributed in such a way that they accurately reflect global tuberculosis epidemiology. There is a heavy concentration of SRLs in Europe, and only a few are in what would be considered “resource-poor” regions, primarily because the WHO relied on existing, reputable laboratories when choosing which labs to certify as SRLs. By 2006, there were 26 SRLs: 11 in Europe, 5 in the Americas, 5 in the Western Pacific region, 2 in South Asia and 2 in Africa.\textsuperscript{142} Meanwhile, of the 22 countries designated by the WHO as having a high burden of tuberculosis, 9 were located in Africa, 5 in South East Asia, and only one in Europe.\textsuperscript{143}

Despite these limitations, one feature of working with the Supranational Reference Laboratories that appealed to Dr. Shah and the CDC was the increased credibility granted to collaborative work by the scientific community. Successfully bringing together these 25 laboratories (or a subset of them) would be a good strategic move. In discussing this study, Dr. Shah stressed the importance of the collaborative interactions between the different SRLs and her, between different tuberculosis researchers at the CDC, and between the CDC,

\textsuperscript{141} Email between Peter Cegielski and Sarita Shah on 31 March 2005.
\textsuperscript{142} There were only 25 SRLs at the time of the study I am discussing here; I am not sure which of these 26 labs was new in 2006.
WHO, and the International Union Against Tuberculosis and Lung Disease (IUATLD). The coordination of such multinational and multi-organizational interactions requires considerable effort, but is highly valued among international health agencies, who often find it difficult to synchronize their activities. In the letters Dr. Shah sent to the SRL directors inviting them to contribute their data to the study, she emphasized the collaborative nature of the project, and reminded them of successful collaborations in the past.

Beginning in October 2004, Dr. Cegielski and later Dr. Shah began approaching the SRL directors, asking them to contribute their computerized data on all Mycobacterium tuberculosis isolates they had tested for second-line drugs during the course of their regular operations between 2000 and 2004. It was Dr. Shah’s responsibility to collate the data into a meaningful paper. This was essentially a retrospective analysis based on convenience – the designers of the study did not have the ability to influence the ways in which data had been collected or processed, but were merely collecting information from databases that were already there. Thus it was important that the data sources be reliable but not too difficult to access. Most of the SRLs agreed to contribute data.

The SRLs’ characteristics as reliable sources of data ensured the credibility of a study whose authors essentially knew what results they were going to find – alarming cases of tuberculosis resistant to second line drugs – before they set out to find them. What wasn’t clear from the onset was how many cases of this new, scary disease would be identified, or exactly which drugs they would be resistant to.

---

144 Supranational Reference Laboratories are affiliated both with the World Health Organization and the International Union Against Tuberculosis and Lung Disease.

145 Dr. Shah repeatedly stressed the collaborative nature of the study to the author and included the following comment in an email: "I think an important thing to emphasize with the SRL survey experience is that there was an incredible spirit of collaboration in the interest of raising awareness for this public health issue. I had never met any of the SRL directors, yet they all quickly and willingly shared their data which they could have chosen to publish on their own. This all took place in a relatively short time span: 8/04-3/06, from inception to MMWR. It’s really quite a beautiful testament to the commitment and collegiality of the SRL network, WHO, and CDC," personal communication, April 11, 2007.
Compiling these cases was not a simple matter of merging the different SRL databases, since each database was constructed based on different rules and represented different facts about drug-resistance. The different SRLs did not all test for resistance to the same drugs. Some laboratories had decided that a particular test was not reliable from a technical standpoint; in other cases a particular drug was not being used in a laboratory’s catchment area, thus making the presence of resistance clinically unimportant. Some reference laboratories (specifically the one located in South Korea) had drug resistance information on every single person in their catchment area who was ever tested for tuberculosis, and had enormous databases filled with cases of drug-resistance which would never have been discovered in other countries. Other SRLs only had data on a small subset of their catchment population – only from people who had failed previous first-line tuberculosis treatment multiple times, for example. Some laboratories had representative data for the country or region they were located in, but also had individual sporadic data on cases from other countries mixed in, making certain types of statistical statements based on geographical area difficult to calculate. Often, the same patient would appear in a database multiple times – this needed to be identified in order to avoid duplicating results. The different ways that information had been generated and placed into the different databases needed to be taken into account before the databases could be merged into a single study. It was Dr. Shah’s job to “clean the data” in order to assemble it and use it to make meaningful results.\(^\text{146}\)

In addition, none of the SRLs included substantial clinical data about the patients whose samples they had tested beyond the drug resistance profiles. How sick were the patients? How lethal was a particular strain of tuberculosis? What kind of tuberculosis

\(^{146}\) Shah, interview by author, 2007.
treatment had the patient received? Was the patient HIV positive? These were questions that for the most part could not be answered by the SRL databases.

**What’s in a name? The uses of the letter X**

The soon-to-be-counted cases of highly resistant tuberculosis needed a name. This was necessary, in part, so that Shah and her colleagues would be able to discuss the results in an efficient and meaningful way. Strictly speaking, these cases would be a subset of multidrug resistant tuberculosis (MDR-TB), since MDR-TB is defined as tuberculosis resistant to *at least* isoniazid and rifampin. This would have to be the minimum requirement for any strain considered even more concerning than the “baseline” MDR-TB. MDR-TB was an old concept at this point, however, and a name was required that could highlight the fact that these cases were worse than the already difficult-to-treat MDR-TB.

Ideally, the new name would capture the attention of public health experts, scientists, and lay media alike. As Dr. Shah tells the story, those working on the project initially used whatever name came to mind in order to communicate about their work. Highly resistant, super resistant and ultra resistant were all used, among others. She and her colleagues felt, however, that a really good name was needed; one that would drum up attention and funds.147

The new disease’s name also needed to be one that worked for tuberculosis researchers working on a diverse set of research problems and regions. Dr. Timothy Holtz was one such tuberculosis researcher; he was a medical epidemiologist working under Kayla Laserson at the CDC’s Division of TB Elimination. One of his research projects involved working together with MDR-TB researchers in Latvia to assess Latvia’s program’s cure rates for MDR-TB treatment depending on what types of drugs were used. (The best treatment strategies for MDR-TB continue to be an object of study.) Something he was

---

taking into account in this research was how specific drug resistance patterns affected treatment outcomes.\textsuperscript{148} Thus he, too, was looking, among other things, at a subset of patients whose tuberculosis strains were resistant to all or most available anti-tuberculosis drugs, including second-line drugs, though he was focusing specifically on the Latvian program.\textsuperscript{149}

By early 2005, both Dr. Shah and Dr. Holtz’s projects were independently making progress. Some of the Supranational Reference Laboratories had submitted their data on second-line drug resistance to Dr. Shah; Dr. Holtz and his collaborators were beginning to see interesting trends in the success of certain subsets of MDR-TB treatment in Latvia. Both groups were separately looking ahead to submitting abstracts summarizing their research to the annual meeting of the International Union Against Tuberculosis and Lung Disease (officially called the Union World Conference on Lung Health, and usually simply called “The Union”), the biggest annual TB-related conference.\textsuperscript{150}

It was during a casual conversation in the hallway at the CDC between Peter Cegielski and Timothy Holtz that the two men acknowledged they were working on related questions. They agreed that it would make sense if both groups used the same language to describe the heightened degree of drug resistance they were documenting in their respective research. Dr. Cegielski had suggested something like “superbugs” – but this had already been used frequently to describe drug-resistant staphylococcus aureus (MRSA) skin

\textsuperscript{148} The drug resistance pattern describes exactly which drugs a given tuberculosis strain is resistant to. While MDR-TB is at least resistant to isoniazid and rifampin, a given strain could also be resistant to any combination of pyrazinamide, ethambutol, streptomycin (these are first-line drugs), as well as the second line drugs, which include fluoroquinolones (such as oxofloxacin), kanamycin, capreomycin, and several others. The general consensus today is that increasing drug resistance is related to worse treatment outcomes, but that certain resistance combinations including fluoroquinolone resistance are particularly difficult to treat.

\textsuperscript{149} Timothy Holtz, interview by author, phone interview, 8 February 2010.

\textsuperscript{150} Union abstracts were due in March 2005; the actual meeting took place in Paris in October 2005.
infections, among other things, and didn’t seem specific enough. Something that sounded similar to MDR-TB, but worse, would be compelling.\footnote{Holtz, interview by author, 2010.}

Dr. Holtz remembers thinking of possible letters and “all of the sudden it just popped into my head […] instead of MDR why don’t we think of another letter, so I remember thinking of the X-men and the X-games, thinking, well, why don’t we just use the letter “X” because a lot of other people use this letter “X” to designate something that’s special or unique, and so why don’t we just call it XDR.”\footnote{Ibid.} Dr. Holtz wasn’t sure what the acronym would stand for, but as far as Dr. Cegielski was concerned, this was “one of those eureka moments. […] We both kind of ran down the corridor and grabbed Sarita and said ‘we’re going to call it XDR.’”\footnote{Cegielski, interview by author, 2010.} As Dr. Sarita Shah recalled: “It sounded like an offshoot of extreme sports, […] it’s like reality TV shows and things like that. And X is an exciting letter, and we thought if we call it Extremely Drug Resistant TB – XDR TB – that would be really catchy. And so it was sort of just like, we were just being creative, standing in the hall, and the whole point of this was to raise awareness of this issue. And so we called it extreme, drug-resistant TB.”\footnote{Shah, interview by author, 2007.}

The quality and credibility of data was very important, but creative naming and creative acronyms were also appropriate, since the point of the study was to raise awareness of the potential threat posed by increasing levels of tuberculosis drug resistance. Cegielski, Holtz and Shah all described being energized by the idea of calling tuberculosis with a heightened degree of drug-resistance “XDR-TB,” or extreme. They explicitly tapped into pre-existing cultural uses of the letter “X” both as an unknown variable (in mathematic equations), unknown origins (as in Malcolm-X), a marker for an unknown and invisible
mechanism (as in X-Rays) as well as a designation for things that are dangerous, powerful, excessive and extreme (as in X-games and X-men), or forbidden (X-rated). X has become a particularly useful designation for things that combine the attributes of mystery and danger, such as "X-files." The new XDR-TB could similarly be understood as being an entity whose precise nature was not known, but which was clearly dangerous.

The cultural valence of the letter "X" was not lost on professional colleagues who worked outside of the CDC. Dr. Friedland, who today is one of the foremost experts on XDR-TB due to his research on XDR-TB in South Africa, later attributed part of the disease’s importance to its name: "I think the fact that it’s X-DR TB really makes a difference, compared to being MDR or mXDR TB. Because, sort of, what's in a word. X equals extreme, exaggerated, [...] Excalibur, extraordinary, you know, and M equals moderate, mild, maybe. [...] From a marketing standpoint, if you want to think about it that way, the fact that it's X has actually contributed to its explosion.”

The importance of an moderate, yet extreme, definition

Once the name of the object of study was determined, Dr. Shah and her colleagues still needed to define it, however. An extreme name seemed to warrant an extreme definition. The initial idea was that XDR-TB should be resistant to "all of the drugs known to man to treat tuberculosis." This turned out to be an impractical definition, since very few labs (even the SRLs) actually test for resistance to all drugs known to treat tuberculosis, and only very few cases would be documented. There was little point in defining a new entity

---

156 At one point there was a discussion about calling a form of XDR-TB that did not quite fit the official definition for XDR-TB "modified" XDR-TB or mXDR-TB.
157 Gerald Friedland, interview by author, 27 March 2007, New Haven, CT.
that could not be measured and was not clinically relevant. The significance of the term did not only require a good name, but a useful “real-world” application. The definition turned out to be the object of extensive negotiations between the parties involved in Shah’s study.

What was clear early on was that XDR-TB would be defined as MDR-TB plus resistance to some other drugs. But which other drugs? Only second-line drugs, or also the first line drugs not included in the minimal MDR definition? If only second-line drugs would be included, which ones? There were dozens of more-or-less effective second-line drugs to choose from, some of which could potentially be grouped into similar classes. Researchers were trying to maximize the sense of risk and danger associated with the name XDR.

Completely untreatable tuberculosis resistant to all drugs available on planet earth may seem frightening, but if only one or two cases are identified, it is hardly alarming. A definition was needed that would both express a sense of urgency (almost untreatable tuberculosis) and yield a relatively large number of cases when the data from the different SRLs, who tested their samples for different second-line drugs under different conditions, were compiled. Scientific limitations potentially had to be taken into consideration, as well, since some of the resistance tests to second line drugs were clinically meaningless. For example, a patient with a strain of tuberculosis that is apparently resistant to cycloserine in the lab may still get better when treated with cycloserine.

All of the CDC researchers I spoke to described the task of settling on a definition as a lengthy process which involved hours and hours of endless meetings with various

159 There are eleven classes of anti-TB drugs. Five are first-line drugs: isoniazid, rifampin, ethambutol, streptomycin, pyrazinamide, whereby isoniazid and rifampin are the most effective; and six are second-line drugs: aminoglycosides other than streptomycin (e.g., kanamycin and amikacin), cyclic polypeptides (e.g., capreomycin), fluoroquinolones (e.g., ofloxacin, ciprofloxacin, levofloxacin, and moxifloxacin), thioamides (e.g., prothionamide and ethionamide), serine analogs (e.g., cycloserine and terizidone), and salicylic acid derivatives (e.g., para-aminosalicylic acid). Not all TB drugs are equally potent, and patients are generally treated with at least four drugs at a time. Kanamycin, amikacin and capreomycin are sometimes grouped together as “injectables.” This categorization of drugs into these eleven classes was first made explicit in Dr. Shah’s work on XDR-TB.
researchers, department heads, CDC editors, and others. Finding a definition that was helpful for Dr. Holtz’s work was well as Dr. Shah’s work turned out to be particularly sensitive. As mentioned earlier, the databases Dr. Shah was working with did not include clinical data that could help portray the clinical impact of increasing MDR-TB resistance. The databases did not conclusively reveal whether or not people with (proposed) XDR-TB were sicker or more likely to die than people with the minimum definition of MDR-TB (resistance to isoniazid and rifampin). Dr. Holtz’s database from Latvia, however, had rich information on treatment and clinical outcomes that provided evidence for the fact that some drug resistance patterns were more difficult to treat (and more fatal) than others.\footnote{Holtz, interview by author, 2010.}

Dr. Holtz’s data could potentially be employed by Dr. Shah in order to justify a particular definition of XDR-TB as clinically meaningful on the basis that the newly defined form of tuberculosis led to clearly worse outcomes than MDR-TB. Combining some of Dr. Holtz’s data with Dr. Shah’s analysis could also make Dr. Shah’s data more compelling by including “the life or death aspect of how this is important,” as Dr. Holtz put it.\footnote{Ibid.} However, Dr. Holtz was not keen on providing too much of his data for Dr. Shah’s paper, since this would put him and his research colleagues at risk of “scooping” themselves, which meant he and his group would not be able to take full credit for the project through publication of a separately authored paper, but instead would merely be subsidiary co-authors in a broader paper under Shah’s leadership.\footnote{Ibid.}

A temporary compromise was finally reached in April 2005, when a traveling Dr. Cegielski sent a 4:00 am email from Russia to his colleagues at the CDC and WHO, suggesting that they define XDR-TB as MDR-TB plus resistance to at least any three second

\footnote{Once a significant amount of data from a given project has been published it becomes difficult to republish it, even in an expanded version, since the content of research article publications must be original.}
line drug classes (out of six classes). In the email Cegielski, like Shah previously, emphasized the collaborative nature of the project, stressing that XDR-TB needed to be defined in a way that would fulfill the needs of everyone involved. He acknowledged to his SRL collaborators that Dr. Holtz’s group was also looking at the effects of resistance to all first line tuberculosis drugs, thus making the inclusion or exclusion of first-line drugs other than isoniazid or rifampin in the XDR-TB definition an important decision.163

In retrospect, Dr. Holtz argued that the people in the meetings within the CDC thought like epidemiologists and tuberculosis promoters, but not like microbiologists or laboratory scientists, in that they took into account epidemiological and clinical statistics, but did not sufficiently consider the feasibility, reliability and significance of different resistance tests performed in the laboratory. We will see in the next chapter why this eventually led to a reconsideration of this much debated and carefully constructed definition.

The definition proposed by Dr. Cegielski was the definition both Dr. Holtz164 and Dr. Shah165 used in separate poster presentations at the Union meeting in October 2005, and which was published (using mostly Dr. Shah’s data and some of Dr. Holtz’s data, in addition to population-based data from the US and South Korea) in the Morbidity and Mortality

163 Email between Peter Cegielski and Sarita Shah on 31 March 2005. Email provided to author by Dr. Shah. In a double emphasis of the importance of collaboration, Dr. Shah highlighted the following passage from Dr. Cegielski’s email: “The breadth of global collaboration in this project has been astonishing, considering the labs themselves are always being asked to do x, y, or z, and they generally refuse to participate. In this case the idea was powerful enough that it motivated almost all of the SRLs to volunteer to participate.”
Weekly Report (MMWR) of the CDC in March 2006.\textsuperscript{166} This is the paper with which I opened this chapter. The choice of definition was officially rationalized clinically, based on data from Latvia, as well as data from the US. The “Editor’s Comment” which accompanied the publication of XDR-TB in the MMRW emphasized WHO treatment guidelines rather than epidemiological data, however: “The proposed definition of XDR TB was based on new WHO guidelines for programmatic management of drug-resistant TB, which recommend treatment with at least four drugs known to be effective. Therefore, with three or fewer remaining classes of SLDs [second-line drugs] to which the infecting organism is susceptible, treatment of these patients is unlikely to meet international standards.”\textsuperscript{167}

Interestingly, this consensus definition of XDR-TB was apparently not extreme enough to warrant the name extremely drug resistant tuberculosis, as originally suggested. CDC researchers as well as collaborators at the WHO had actually been quite happy with the name extremely drug-resistant tuberculosis and had submitted abstracts to the 2005 Union conference using variants of that designation. The original title of Sarita Shah et al.’s abstract was: "Extreme Drug Resistance in Tuberculosis ("XDR TB"): Global Survey of Supranational Reference Laboratories for Mycobacterium tuberculosis with Resistance to Second-line Drugs." However, when the time came to draft the publication in MMWR, CDC editor Ann Lanner pointed out that “extreme” was too strong a name for strains of tuberculosis that were potentially still susceptible to several drugs.\textsuperscript{168} It was possible, for example, to have a strain of XDR-TB that still responded to the two weaker first-line drugs, as well as three out of six classes of second-line drugs. This would perhaps be a relatively treatable form of tuberculosis, assuming the correct drugs were selected. What would

\textsuperscript{166} Wright et al., “Emergence of Mycobacterium tuberculosis with Extensive Resistance to Second-line Drugs – worldwide, 2000-2004.”

\textsuperscript{167} Ibid. SLDs is the abbreviation for second-line drugs.

\textsuperscript{168} Ibid.; Castro, interview by author, 2010.
epidemiologists call strains of tuberculosis that really were resistant to all available drugs? A suggestion to continue calling XDR "extreme" when it was resistant to all anti-tuberculosis drugs, while calling less extreme XDR strains extensively resistant was discarded. In another discussion someone unsuccessfully suggested using XXDR for extreme and XDR for extensive TB. Sometime between the March abstract submission deadline for the 2005 meeting of the International Union against Tuberculosis and Lung Disease and the September poster completion deadline for the same meeting the meaning of the abbreviation was permanently changed to extensively drug-resistant tuberculosis. The title of Shah et al.’s poster as it actually appeared at the meeting was: “Extensive Second-Line Drug Resistance in Tuberculosis (“XDR TB”): Global Survey of Supranational Reference Laboratories.”

Shah’s poster at the October 2005 Union meeting in Paris generated some interest among tuberculosis drug resistance experts but did not receive broader play – Dr. Cegielski recalls that he tried to set up a press conference for the media, but that there was not enough interest in the results. The following report on XDR-TB in the March 2006 issue of Morbidity and Mortality Weekly Report (MMWR), which was dedicated to World TB Day, received some more attention. Dr. Holtz remembers feeling that he had been part of something important when he heard his division boss, Dr. Kenneth Castro, being

---

169 By the time of writing the debate has moved on, and forms that are resistant to “everything” are usually called TDR, or totally drug-resistant tuberculosis. For example: Maryn McKenna, “TDR-TB: The Indian Government Denies it,” Wired Science Blogs/Superbug (blog) Wired.com, January 29, 2012, http://www.wired.com/wiredscience/2012/01/tdr-india-denies/.
171 Cegielski, interview by author, 2010.
172 World TB day commemorates Robert Koch’s demonstration of the TB bacillus, which took place on March 24, 1883.
interviewed about XDR-TB on the radio. The CDC used its press office to successfully generate and place sound bites about XDR-TB in the news at this time. The MMWR report itself framed XDR-TB as the global emergence of a new and potentially dangerous infectious disease, stressing that the findings “suggest that urgent measures are needed to establish population-based surveillance for SLD resistance and to plan public health responses,” arguing that “this report documents the existence of XDR TB as a serious and emerging public health threat.”

According to Sarita Shah and Timothy Holtz, the media uptake of the MMWR report went well, and the collaborators were happy with what they had achieved. Within a few months, some tuberculosis researchers were using the term XDR-TB in their published analyses of drug-resistant tuberculosis. Many established researchers were less impressed with the new concept, however, and wondered about its clinical utility. In particular, researchers in those countries in the former Soviet Union that had been struggling with significant MDR-TB outbreaks at least since the mid-1990s were less interested in whether or not their severe MDR-TB cases qualified as XDR-TB than in the strategies to treat specific drug-resistance patterns and approaches to avoiding this increased resistance in the first place. Dr. Vaira Leimane, one of the leading MDR-TB researchers in Latvia – a country which is now well-known for its large MDR-TB problem and its strong MDR-TB program – points out that “the definition is not so important, because the severity of disease and the possibility of cure depends on how many drugs have

real resistance. But for policy makers the definition is very good.”¹⁷⁷

The new category of XDR-TB as presented in Shah’s paper only gradually became a compelling tool for policy makers, however. Shah had identified 347 cases of XDR-TB around the world (including 200 from South Korea), and there was good reason to believe that XDR-TB was a growing problem. The fact that 7% of the identified MDR-TB cases could be classified as XDR-TB was alarming. Yet one of the weaknesses in terms of public interest for this first paper about XDR-TB was the fact that dispersed cases of XDR-TB were drawn from countries across the world, and very little information was available about these cases’ fates. While the database approach allowed Shah and her collaborators to argue that XDR-TB was already a dangerous global problem at its inception, it did not lend itself to the geographically localized outbreak narrative that is popular with journalists and fiction-writers alike.¹⁷⁸ There was no patient zero (or location zero) who could be looked at as the origin as the epidemic.¹⁷⁹ The paper also did not provide the potential for individualized human-interest stories that feature the experience of illness and recovery – or death.

Sarita Shah’s MMWR report found XDR-TB around the world, yet it was not until XDR-TB came to be understood as a lethal disease emerging from a particular location – rural South Africa – that XDR-TB truly gained sufficient rhetorical power to mobilize public health policy makers and funders. In the following chapter I turn to South Africa to consider the processes that enabled this to happen and begin to look at the consequences.

¹⁷⁷ Vaira Leimane, interview by author, phone interview, 16 February 2010.
CHAPTER 2: How XDR-TB Became South African

On August 17, 2006, Dr. Neel Gandhi, a young physician affiliated with Yale University, gave a late-breaker presentation to thousands of people in a packed room at the XVI International AIDS Conference in Toronto. In his talk, titled “High Prevalence and Mortality from Extensively Drug-Resistant (XDR) TB in TB/HIV Coinfected Patients in Rural South Africa,” he announced 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). Fifty-two of the 53 cases of XDR-TB in Tugela Ferry had died (a mortality rate of 98%); almost all of them were known to be HIV positive. When Neel Gandhi sat down at the end of the presentation, he wasn’t sure what people’s reaction would be. As is often the case with conference presentations the program was running behind schedule and there was no time for questions.

The international media’s response soon became apparent. The next day, the New York Times and American National Public Radio, as well as other international and South African media outlets ran stories about a powerful and resistant tuberculosis strain striking South Africans with HIV/AIDS. In the following months, many highly reputable

---

180 Gandhi had been a Robert Wood Johnson Clinical Scholar at Yale working with Dr. Gerald Friedland; at the time of the presentation he was faculty at Albert Einstein College of Medicine.


biomedical science journals included pieces summarizing Gandhi’s findings in their news and editorials sections; in Tugela Ferry itself, local health officials found themselves warding off interview requests from local and international journalists, with the resulting reporting ranging from tabloid sensationalism to high-brow analysis. As the editors of the journal *Lancet Infectious Diseases* commented in November 2006, “huge global interest was sparked by a report at the International AIDS Conference in August of a cluster of cases in South Africa of XDR tuberculosis with high mortality among HIV co-infected patients, with a Google search finding 130,000 hits.” By January 2007, the *New York Times* reported that this “virtually untreatable,” “rapidly fatal,” “extreme” illness was poised to “imperil millions.” A writer for *Nature Medicine* apocalyptically warned of impending disaster, comparing XDR-TB to “something out of a horror movie, [that] blazed across Tugela Ferry, a small village in South Africa, striking down nearly everyone it touched.” The name of the town Tugela Ferry became almost synonymous with XDR-TB in international reporting and at scientific conferences.

The response to XDR-TB in South Africa was not limited to media outlets and journal articles. International health agencies formed task forces, had meetings, and

---


186 Fikile Ngema, interview by author, 13 October 2010, Tugela Ferry, South Africa; Anthony Moll interview by author, 23 July 2007, Tugela Ferry, South Africa.


dispatched experts; 190 bioethicists called for indefinite quarantine of patients with drug-resistant tuberculosis; 191 embarrassed government agencies called for more data and warded off accusations of negligence; 192 non-governmental and transnational organizations raised funds to generate new programs for XDR-TB focusing on research and treatment. 193 Tugela Ferry itself became the center of much health research activity by international and local researchers. Topics of international research in Tugela Ferry included tuberculosis infection control, cheaper and improved diagnostics for drug-resistant tuberculosis, and the relative effectiveness of hospital based and community based tuberculosis treatment interventions, among others. Over the following years the publicly funded tuberculosis programs in KwaZulu-Natal (the province in which Tugela Ferry is located) were significantly restructured in order to find ways to treat people with drug-resistant tuberculosis more effectively.

XDR-TB’s characteristics as a contagious, airborne disease with a high mortality rate of 98% (in Tugela Ferry) and no known effective treatment made it a frightening disease, indeed. Yet it should not be taken for granted that a sad but indeed commonplace occurrence – the death of rural South Africans from HIV and tuberculosis – became an urgent global health crisis that demanded – and received – attention and resources. As we saw in the previous chapter, at the time of Gandhi’s presentation in August 2006, the term XDR-TB itself had only recently been conceived and published. It had been consciously assembled with the goal of piquing the interest of those who heard about it. The original

---

global survey of XDR-TB (published in March 2006) had only identified one case of XDR-TB in all of Africa and the Middle East, however, and had focused on clinical data from cases in Latvia, South Korea and the US. Soon after publication of the global XDR-TB survey, cases of XDR-TB from Norway and Iran were reported.¹⁹⁴ Yet it was the cases of XDR-TB in Tugela Ferry, South Africa which captured the imagination of public health promoters and journalists, and around which MDR-TB experts and global health funders successfully rallied in order to call for increased action against drug-resistant tuberculosis.

The rest of this chapter considers how a small town in rural South Africa became the center of global discussions around XDR-TB. I will pay particular attention to the historical circumstances through which Tugela Ferry became the host for a small academic HIV/TB cotreatment study that eventually uncovered the surprising cases of XDR-TB. Dr. Gandhi’s presentation on XDR-TB in South Africa emerged from the context of a global AIDS pandemic which had motivated a multi-billion dollar global health enterprise of research and care, a South African government which had long denied that HIV/AIDS was a problem despite rapidly rising HIV infection rates, and a South African health system which had significant public structures to address tuberculosis, though they were struggling to keep tuberculosis at bay. In this chapter, I will first provide a brief overview of the recent history of tuberculosis epidemiology and policy in South Africa. In the second half of the chapter I explain how international tuberculosis research made its way to the remote trade town of Tugela Ferry, South Africa.

**South African tuberculosis and the world**

In South Africa alone, an estimated 64 000 people died of tuberculosis in 2004.\(^{195}\)

Tuberculosis is considered endemic in South Africa, which is categorized as a “high burden country” by the World Health Organization (WHO). According to tuberculosis experts, most of the country’s population is exposed to tuberculosis at some point during their lifetime. This is usually not a big problem for people with healthy immune systems – in most people the tuberculosis germs are kept in check and remain dormant. People with this form of inactive tuberculosis (called “latent” tuberculosis) have a ten percent chance of having active tuberculosis during their life times. But HIV positive people infected with latent tuberculosis have a much higher chance - about ten percent a year - of becoming sick with active tuberculosis.

The South African tuberculosis epidemic is in part a result of the huge disparities in economics, infrastructure and job opportunities between different racial groups that are a legacy of apartheid. Throughout the 20th century some parts of South Africa had strong anti-tuberculosis programs, but they focused primarily on protecting the health of white citizens, as well as on maintaining a productive black labor force in South Africa’s mines. The mines of South Africa were an incubator for tuberculosis. Difficult work conditions in moist conditions underground, crowded dormitories, and poor nutrition all contributed to high rates of tuberculosis, as well as other illnesses, in the mines. One key strategy for minimizing tuberculosis in the mines was to send sick miners back home to the native reserves – the segregated areas allocated to blacks in South Africa. Predictably, this led to

\(^{195}\)WHO, *Global Tuberculosis Control: Surveillance, Planning, Financing: WHO Report 2006.* (World Health Organization, 2006) I calculated the number of deaths from a mortality rate of 135 deaths per 100 000 population per year and a total population of 47 208 000.
the spread of tuberculosis among those at home in the reserves who did not themselves work in the mines.\textsuperscript{196}

In the second half of the 20\textsuperscript{th} century, tuberculosis rates in apartheid South Africa differed dramatically by race. Tuberculosis notification rates among whites were already low in the 1950s and declined further into the 1980s, and a dramatic drop in urban tuberculosis mortality rates was seen for all races when the drug isoniazid (still the most important anti-tuberculosis drug) was introduced in 1952. Yet the relatively high rates of tuberculosis notification among black Africans dramatically increased further from 1952 to the late 1960s before they began to drop. In his study \textit{White Plague, Black Labor}, Randall Packard concludes that this late drop was not evidence of an actual drop in tuberculosis rates among black South Africans, but rather an indicator of the fact that with the increased forced displacement of black South Africans to rural reserves (also called homelands or Bantustans), tuberculosis cases among black South Africans were no longer being counted by South African statistics.\textsuperscript{197}

By the early 1980s tuberculosis rates in South Africa were rising again, as they were in much of the world, though the reason was not immediately apparent. In 1995, Packard and Coetzee argued that HIV/AIDS alone could not account for the rise in documented tuberculosis cases and cited other social causes, including the changing demographics of the mining labor force in South Africa.\textsuperscript{198} Today, however, the still-increasing rates of tuberculosis in South Africa and in many other Sub-Saharan African countries are attributed


primarily to the increased numbers of people who are at increased risk for tuberculosis due to HIV infection.199

Tuberculosis in South Africa, then, was driven by a recent and dramatic rise in HIV/AIDS, and by the early 2000s it had become a commonplace occurrence for patients with tuberculosis to die, even when they had access to appropriate medical care and took their tuberculosis medications as intended.200 Medicines to effectively treat HIV (called antiretrovirals, or ARVs) were not available to most South Africans at that time, and people with AIDS eventually succumbed to opportunistic illnesses like tuberculosis, even if the opportunistic illness was correctly treated. Tuberculosis became the most common cause of death for South African people with HIV/AIDS, and inversely 70% of tuberculosis patients in the country were coinfected with HIV.201 As a result, many tuberculosis-related deaths were attributed to end-stage AIDS without further investigation.202 In this context, a death from tuberculosis was not considered particularly mysterious and did not raise questions about whether or not the anti-tuberculosis drugs would have been effective if the patient had not had HIV. At the same time, many AIDS deaths were documented as tuberculosis-related deaths on death certificates in order to avoid AIDS-related stigma.203 Of the approximately 64,000 South African deaths from tuberculosis in 2004, some were treated for tuberculosis while others were not. In most cases, however, those who died had never

200 According to sentinel studies, HIV prevalence among pregnant women in South Africa dramatically rose from 0.8% in 1990 to 7.6% in 1994, to 20.5% in 2000. Some areas of the country were more heavily affected than others; one community in KwaZulu-Natal had a prenatal prevalence rate of 50.8% in 2001. See Salim S. Abdool Karim et al., “HIV Infection and Tuberculosis in South Africa: An Urgent Need to Escalate the Public Health Response,” The Lancet 374, no. 9693 (2009): 921–933.
201 Ibid.
been tested for resistance to tuberculosis drugs. A national drug resistance survey from 2001-2002 estimated the prevalence of multi-drug resistant tuberculosis in South Africa to be a relatively low 3%, though this is now considered to be a likely underestimate (and even a low percentage represents a large total number).

Thus it is difficult to say with any certainty what proportion of tuberculosis deaths in South Africa have been due to drug-resistant tuberculosis.

The absence of routine drug-resistance testing in basic tuberculosis management was not unique to South Africa, but followed the standard protocol recommended by the World Health Organization. As we have seen, the WHO's strategy for managing tuberculosis, known as DOTS (Directly Observe Therapy, Short Course), originally recommended that tuberculosis programs in low and middle-income countries should focus on treating infectious, drug-susceptible tuberculosis. This meant ignoring the possibility of drug resistance at the beginning of treatment, and making sure that patients take their anti-tuberculosis drugs properly. By the end of the 1990s, however, the WHO had acknowledged the importance of multi-drug resistant tuberculosis and recommended that tuberculosis programs should monitor for the possibility of drug-resistance and provide patients who had MDR-TB with second-line treatment when appropriate.

South Africa put a version of this WHO policy in place quite early, even though the country did not receive direct support from the Green Light Committee. The South African tuberculosis program followed the new WHO recommendations to test only patients who

---


failed regular tuberculosis treatment for first-line drug-resistance and to refer MDR-TB cases identified this way to specialized regional tuberculosis hospitals, where they would be treated with second-line drugs.\textsuperscript{206} South Africa had first restructured its tuberculosis programs according to the WHO’s DOTS guidelines around 1996, and added the MDR-TB component around 1999/2000.\textsuperscript{207} Despite this forward-looking policy, however, many of South Africa’s tuberculosis programs were struggling to keep up even with the treatment of regular drug-susceptible tuberculosis. One major reason for this was South Africa’s rapidly rising HIV/AIDS epidemic, which was evident by the late 1990s and led to increasing numbers of tuberculosis patients, more and more of whom were not getting better despite appropriate tuberculosis treatment.\textsuperscript{208} In addition, health programs across the country, and tuberculosis programs in particular, were undergoing ongoing dramatic, structural change as a result of the transition from apartheid to democratic majority rule in 1994.

The apartheid system, which had legally enforced the political and economic superiority of the white minority population since 1948, had maintained at least fourteen separate health systems, including segregated health departments for four different racial groups and for each of the ten “homelands.”\textsuperscript{209} Homelands, or Bantustans, were the less desirable geographic areas that the apartheid government set aside for black people, according to tribal designation.

These homelands were incorporated into the new democratic South Africa in 1994, yet compared to the areas that had been reserved primarily for whites they had suffered

\textsuperscript{206} Karin Weyer, interview by author, phone interview, 8 July 2010.
\textsuperscript{207} \textit{Ibid.} My sources do not precisely agree regarding these dates. Implementation occurred over time and did not occur across the country at the same pace.
tremendous neglect and often lacked basic infrastructure. This included lack of access to clean water, sanitation, electricity, and formal education. In the 1990s, South Africa was one of the most unequal societies in the world. This was also reflected in its health system, which ranged from urban, high-tech academic hospitals of international repute (among other things, the first ever successful heart transplant took place in Cape Town, South Africa in 1967) to dilapidated clinics in slums and rural areas which were understaffed, understocked, and served populations with dismal rates of infant mortality and malnutrition. Integrating these radically disparate health systems post-1994, as well as changing the focus from hospital-based curative care to clinic-based and nurse-driven primary care, was only one subset of the many daunting tasks of service and infrastructure-provision facing the new government. Efforts to improve health systems were also more effective in places that were already better off, leading to increasing inequality even as attempts were made to improve the public health system.

Providing quality diagnosis and treatment for tuberculosis through the public sector was only one of many health priorities that needed to be addressed systematically, next to cholera and measles outbreaks (the former due to poor water and sewage access, the latter due to low childhood vaccination rates), as well as growing epidemics of diabetes and hypertension. These public health programs in transition were not ready for the rapidly

---

211 Cullinan, *Health Services in South Africa: A Basic Introduction*.
increasing rates of tuberculosis and other diseases that began to unrelentingly flood clinics and hospitals in the mid to late 1990s due to dramatically increasing rates of HIV/AIDS. By the late 1990s, as a rising AIDS epidemic also caused an increase in tuberculosis cases, many facilities found themselves completely overwhelmed by the increased burden. The Church of Scotland Hospital in Tugela Ferry, which would eventually become famous in 2006 for its high rate of XDR-TB, was no exception. Dr. Anthony Moll has been one of the main physicians at that hospital since the 1980s and witnessed the arrival of AIDS and tuberculosis patients in Tugela Ferry turn from a trickle into a stream and then into a flood. The central tuberculosis hospital in Durban often had a waiting list that was several months long and was not really in a position to help. Articles from the late 1990s and early 2000s document how South African hospitals and clinics transformed from places of potential healing to places of death and hopelessness, with up to 80% of hospital beds being taken by patients with HIV/AIDS. There was no treatment for HIV available at this time, and stories about this period were inhabited by despondent nurses, physicians-in-training complaining that they weren’t learning proper medicine, and jaded senior physicians who either tried to avoid AIDS patients entirely, or fought seemingly pointlessly to help those patients whom they could.

---

214 Anthony Moll, interview by author, 13 May 2011, Tugela Ferry, South Africa.  
215 Iqbal Master, interview by author, 30 April 2010, Durban, South Africa; Sheila Bamber, interview by author, 26 August 2010, Tugela Ferry, South Africa.  
216 Katherine Floyd et al., “Admission Trends in a Rural South African Hospital During the Early Years of the HIV Epidemic,” JAMA 282, no. 11 (1999): 1087–1091; Oppenheimer and Bayer, Shattered Dreams?; Author’s observations.
Tuberculosis before the time of AIDS

Treating tuberculosis had once been one of the easiest tasks for physicians at remote, rural hospitals in South Africa, including at the hospital in Tugela Ferry. In the 1980s, it was the norm in Tugela Ferry to admit every single patient diagnosed with tuberculosis to the hospital for the full duration of his or her treatment. This generally meant six months of supervised treatment as an inpatient, usually in the designated tuberculosis ward. Dr. Theo van der Merwe, another physician who worked at the hospital in Tugela Ferry for over two decades, longingly remembered the days before HIV/AIDS when being the doctor in charge of the tuberculosis ward meant visiting it once a month to discharge patients who had completed treatment. In the meantime, patients’ care was supervised by nurses who made sure patients took their treatment every day, and who provided them with regular meals. According to the somewhat nostalgic Dr. van der Merwe there was very little turnover. Patients rarely died while undergoing tuberculosis treatment, and most of them went home healthier than they had been when they had arrived.

It wasn’t just in rural Tugela Ferry that tuberculosis was considered a relatively unproblematic, treatable and low intensity disease. At King George V hospital, the tuberculosis hospital in Durban that specializes in complicated cases of tuberculosis, the work of treating tuberculosis was considered routine and not too hectic. According to Dr. Sheila Bamber, a physician who worked in the pediatric tuberculosis ward at King George V hospital from 1982 to 2006 and later worked in Tugela Ferry, employment at the tuberculosis hospital in Durban was appealing to physicians looking for a relaxed schedule and a job that was not too challenging. She herself did not shirk hard work, yet the

---

217 Van der Merwe, interview by author, 2011.
218 Van der Merwe, interview by author, 2011.
219 Bamber, interview by author, 2010; Master, interview by author, 2010.
government tuberculosis hospital brought certain advantages for her, as well. There, she could practice as a general physician without the administrative duties of private practice, and without having to perform bloody procedures like Caesarian sections, which she would have had to do in a general hospital.\textsuperscript{220}

Over the course of the 1990s and 2000s, however, the tuberculosis wards in Tugela Ferry and in Durban became increasingly busy and changed from low-intensity spaces where patients mostly waited until they got better, to places with increasing turnover of seriously ill patients who needed increased attention and often got worse. By the early 1990s, the 60-75 beds that were available for tuberculosis patients at the hospital in Tugela Ferry became insufficient for the number of people diagnosed with tuberculosis. Over the course of that decade, hospital stays were successively shortened, with the balance of treatment being given to the patients to take back home.\textsuperscript{221} As Dr. Moll recalled: “We became overwhelmed with HIV plus TB and no longer could we admit patients for full duration of their six months. I can remember making a decision with other hospitals to bring it down to five months, to bring it down to four months, later on to bring it down to two months, we lost complete control after that, and basically it became round about 2001/2002, any patient who could walk and got a diagnosis of TB and HIV mostly was given his treatment and sent home.”\textsuperscript{222} Inpatient care was reserved for the seriously sick and dying.\textsuperscript{223}

Dr. Moll described the changing outpatient management of tuberculosis as the result of hospital overcrowding in the context of conversations between different hospitals about the appropriate response. The increased move to outpatient treatment was not merely an

\textsuperscript{220} Bamber, interview by author, 2010.  
\textsuperscript{221} Moll, interview by author, 2007.  
\textsuperscript{222} Ibid.  
\textsuperscript{223} Ibid.
ad hoc reaction of hospital administrators to the rising tuberculosis burden, however. By 1996, South Africa had decided to introduce the relatively new WHO DOTS policies for managing tuberculosis, which emphasized ambulatory (out-patient) tuberculosis care in the community. As the WHO and South African policy makers stressed, DOTS as it was implemented in South Africa consisted of a package of interventions, which included “four elements: case detection using sputum smear microscopy among symptomatic patients presenting to health services, establishment of regular supplies of essential antituberculosis drugs, enhancement of patient adherence to therapy by ambulatory supervised care, and the establishment of standardised reporting systems allowing the assessment of treatment results.”\(^{224}\) The name of the program, however, clearly emphasized its observational and somewhat coercive aspects, which called for patients to take their daily doses of medication in the presence of a treatment supervisor or supporter.\(^{225}\) In theory, this supporter could be a paid health professional, a volunteering shopkeeper, schoolteacher, neighbor, or a friend. Some tuberculosis programs even sought to work together with traditional healers and community leaders.

Several South African health professionals I spoke to perceived DOTS as a top-down WHO intervention that did not sufficiently consider the realities of health care provision in South African communities, and in fact did not provide the conditions that allowed even observed treatment. As Dr. van der Merwe explained: “beginning of the 90s the DOTS program came in to being. [...] And they [WHO] say, no, they [patients] must be DOTSed. [...] That means you must get a care giver and you make the diagnosis, admit them, maybe, treat them, stabilize them, and then they go out and they are DOTSed there. [They are


treated at home.] But, as we all know, it is a fantastic program, and we appreciate that very much, but, it was again a World Health Organization program and I don’t think they really realized what is going on at the coalface; at the grass roots level. You don’t get supporters. They didn’t make any provision for paid supporters, so [...] you couldn’t get supporters. [...]The World Health Organization brought that program out, and obviously we adopted it. And there we are.”226

In the quote above, Dr. van der Merwe touches upon a common, fundamental critique of the DOTS program. Essentially, the DOTS strategy relied heavily on minimally trained community members to carry the responsibility for ensuring that tuberculosis patients successfully took their medication. Yet no provision was made to pay these workers who were the backbone of the DOTS program, and often the organizational connection between the designated treatment supporters and the trained tuberculosis nurses was tenuous.227 Physicians and nurses working in clinics and district hospitals like the one in Tugela Ferry struggled with the fact that few resources had been allocated to actually identifying, training and compensating treatment supporters “out in the community,” who generally were not directly affiliated with health facilities. More recently, the weakness of this strategy has been acknowledged in South Africa and efforts have been made to pay some of these community health workers stipends, yet DOTS is still considered to be weak in South Africa. Several South African tuberculosis experts even went so far as to argue that DOTS did not in fact exist in South Africa at all. When I asked long-time tuberculosis physician Dr. Bamber when South Africa “became a DOTS country” she replied: “Well, let’s face it, it’s

---

226 Van der Merwe, interview by author, 2011.
227 See, for example, Partner in Health’s discussion of the payment of community health workers at http://www.pih.org/priority-programs/community-health-workers/about.
never been a DOTS country. Never been. I mean, a couple of places, like Hlabisa,\footnote{Hlabisa is a town in KwaZulu-Natal province in which there was an innovative tuberculosis program in the late 1990s. I briefly discuss this program later in this chapter.} where they had a very dynamic superintendent and he organized DOTS with the shopkeepers, etc. [...] But that was driven by him. And then he left and things just got, you know, overwhelming.”\footnote{Bamber, interview by author, 2010.} According to Durban-based tuberculosis researcher Nesri Padayatchi, “of course South Africa subscribes to the WHO guidelines, which talks about DOT [directly observed therapy], but I can assure you [...] DOT’s not happening here.”\footnote{Nesri Padayatchi, interview by author, 13 July 2007, Durban, South Africa.} In another instance, she quoted a colleague of hers as saying that “the only patients that get DOT are prisoners.”\footnote{Nesri Padayatchi interview by author, 6 April 2010 Durban, South Africa.}

According to Dr. van der Merwe, inpatient treatment would still be the preferred method of treating tuberculosis if the hospital had the capacity for it, since patients could be closely monitored in the hospital and could be prevented from defaulting from their treatment course. One nurse I spoke to in Tugela Ferry pointed out that inpatient tuberculosis treatment at least ensured that sick, poor, rural patients received daily meals. But as Sister Sithole, one of the matrons for Tugela Ferry’s primary health care program, responded when I asked if inpatient tuberculosis treatment should be reinstated: “I don’t think we could go back to admitting all of the TB patients. Where would they all sleep?”\footnote{Lindiwe Sithole, interview by author, Tugela Ferry, South Africa, 2011.}

Thus, physicians and nurses working at district hospitals in South Africa struggled with the practical aspects of keeping track of overwhelming numbers of tuberculosis patients who had been dispersed from tuberculosis wards to their homes. Some South African tuberculosis experts associated with academic centers in Cape Town, Stellenbosch, Pretoria, and Durban were unimpressed by the WHO guidelines for other reasons. They felt
that their TB expertise as well as success in treating tuberculosis was being undermined by the standardized (and thus simplified) tuberculosis treatment protocols generated by the WHO in Geneva.233 Prior to the DOTS strategy, South African tuberculosis physicians would use their own individual judgments in deciding exactly which combination of treatments a particular tuberculosis patient should take and decided when to test a patient for drug-resistance. The WHO guidelines set standard drug regimens and a testing schedule that did not require a physician’s individualized intervention. While the WHO’s push for DOTS attempted to increase access to anti-tuberculosis treatment by providing standardized and simplified procedures for managing the most infectious cases of tuberculosis, some people worried that DOTS would decrease the quality of tuberculosis care by shifting the task of caring for uncomplicated tuberculosis patients away from physicians in the hospitals to nurses and lay-workers in the community.234

Interestingly, the resistance and critique of the DOTS strategy by well-established tuberculosis specialists working in South Africa parallels the resistance by tuberculosis experts working in the former Soviet Union documented by physician-anthropologist Gene Bukhman.235 The post-Soviet physicians he spoke with pointed out that the DOTS strategy was based on studies conducted in African countries in the 1960s and 1980s, and that it was designed to be simple enough for Africa. One medical officer quoted by Bukhman stated “They say it is a very primitive system that could be used in Africa, and Russia is not


Africa.”

Being asked to introduce “African” (and thus presumed inferior) standards into the Russian system was considered insulting and inappropriate by some of the tuberculosis experts who believed in the superiority of their training, resources and clinical acumen over the standardized DOTS protocols. Intriguingly, the South African experts resisted that same “Africanization” of tuberculosis care, though this was not the language they used. They, too, believed that their own clinical skills and superior laboratories would lead to better outcomes than a standardized, simplified strategy.

Some clinics and hospitals in South Africa responded proactively to the increasing tuberculosis burden, as well as the new global tuberculosis policies, by putting in place programs seeking to maximize the effectiveness of tuberculosis treatment, and documenting the outcomes. One such effort was led by Dr. Wilkinson in rural Hlabisa, KwaZulu-Natal. He worked closely with community leaders to assist patients and demonstrated that patients did well even if they took anti-tuberculosis treatment every other day instead of daily. Other responses to the increased burden included actively putting in place care programs to help those sick and dying of AIDS, while merely trying to keep up with the increasingly sick tuberculosis patients. In either case, overburdened health systems sought help from volunteer community members to extend their reach into sick communities, and South African health programs (both public and charitable) increasingly promoted “home-based care” by lay people in various forms. Providing professional medical care for people with AIDS and tuberculosis was made very difficult by the fact that the South

---


237 Bukhman, “Reform and Resistance in Post-Soviet Tuberculosis Control.”


African President and his Minister of Health chose for several years to deny that AIDS was a problem in South Africa, actively undermined programs that sought to address it, and blocked the introduction of anti-HIV drugs into the public health system for several years.240

**Complexities of Co-Infection**

Once HIV treatment finally did become available in South Africa (first through HIV/AIDS research and pilot projects; after 2004 through government-funded programs in government hospitals and clinics), clinicians were faced with the challenge of treating HIV and tuberculosis at the same time. This was not always a straightforward task. Many of the opportunistic infections seen in people with AIDS (such as PCP pneumonia, cryptococcal meningitis and Kaposi’s Sarcoma) improve on their own once anti-HIV medications are introduced. Tuberculosis, however, persists and still needs to be treated with anti-tuberculosis drugs, even once an HIV positive person is being treated for HIV. Successful treatment of either tuberculosis or HIV disease requires patients to take several drugs a day, several times a day for prolonged periods of time. Standard tuberculosis treatment requires at least six months of medication; HIV requires daily medications for life. Treating both simultaneously can require high daily pill-consumption. Some tuberculosis drugs interact with some HIV drugs, so clinicians ideally need to pay attention to this and monitor carefully for certain side-effects. In addition, treating HIV in a person who has tuberculosis can sometimes actually make that person temporarily sicker, due to a phenomenon called Immune Reconstitution Inflammatory Syndrome (IRIS). As a person’s immune system recovers from HIV, it starts to recognize other diseases in the body (such as tuberculosis).

---

that until then it had been unable to fight – and starts an overwhelming immune response which has the potential to damage the body more than the tuberculosis itself.\textsuperscript{241}

Most importantly, however, South Africa’s tuberculosis programs were generally run separately from other medical and public health programs. To be diagnosed or treated with tuberculosis patients would go to the nurse-operated tuberculosis or DOTS office where protocols specific to tuberculosis were followed, according to South Africa’s version of WHO guidelines. Most new HIV programs, on the other hand, were set up to take place in separate offices or at separate hours than other programs. People diagnosed with HIV would be referred to mostly physician-run HIV clinics, where their HIV disease would be managed. People with tuberculosis and HIV might find themselves going to the same health facility to stand in line twice a week – once to pick up anti-tuberculosis medications from the TB office, and on another day to be seen about HIV and pick up antiretroviral medication. The clinicians who treated the patients did not usually coordinate HIV and TB care, and it could easily happen that a TB patient was never tested for HIV (despite a high chance that he/she could be HIV positive), or that an HIV patient was not thoroughly screened for tuberculosis. In the days before antiretroviral medications were available in the public sector, a patient might receive their HIV treatment through an academic study, a private hospital, or a charitable organization – but if they wanted to be treated for tuberculosis, they would still have to seek out the public hospital system for free tuberculosis care. In such cases, coordination of medical care was even less likely.

The disjointed nature of TB and HIV care led some experts to call for the integration of TB and HIV treatment.\textsuperscript{242} In the early 2000s, several international researchers, non-

governmental organizations, and donor organizations established HIV treatment and care programs in South Africa, some of which focused on the simultaneous treatment of HIV and TB co-infection. Doctors without Borders (MSF) initiated an HIV treatment pilot project at a municipal clinic in Khayelitsha, South Africa and soon famously knocked down the walls (quite literally) between the adjacent HIV and TB clinics and advocated for an organizationally and physically integrated approach to TB and HIV care. Other HIV treatment programs in South Africa explored the effective co-treatment of HIV/ TB co-infection from different perspectives. This included large, internationally funded trials addressing the perfect timing for starting TB and HIV treatment, as well as smaller proof-of-concept studies demonstrating that TB and HIV treatment could be successfully integrated.

It was in this context of a South African post-apartheid public health system in transition; a burgeoning AIDS epidemic which was not being sufficiently addressed; a complex relationship to global tuberculosis expertise; and growing global health research and care activity that a group of researchers affiliated with Yale University started an HIV and TB co-treatment study in Tugela Ferry, South Africa. This research eventually led to the discovery of XDR-TB and to the presentation with which I started this chapter. In the rest of this chapter, I will describe how the American-South African collaboration that eventually made Tugela Ferry and its researchers famous in public health circles came about.

---

Managing TB/HIV coinfection in Tugela Ferry

In 2001, Dr. Gerald Friedland, an American HIV clinical researcher based at Yale University, traveled to South Africa on a research sabbatical with the intention of beginning a collaboration with South African researchers at the Nelson R. Mandela Medical school of the University of KwaZulu-Natal (UKZN) in Durban. They had received funding from the US National Institutes of Health to look at the combined management of HIV and TB. Since the planned large-scale international research collaboration ran into complex bureaucratic hurdles and was slow to take off, Dr. Friedland spent some of his time in Durban working at a public inner-city clinic specialized on sexually transmitted infections and tuberculosis. There, he and South African colleagues conducted a small pilot program introducing HIV treatment into the government tuberculosis treatment program. The publication that resulted from this research showed good tuberculosis cure rates and stressed the advantages of introducing HIV treatment into the already existing public tuberculosis treatment infrastructure.245

While working in Durban, Dr. Friedland decided to seek out a more rural location, where he felt his research would have a greater impact. As Dr. Friedland put it, once he started looking for an appropriate research site, “all roads led to Tugela Ferry,” a small trade town in the municipal district of Msinga, in rural KwaZulu Natal, about 2.5 hours drive from Durban, where Dr. Friedland encountered a kindred spirit and a “magnificent, brilliant, incredible colleague” in Dr. Tony Moll.246 As we saw in the introduction, Dr. Moll and his colleagues at the Church of Scotland Hospital (a district hospital which is part of the government hospital system and no longer affiliated with any church or mission) in Tugela


Ferry had been caring for AIDS patients with extremely limited tools. Unable to access life-saving antiretrovirals, Dr. Moll had brought nurses, church-leaders, and other community leaders together in 1997 to found Philanjalo (Zulu for “live forever,” or “live well”), an organization which trained community members to take care of sick and dying people with AIDS, and then in 2002 opened a small hospice for people who needed palliative, end-of-life care.247

By 1997, the cause and manner of infection of HIV/AIDS was well known in much of the world, and life-saving, though very expensive, medications had become available in the US and Europe the preceding year. Yet among the communities in Msinga – the rural area that surrounds the trade town of Tugela Ferry – there was great consternation concerning the cause for the recent increase in dramatic AIDS deaths, and there was no sign of effective treatment. As Dr. Moll recalls it, his group’s early efforts to educate and mobilize community volunteers fell on fertile ground: “The willingness and the desire to participate was incredible. [...] The community [...] didn’t know what to believe, because there was such a lot of different information coming through. [...] When we started to bring in groups of community members for a full week of training on what HIV was, how it worked, what was the natural course of the disease [...], they felt empowered, they felt they had the right information, they understood the sickness, it dispelled a lot of the myths surrounding HIV disease, and these people went back into their communities and became strong pillars of information.”248

When Yale Professor Dr. Friedland first visited Tugela Ferry, its hospital, and Moll’s Philanjalo Care organization in 2002, Dr. Moll steered him away from the district hospital in town and instead took him in a four-by-four vehicle on a series of home-visits into the

remote hills surrounding Tugela Ferry. They left the busy commercial and administrative crossroads near the river, where the hospital is located, and, as Dr. Moll later described it, “went into the tracks, left the tar roads and started going back into time to real old Africa, where patients basically don’t have electricity, don’t have water supply, live off the ground, you can say, there’s no cell phone communication, basically cut off from modern facilities and these patients are really in bad circumstances out there in the rural community. And it was absolutely amazing.”249 They drove along winding dirt paths to an area dominated by modest and crumbling Zulu huts, rocks, acacia trees and aloes, to visit a man who was desperately ill, lying on the dirt-floor of his hut, with open, oozing sores all over his body.250 To Dr. Moll’s surprise, Dr. Friedland was soon by his side, examining him – touching him.251

The idea that a drive into the hills of Msinga allows a sort of time travel to “old Africa” is certainly problematic (and will be discussed in chapter 5). Yet Dr. Friedland was clearly affected emotionally by the trip with Dr. Moll. Dr. Friedland had experienced the early days of AIDS as an Infectious Disease specialist in New York City, and the intense personal suffering and loss caused by AIDS in KwaZulu-Natal reminded him of the time when all he could offer his own dying AIDS patients was comfort.252

The day of visiting sick patients in the hills of Msinga became the beginning of an intense and fruitful collaboration and professional friendship between the two physicians. Dr. Friedland was motivated by the possibility of conducting interesting research on the combined management of HIV and TB in Tugela Ferry, as well as the opportunity of

250 The following is Dr. Friedland’s description of the research site: “Tugela Ferry is about 2.5 hours from Durban; there’s one tarred road that leads into what was the former Zulu homeland. Everything else is dirt roads or paths. About 70% of people don’t have piped water or electricity. It’s really a quite impoverished, but very traditional Zulu community, so it’s very interesting in that way as well.” Friedland, interview by author, 2007.
providing life-saving treatment – whose dramatic effects he could personally vouch for – to people who would otherwise die sooner than later. Dr. Moll, meanwhile, was highly motivated to collaborate with Dr. Friedland on a program that would provide antiretroviral treatment to even a fraction of his patients who were HIV positive.

The Sizonqoba Study

Dr. Friedland and Dr. Moll designed a study in which they treated patients infected with HIV and tuberculosis and documented the outcomes. They named the study “Sizonqoba,” which in Zulu means “we will conquer.” As Dr. Moll described it, they put together a “very basic protocol looking at caring for HIV patients co-infected with TB in the community using the DOT program, and introducing antiretroviral therapy in those existing circumstances using existing infrastructure.”253 The emphasis here, like in Friedland’s previous HIV/TB co-treatment study at the clinic in downtown Durban, was the integration of HIV treatment into the pre-existing public tuberculosis program.

At that time, the hospital in Tugela Ferry had a relatively well-established tuberculosis treatment program which, according to Dr. Moll, was more successful than the programs in neighboring health districts in identifying tuberculosis patients and starting them on treatment. However, the tuberculosis office consisted of only two full-time staff-members, who were mostly grounded to the hospital due to a lack of vehicles. All the same, there were plenty of patients to be seen and administered to at the hospital every day. The program was called the DOT program – directly observed therapy program – but it was only nominally seeking out treatment supporters who could “directly observe” patients who were sent back home ‘into the community.’ There was only occasional successful contact tracing or follow-up of patients who stopped taking their treatment or left the hospital’s catchment area. As Dr. Moll described it six years later, there was good, passive case-finding

meaning that when sick people came to the hospital they would be diagnosed and put on
treatment – but the program was crippled by the lack of a community system. Thus the
“very basic protocol” that was put together required a significant amount of coordination
and strengthening of existing services – not only did the HIV treatment component need to
be added, but the tuberculosis program needed to be expanded, as well. Conveniently, the
new study program was able to take advantage of Philanjalo’s community-based lay
volunteers (which Dr. Moll described as lay “nurses in a huge community ward”) to
function as DOT supporters. In addition, a network of outlying government-run primary
health clinics affiliated with the hospital in Tugela Ferry meant that the tuberculosis
program’s physical reach did in fact go farther than the district hospital itself. The study was
able to provide funding for vehicles and additional staff to trace patients, as well as
administrative support to allow study files to be properly organized and completed, and for
results to be entered into databases.

Officially, the TB/HIV study was run from Philanjalo, the care organization Dr. Moll
had founded. Yet Dr. Moll was also a full-time physician employed by the department of
health to work at COSH, the government hospital. Philanjalo offices were in or adjacent to
the hospital, and the patients for the study were identified through the hospital system.
Thus, I might say that the hospital provided antiretrovirals or engaged in this study, but
strictly speaking, the study took place through Philanjalo, a non-governmental entity only
loosely affiliated with the government hospital. Over time, Philanjalo became more
established and more independent both physically and organizationally. In view of the
South African government’s hostile stance towards HIV treatment at the time it would have
been difficult (though not impossible) to run this study through the government system

255 Moll, interview, 2011.
256 Moll, interview, 2011. Author’s fieldnotes.
itself. In addition, Dr. Moll and his colleagues found that working through Philanjalo allowed them to launch small projects and identify next steps more quickly and effectively than would be possible through cumbersome bureaucratic channels.\textsuperscript{257}

\textbf{The power of treatment and the disappointment of treatment failure}

By 2003, Philanjalo was able to start providing HIV treatment to about 100 HIV and TB patients. Initially, the research program went very well. It was a time of great excitement and hope, as people who had previously apparently been sentenced to death rose from the dead. Stories abound of Lazarus-like recoveries and of patients returning to thank their nurses and doctors, only to find that their caregivers did not recognize their fatter, healthier selves. Many of the patients who joined the study were very sick when they began taking antiretroviral medication and it was hard to believe that recovery could be possible. Gradually, Dr. Moll and his colleagues became accustomed to using the new, powerful HIV medications on these sick patients. Dr. Moll found that the first few months could be very difficult for patients. Once they had managed to take their pills for a few months, however, the positive and transforming benefits of their treatment usually became apparent.\textsuperscript{258}

By the end of 2004, however, Dr. Moll noticed that a few patients were dying despite having taken antiretroviral medication for several months, and despite having successfully suppressed the HIV according to laboratory tests. These patients’ HIV was kept under control by their antiretroviral medicines, and the patients were being treated with standard anti-tuberculosis drugs, but they were still dying. What was going on?

\textbf{Death despite conquering AIDS – MDR-TB was a surprising killer}

By the time that HIV and TB co-treatment was up and running, Dr. Friedland had returned to New Haven, Connecticut full-time, though he still visited South Africa at regular

\textsuperscript{257} Moll, interview by author, 2011.
\textsuperscript{258} Moll, interview by author, 2007.
intervals. Dr. Friedland, Dr. Moll and others involved in the study had weekly international conference calls to coordinate and discuss the progress of the study.²⁵⁹ They both remember the phone calls where they debated what might have been the cause of the unanticipated and disappointing deaths in patients who had consistently taken both their HIV and TB medicines. Dr. Moll pointed out that at least one study death had been found to be due to multi drug-resistant tuberculosis (MDR-TB). The tuberculosis culture and drug-susceptibility results had only come back from the lab after the patient had passed away, however. Dr. Neel Gandhi, who was a young physician working under Dr. Friedland as a clinical research fellow at the time, wondered if drug resistant tuberculosis might explain other deaths and wanted to know how wide-spread drug-resistant tuberculosis was among patients in Tugela Ferry.²⁶⁰

I mentioned earlier that the South African tuberculosis programs recommended monitoring patients who were on tuberculosis treatment and testing them for drug-resistance if, after several months of treatment, they were not getting better. This was part of South Africa’s DOTS-Plus strategy that was introduced in the years preceding the study. In practice, however, drug resistance testing rarely provided valuable information, because it could take over six months to get a tuberculosis drug-resistance test result from the lab, at which point the patient would no longer be within easy reach of the hospital, and in many cases would have already died. In addition, samples were not generally sent to a lab for culture and drug-resistance testing at the beginning of tuberculosis treatment, but instead were only sent once it became apparent that a patient was not getting better despite several months of treatment. Thus it could take eight months to a year from the point of starting

²⁶⁰ Moll, interview, 2007; Friedland, interview.
tuberculosis treatment before a diagnosis of drug-resistant tuberculosis was made, even when the patient was carrying drug-resistant tuberculosis from the onset of treatment. Understandably, such delayed results were rarely useful to busy clinicians or their patients, especially since mechanisms to ensure that lab results of absent patients actually made it into their files or were brought to a practitioner’s attention were weak. This meant that even in cases where drug-resistance might be considered, clinicians did not always send samples to the lab, since they did not expect to receive them back on time.

When the protocol for the Sizonqoba HIV/TB co-treatment study was originally developed, Dr. Friedland and Dr. Moll decided to use the existing South African tuberculosis infrastructure and guidelines.\textsuperscript{261} This meant that for the tuberculosis component of the study South African diagnostic and laboratory protocol was followed, and tuberculosis patients were only tested for drug resistance if tuberculosis treatment failure was suspected. The researchers in Tugela Ferry hoped to avoid dealing with MDR-TB patients entirely by excluding patients from the study who had been treated for tuberculosis before (retreatment cases), and by actively supporting drug adherence through directly observed treatment. The assumption was that patients who had never been treated for tuberculosis before were unlikely to carry a drug-resistant strain of tuberculosis. Excellent drug adherence would prevent drug-resistant tuberculosis from having the opportunity to develop. In the context of the unexplained deaths in this new TB/HIV co-treatment study, however, it became clear that a heightened level of surveillance for tuberculosis drug-resistance was needed. Thus, Dr. Gandhi and Dr. Moll decided to look more actively for drug-resistant tuberculosis at the hospital in Tugela Ferry.

\textsuperscript{261} An alternative approach would have been to introduce more intensified monitoring and send tests to a commercial or international laboratory and pay for them from study funds.
Though Dr. Moll was the primary South African point person and researcher on the Sizonqoba co-treatment study, he was first and foremost a full-time clinician at the district hospital. He was also the main physician managing the HIV clinic where study participants were being treated, along with many other HIV patients whose treatment was now finally being paid for by the South African public health system. After several years of resistance, the South African government had agreed in 2004 to provide HIV treatment through the public sector.

Additional research activities investigating the unexpected deaths in the co-treatment study had to be fit in around Dr. Moll's already very busy schedule. Conveniently, there were two medical students from the University of KwaZulu-Natal visiting Tugela Ferry in February 2005 looking for a small project to do. As Dr. Moll put it, such medical students were usually sent to the HIV program “because there’s so much stuff to go on there that it’s easy to think up a project.” On February 7, 2005, these students agreed to the task of collecting a sputum sample from every single coughing patient in the hospital. Dr. Moll had decided that this would be the fastest way to get a snapshot of the tuberculosis situation at the hospital, and received permission from the tuberculosis laboratory in Durban, which was in charge of processing samples from Tugela Ferry, to send a large batch of sputum for tuberculosis culture and drug-susceptibility testing.

The process of collecting these samples must have been quite a sight: "We set up a little table on a Monday morning between male TB ward and female TB ward outside in the sun, and we had a list of all coughing patients in the whole hospital. There were probably about 55 or so names [...]. And so one by one we brought these patients outside and we provided them with sputum bottles, we set them up with chairs under the trees in the sunshine and we asked them to produce sputum. We created lists, we wrote down their

names and quite a few of the patients came out with wheelchairs, you see, because I really wanted every sick patient who could cough a sputum sample to produce us a sample. In the end we had nearly covered our list of 55, we were probably in the late 30s or 40s, and there was a group of patients left that couldn’t get in a wheelchair that were just so sick on their beds, and fortunately we had the determination to bring the whole jolly bed out on wheels outside, and we actually invited the physiotherapists from the hospital to come and help us to induce sputum with some kind of pummeling and chest massaging. Oy, these guys were so sick, I mean, I was afraid that they were going to die outside there on the bed during the procedure of getting sputum from them, and at the end of the day we had 45 samples, which we submitted. A few again the next day which followed afterwards, and basically we just carried on with our work. The students went home, they wrote up their little study. And what we had done was a cross-sectional snapshot across the hospital at that one time of all coughing patients." It was this ad-hoc and in retrospect perhaps somewhat comical scenario acted out by un-named South African medical students and coughing patients which eventually formed the basis for the scientific paper on XDR-TB that was presented at the 2006 International AIDS Conference by Dr. Gandhi.

It should not be taken for granted that the microbiology laboratory at the large, modern, public, academically connected referral hospital in Durban readily agreed to accept sputum samples from Dr. Moll’s snapshot. According to South Africa’s protocols at the time, tuberculosis samples were only to be sent for culture and drug-susceptibility testing once treatment failure was suspected, not for a sweeping hospital screen. In addition, standard drug-susceptibility testing recommended by the WHO at that time only checked for resistance to the two most important first-line tuberculosis drugs: rifampin and isoniazid.

---

263 It is best to perform sputum tests outdoors in order to reduce the risk of transmission of the aerosolized bacteria (released by induced coughing) to other patients in the wards.
The hospital in Tugela Ferry, however, routinely sent its tuberculosis lab work to one of very few labs in South Africa that tested tuberculosis strains for resistance to all first-line tuberculosis drugs, as well as some second-line drugs. In most other parts of the country the tests would not have been available, or, at the very least, the American researchers would have had to identify and pay a specialized research laboratory to conduct the test.

Instead, Prof. Willem Sturm, the head of the microbiology lab in Durban that provided most tuberculosis culture and drug-susceptibility testing for the province of KwaZulu-Natal’s public health system, had a keen interest in tuberculosis drug-resistance. Originally from the Netherlands, Sturm had spent some time working in Karachi, Pakistan before coming to South Africa in 1993. In Pakistan he had conducted work which showed a significant amount of tuberculosis drug-resistance among patients in Karachi,²⁶⁵ and when he arrived in Durban, he set up a laboratory which could conduct conventional phenotypic tuberculosis drug susceptibility testing, as well as employ more sophisticated molecular methods that allowed specific strains of tuberculosis to be identified and traced in South Africa. These methods were not commonly available outside the developed world at the time.²⁶⁶ Between 1996 and 2000 he co-authored several papers with David Wilkinson, looking at tuberculosis treatment and transmission in Hlabisa, a rural research site four hours north of Durban, where Wilkinson tested innovative strategies for managing tuberculosis.²⁶⁷ The timing of this research allowed Wilkinson, Sturm and colleagues to document the parallel rise of TB and HIV in a rural region of KwaZulu-Natal. They showed

²⁶⁷ Hlabisa and Tugela Ferry are both rural towns in KwaZulu-Natal but they are not close to each other.
an increase in nosocomial (hospital-based) transmission of tuberculosis (especially the increased susceptibility of hospital nursing staff to tuberculosis infection),268 as well as the gradual rise of drug-resistant tuberculosis (including MDR-TB)269 in the context of an ambitious twice-weekly tuberculosis treatment program. This program was promoted by Wilkinson, and caught the attention of tuberculosis specialists and rural doctors across the region.270

By 2005, Professor Sturm had developed an interest in documenting the development of fluoroquinolone-resistant bacteria. Physicians were increasingly using fluoroquinolones broadly for various types of infections, including respiratory infections (pneumonia), meningitis, and gonorrhea.271 Fluoroquinolones (specifically ofloxacin) were also increasingly being used in tuberculosis treatment, and were considered effective for treating multi-drug resistant tuberculosis (MDR-TB). For this reason, Prof. Sturm had asked Lynne Roux, the manager of the tuberculosis diagnostics laboratory in Durban, which was


under his administration, to keep an eye out for cases of tuberculosis coming through the lab that demonstrated ofloxacin resistance.\textsuperscript{272}

On May 13\textsuperscript{th} 2005, a few months after Dr. Moll’s tuberculosis “snapshot” at the Church of Scotland Hospital in Tugela Ferry, Lynne Roux was reviewing the tuberculosis drug-susceptibility results in her laboratory database, looking especially for ofloxacin resistance, following her boss’ instructions. According to Roux, some of the technicians in the lab had mentioned to her that they might have tested such cases and entered them into the database. “I looked for it, and I couldn’t believe what I saw: [...] As I pulled these up, I saw this pattern of resistance that shocked me. Kanamycin and ofloxacin.”\textsuperscript{273} In fact, the cases she had compiled were not just resistant for the ofloxacin she was looking for, but resistant to all four first-line tuberculosis drugs (isoniazid, rifampin, pyrazinamid, ethambutol) \textit{and} the two second-line drugs the lab routinely tested for (kanamycin and ofloxacin). 80\% of the cases she found came from the Church of Scotland Hospital, which had sent dozens of samples containing tuberculosis that was resistant to all six of these drugs. She had never heard of this hospital and did not know where it was located. Even though it was after-hours by the time she had finished gathering all the data, Roux knew she needed to alert someone immediately, or she would not be able to sleep that night. Rather than first discuss the finding with her supervisor, Professor Sturm, she called the Church of Scotland Hospital switchboard and asked to talk to the doctor who manages tuberculosis.\textsuperscript{274}

The switchboard connected her to Dr. Moll, and as Lynne Roux remembers it, he already suspected what she was talking about when she broke the news to him. She told him that she had come across an alarming cluster of drug resistance coming from his hospital. The notes Lynne Roux took during that phone call show that she had also found

\textsuperscript{272} Roux, interview by author, 2011.
\textsuperscript{273} Ibid.
\textsuperscript{274} Ibid.
cases of drug resistance at other hospitals in the province of KwaZulu-Natal; Dr. Moll explained to her that some of those cases were also not too far from Tugela Ferry, where his hospital was located. Several of the cases she had identified were duplicates from patients who had had more than one sample sent to the lab, but whose name had been spelled differently each time. All told, Dr. Moll remembers that Lynne Roux had identified about ten patients from Tugela Ferry who were resistant to all of the drugs the lab had tested, including the “salvage drug” streptomycin which is used in retreatment cases in South Africa, as well as the two most important second-line tuberculosis drugs (kanamycin and ofloxacin) that were used to treat MDR-TB.275

MDR-TB itself would have been bad enough, but there were at least theoretically government health programs in place to deal with that.276 Dr. Moll was devastated by Roux’s report: “I kind of just remember holding my cellphone and just feeling like all the energy was draining out of my body and feeling really hopeless because of the implications of this in terms of us as health care professionals providing a service to our patients. [...] What came to my mind was the early days of HIV where we had to get used to dealing with a death sentence disease and understanding its transmission and getting used to it. And I can remember in the early days even with HIV, having the information that it is safe to touch a patient, that you can hug a patient. But taking those initial steps to actually do it took some guts from everybody, I think, [...] and over the years we had got used to the fact that [...] it was quite safe as a health care provider to work with HIV patients and there wasn’t really an issue of transmission. But now, face something of this nature where it’s [...] an

276 My endorsement of KwaZulu Natal’s MDR-TB program in 2005 is tentative at best. MDR-TB patients were not quickly identified, and when they were, they were transported to Durban for and extended hospitalization at a central TB hospital. Durban is over 2 hours away from Tugela Ferry and potentially farther from the patient’s home. Beds in Durban were often not available, and patients that were admitted often struggled to complete their treatment for social, financial and personal reasons. Furthermore, the treatment had many potential side-effects and did not always lead to cure.
untreatable airborne disease and that these patients were right amongst us and we’d been
caring for them and looking after them. [...] I immediately thought, perhaps I’ve already got
it, I’ve breathed it in already, you see, I really had this feeling now. Well now we managed to
get used to managing HIV patients, but now this is a completely different ballgame.
Managing patients with a deadly airborne disease that’s untreatable. And kind of in my
mind I just saw the deterioration of these patients.”

From the onset, the significance of this very drug-resistant form of tuberculosis in
Tugela Ferry was understood in the context of HIV/AIDS. HIV made patients more
susceptible to tuberculosis infection and made tuberculosis more difficult to manage. In
addition, HIV/AIDS was the terrible disease against which the impact of drug-resistant
tuberculosis was measured. As can be seen from the quote above, Dr. Moll had learned how
to deal with HIV/AIDS and was able to contain its impact, both emotionally and physically.
Highly drug-resistant tuberculosis, on the other hand, was an airborne disease whose
management had not yet become routine. The threat emanating from it was not clearly
containable.

The report from the Durban lab was alarming, indeed. In addition to the frightening
cases of highly drug-resistant tuberculosis, Dr. Moll’s snapshot had identified a large
number of patients with “regular” MDR-TB. Dr. Moll went to Durban the next day to pick up
the lab results from Lynne Roux in person at Inkosi Albert Luthuli Central Hospital. There
he conveniently encountered Professor Green-Thompson, who was the Head of Department
of the Department of Health in KwaZulu-Natal. Moll took the opportunity to inform Green-
Thompson of this new problem personally.\textsuperscript{278}

\textsuperscript{277} Moll, interview by author, 2007.
\textsuperscript{278} Moll, interview by author, 2011.
As Dr. Moll tells it, the initial, official response to his reporting of severe drug-resistance was rather tepid. In June 2005 the department of health sent Durban's Professor Sturm to Tugela Ferry to meet with tuberculosis staff and physicians at the Church of Scotland Hospital and to discuss ways staff could protect themselves from infection. Among other things, Prof. Sturm stressed the need to isolate infected patients and to wear protective masks. Yet many of his suggestions were more frustrating than helpful, since the hospital did not have separate isolation facilities. Rather, the hospital was designed as a series of open wards, with dozens of beds in each ward. Similarly, the N95 masks that could be used to filter airborne tuberculosis were not yet available at the hospital. There was also no mechanical ventilation system in place in the tuberculosis ward.

In addition to promoting infection control, Prof. Sturm, as a researcher, was interested in getting a better picture of the epidemiology of drug-resistant tuberculosis in the Tugela Ferry area. If ten cases of highly drug-resistant tuberculosis were identified in a single day, how much bigger was this problem really?\footnote{Moll, interview by author, 2011; Sturm, interview by author, 2011.} Over the time Prof. Sturm had worked in KwaZulu-Natal, he had accumulated samples of drug-resistant tuberculosis from all over the province in his freezers at the medical school. He hoped to shed light on the origins of the drug resistant cases by conducting molecular studies on samples from Tugela Ferry and comparing them to the samples he had stored. As a result, Dr. Moll, Prof. Sturm, the Yale research team (specifically Dr. Friedland and Dr. Gandhi) agreed, with the permission of the KwaZulu-Natal Department of Health, that they would send samples from as many tuberculosis suspects in Tugela Ferry as they could to the microbiology lab in Durban drug-resistance testing. In addition to providing research data for Sturm, this would also be clinically useful for the clinicians in Tugela Ferry, since they would be able to identify drug-resistant tuberculosis more quickly.
Over the course of the next several months, researchers affiliated with Yale, Tugela Ferry, and the medical school in Durban conducted a more formal series of studies to identify tuberculosis in the hospital wards and in the outpatient department at the Church of Scotland Hospital. Between January 2005 and August 2006, a total of 53 patients with tuberculosis resistant to all first-line tuberculosis drugs as well as the second-line drugs ciprofloxacin and kanamycin were identified. By the end of the study period, 52 of those 53 patients died (a mortality rate of 98%), most within weeks of having had their sputum collected for tuberculosis drug-resistance testing. This study also identified 221 patients with "garden variety" MDR-TB, which itself had a mortality rate of 68% in this series. As Gandhi pointed out when he later presented this information at the 2006 International AIDS Conference, the total number of MDR-TB cases in the entire US in 2004 was only 128.

What was the appropriate response?

These alarming numbers were only gradually compiled over that time period, however. In the meantime, Dr. Moll and others were trying to get the local and provincial department of health to understand that the Church of Scotland Hospital in Tugela Ferry was facing a severe problem with very drug-resistant tuberculosis, and to motivate for the resources they needed to get the apparently increasing tuberculosis problem under control.

The early response in Tugela Ferry was dominated by questions and uncertainty about the extent, pervasiveness, and danger of this relatively new form of drug-resistant tuberculosis. There was also a perceived lack of assistance and support from superiors in the department of health. It was unclear if the cases of drug resistant tuberculosis that were

---

280 Neel R. Gandhi et al., “Extensively Drug-resistant Tuberculosis as a Cause of Death in Patients Co-infected with Tuberculosis and HIV in a Rural Area of South Africa,” The Lancet 368, no. 9547 (2006): 1575–1580. Mortality in MDR-TB patients with HIV is generally cited as over 50%. The MDR-TB cohort in Tugela Ferry had a mortality rate of 68%. Though this is not as shocking as the initial mortality rate of 98% for XDR-TB it is clearly serious. As new cases were identified, the mortality rate for XDR-TB stabilized at around 85% by mid 2007. (Friedland, interview by author, 2007.)
uncovered constituted a localized outbreak specific to Tugela Ferry and surroundings or if it was part of a broader problem. Where did these cases of drug-resistant tuberculosis originate? Researchers suspected early on that this was at least in part an outbreak that had originated in Tugela Ferry’s hospital itself, or at least been amplified there. Existing infection control practices and resources in the hospital were not sufficient, and many nurses were afraid to work with tuberculosis patients and wondered what was being done to protect them.

Protocol in KwaZulu-Natal called for every MDR-TB patient in the province to be referred to King George V hospital in Durban for treatment – yet that hospital was almost immediately full with patients from Tugela Ferry and had a waiting list that was several months long, even as physicians in Tugela Ferry continued to identify more patients. This left the physicians in Tugela Ferry with the problem of what to do with patients who had been diagnosed with MDR-TB in the meantime. It would be both dangerous and pointless to keep patients with drug-resistant tuberculosis at the hospital in Tugela Ferry, since they could infect other people, and were not receiving effective tuberculosis treatment there anyway. At the same time, however, it might be irresponsible to send them back home, where they could put their families at risk. Once people with drug-resistant tuberculosis were identified, the very location of their sick bodies became problematic.

Thus, as the research team revealed increasing numbers of drug-resistant tuberculosis cases that they were unable to treat, the problem of how and where to treat these newly identified patients became increasingly urgent. Yet, from the perspective of local clinicians, the immediate response from the leadership in the department of health seemed mostly absent. As we shall see in chapter 4, later assessments of the South African government’s response were more nuanced and positive, but at least at first doctors in Tugela Ferry did not get the sense that the severe form of MDR-TB found in Tugela Ferry
was being considered sufficiently urgent by the authorities. In early 2006 there was some South African news coverage on the increased number of drug-resistant cases of tuberculosis in the Tugela Ferry region, prompting the provincial department of health to issue a press statement on March 28th 2006, a few days after world TB day. The headline argued, among other things, that “MDR TB cases in Tugela Ferry [were] not an outbreak but reflection of poverty and hunger intensity.” The press statement did acknowledge that the provincial minister of health, “Neliswa Peggy Nkonyeni, is aware of the 225 cases of MDR TB for the period of January 2005 to January 2006 in the uMsinga area.” The statement then continued to describe MDR-TB as a moral and nutritional threat that results from poverty, the lack of food, and the fact that poor people “refrain from taking medication.”

While the provincial department of health was able to list several activities that had taken place in response to the increased number of MDR-TB cases, including an increased number of tuberculosis tracing teams (who go to patient’s homes to find patients with drug-resistant tuberculosis and to identify contacts who might be at risk for tuberculosis infection), a training session for physicians, plans for improved ventilation in the hospital ward, and daily laboratory tests, this statement was interpreted by physician and research colleagues in Tugela Ferry as a dismissive brush-off. In particular, the reference to poverty and nutrition as the major problem echoed other language coming from the national department of health during that period. In years past, South Africa’s president Thabo

283 uMsinga, or Msinga, is the rural sub-district in which Tugela Ferry is located.
284 Department of Health, Province of KwaZulu-Natal, Corporate Communication Services, “To All Media: MDR TB Cases in Tugela Ferry Not an Outbreak but Reflection of Poverty and Hunger Intensity.”
285 Ibid.
Mbeki and his health minister Manto Tshabala-Msimang had tried to deny the impact of HIV/AIDS on South African mortality and morbidity statistics by arguing that South Africans were dying of poverty, not AIDS. This reasoning also partially justified the South African government’s initial decision not to provide HIV medications via the public health system. It was only through aggressive activity on the part of activists’ organizations and civil society as well as the courts that the government eventually agreed to roll out HIV treatment in the public sector in 2004.286

In fact, South African health minister Dr. Manto Tshabala-Msimang promoted immune boosters and a diet of olive oil, beetroot, African potato, and lemon juice as the best treatment for AIDS. KwaZulu-Natal’s provincial minister of health Peggy Nkonyeni followed suit, and openly antagonized rural physicians who prescribed antiretroviral medication as a way to prevent HIV infection for rape-victims.287 She also actively promoted uBhejane, an untested “traditional” medicine which its makers claim can cure AIDS.288 Thus, while no such claims were made about MDR-TB, the doctors in Tugela Ferry still interpreted the press statement as a frustrating denial.

The three physicians who had been working at the Church of Scotland Hospital in Tugela Ferry the longest (Dr. Moll, Dr. van der Merwe, and Dr. Eksteen) decided to send a letter to the provincial minister of health explaining to her that there was indeed something happening in Tugela Ferry that required further action. Specifically, they asked for the resources to do improved epidemiological surveillance, for extraction fans to be able to effectively ventilate the hospital wards, and for the construction of facilities where MDR-TB


patients could be isolated. In the department of health hierarchy it was considered highly irregular for three rural doctors to write such a letter directly to the provincial minister of health. Yet they were able to convince their hospital CEO to accept the letter from them and to channel it to the minister’s office. According to Dr. Moll and Dr. van der Merwe no formal response was ever received to their pleas.289

In a sense, then, the story of a MDR-TB outbreak in a rural town in KwaZulu-Natal could have ended there – alarm among a small group of involved researchers and clinicians, tepid acknowledgement, some activity and news interest, some minor improvements of services, an eventual fading of interest, and ongoing deaths of poor rural people living with AIDS. In fact, however, there is not where this story ended. As I already laid out at the beginning of this chapter, the cases of MDR-TB in Tugela Ferry instead came to be reinterpreted as a local manifestation of the international XDR-TB phenomenon that I described in the previous chapter. In the process, the discovery of drug-resistant tuberculosis in Tugela Ferry became an event of international significance, which required rapid action on the part of public health experts, global health donors, and local government. In the following chapter, I will consider the networks that allowed this to happen, focusing on the role of the American Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), and national and international news media.

---

289 Hans Human, interview by author, 14 January 2011, Tugela Ferry, South Africa; van der Merwe, interview by author, 2011; Moll, interview by author, 2011.
CHAPTER 3: XDR-TB: A Global Threat Emerging from Africa

In the last chapter we took stock of the local and global conditions around tuberculosis control and HIV/AIDS research that allowed international researchers to uncover a cluster of highly drug-resistant tuberculosis in the rural town of Tugela Ferry. Here I consider how news about deadly drug-resistant tuberculosis spread from an isolated-looking rural area to the most prestigious and powerful venues of elite biomedical research and global health policy formation. The story places a particular emphasis on professional and personal networks, as well as the close relationship between scientists, policy makers, and the media. I explain how the highly drug-resistant cases of tuberculosis in Tugela Ferry eventually became the most important cases of XDR-TB and argue that the WHO took a pro-active role in facilitating this process, in part to make up for its lack of early action when MDR-TB first became a global issue in the 1990s and to re-establish its authority in the field of drug-resistant tuberculosis. In addition, officials of the WHO saw in drug-resistant tuberculosis an opportunity to engage productively with the South African department of health, which had a very difficult relationship with international health agencies and funders due to its refusal to acknowledge its HIV/AIDS epidemic.

Spreading the Word

News about the high levels of drug-resistant tuberculosis in Tugela Ferry spread quickly. The first person to realize that the Church of Scotland Hospital in Tugela Ferry was facing a problem with MDR-TB and an even less treatable form of drug-resistant tuberculosis was Lynne Roux, laboratory manager for the microbiology laboratory in Durban, who noticed a cluster of cases in her data in May 2005. She immediately called the hospital, where she reached Dr. Moll. By the next day, Professor Sturm, who was the head of the laboratory, as well as Dr. Green-Thompson, who was head of department in the
KwaZulu-Natal department of health, had been informed of the problem. The news did not remain within official government health channels for long, of course. Dr. Moll soon apprised his research collaborators Dr. Friedland at Yale University and Dr. Gandhi (then at Emory University) of the situation; they in turn soon spoke with contacts at the American Centers for Disease Control and Prevention (CDC). Professor Sturm in Durban told colleague Dr. Nesri Padayatchi, an HIV/TB researcher at CAPRISA about the MDR-TB cluster. When Dr. Padayatchi gave a presentation on MDR-TB to the Southern African HIV Clinicians Society in July 2005 (only two months after Lynne Roux had compiled the highly drug-resistant TB cases from Dr. Moll’s snapshot study), she included Sturm’s data on MDR-TB in Tugela Ferry. Sturm did not want the location of the potential outbreak to be disclosed, however. According to Dr. Padayatchi, ‘he actually ran down to my office to say, ‘do not mention the area where this has been uncovered.’ [...] He did not want to create a media frenzy.’ At the meeting, Dr. Padayatchi described these highly drug resistant tuberculosis cases to the HIV Clinicians Society in general terms, as a possible nosocomial (hospital-caused) outbreak in KwaZulu-Natal, but she did not highlight their exact location. She explained that Professor Sturm’s lab had analyzed 18 samples of tuberculosis, all of which were resistant to all six tuberculosis drugs tested, and 16 of which

---

291 CAPRISA (Centre for the AIDS Programme of Research in South Africa) is an HIV/AIDS research institute at the Nelson R. Mandela School of Medicine (University of KwaZulu-Natal, Durban) and was funded by the US National Institutes of Health (NIH). It was the then-new institute with which Dr. Friedland intended to conduct HIV/TB research when he arrived in Durban for a sabbatical in 2001. Now it is a well-established research institute that has successfully conducted several high-profile clinical trials, including HIV/TB co-treatment studies and studies of HIV-preventing microbicides.
292 Dr. Padayatchi is also the former medical director of King George V hospital, where all MDR-TB cases in the province are seen. She heard about the cases in Tugela Ferry through several channels.
293 Nesri Padayatchi, interview by author, 6 April 2010, Durban, South Africa.
294 According to a draft of the talk, which Dr. Padayatchi shared with me, she described the outbreak as being in “the KZN midlands.” In fact, only someone not too familiar with the area would describe Tugela Ferry as located in the midlands, though the region does border the midlands.
could be classed as belonging to the same “highly resistant KZN strain,” whereby “KZN strain” is the name that Prof. Sturm’s research group gave the predominant molecular tuberculosis strain among the samples they were studying. Other strains also have place-based designations like the “Beijing strain,” for example, though their actual distribution can be worldwide.

In response to Dr. Padayatchi’s presentation, one of the physicians in the audience commented that it was unethical not to identify the location of a highly resistant MDR-TB outbreak. At that time, however, the presentation did not lead a broader discussion or to the media frenzy which Prof. Sturm had feared. According to several South African clinicians I spoke to deadly tuberculosis had become commonplace enough that it was not in itself surprising or frightening. In addition, Padayatchi’s presentation was based entirely on laboratory data provided by Professor Sturm’s lab and did not include information about how deadly this form of tuberculosis might be.

At the American Centers for Disease Control and Prevention (CDC), Dr. Sarita Shah (who compiled the first scientific paper on global XDR-TB) was probably one of the first people to hear about the highly drug-resistant cases in Tugela Ferry. She and Dr. Neel Gandhi, who, as we have seen, was one of the main US researchers working on HIV and TB in Tugela Ferry with Dr. Friedland, were married and communicated about their work. Dr. Gandhi and Dr. Friedland officially debriefed members of the CDC in June 2005 at a side

298 Padayatchi, interview by author, 2010.
meeting of the Center for AIDS Research (CFAR) conference in Boston. Peter Cegielski, who was Sarita Shah’s mentor on the XDR-TB study, was present. In response, the CDC offered to support the investigation of drug-resistant tuberculosis in Tugela Ferry. However, South African bureaucrats in KwaZulu-Natal insisted that the CDC, as a government agency, was not free to start research or support activities in South Africa without first receiving a formal invitation from a national agency of the South African government. This invitation was not forthcoming despite the fact that the CDC had been providing technical assistance on tuberculosis-related research projects in South Africa for several years. Thus, while they did not collaborate directly, the CDC and the Yale/Philanjalo group, which later came to be called the TFCARES collaboration, each continued to work separately on documenting increasingly drug-resistant tuberculosis, either worldwide (in the case of the CDC) or in a specific region of South Africa (in the case of Yale/Philanjalo).

In mid 2005, while Dr. Moll and his colleagues were grappling with the impact of the newly discovered cases of intense tuberculosis drug resistance in Tugela Ferry, Dr. Shah and her group at the CDC in Atlanta were still in the process of solidifying their definition of XDR-TB and compiling global cases from the WHO-certified Supranational Reference Laboratories (SRLs). According to the laboratories’ records there were almost no documented cases of the new XDR-TB in Africa. Even if the Tugela Ferry cases of drug resistant tuberculosis had been captured by these laboratories’ databases (which they were not), the cases would not have fulfilled the CDC’s working definition for XDR-TB, which

300 Ibid. The CFARs are a national network of centers funded by the National Institutes of Health that facilitate HIV/AIDS related research. This Boston side meeting was most likely at a national symposium co-hosted by the UPenn and Harvard CFARs entitled “Confronting TB-HIV Co-infection” which was held on June 30, 2005.
301 Moll, interview by author, 2011; Timothy Holtz, interview by author, phone interview, 8 February 2010; Karin Weyer, interview by author, phone interview, 8 July 2010.
302 Tugela Ferry Care and Research Collaboration (tfcares.org).
required documented resistance to at least three second-line drugs. Prof. Sturm’s lab only
tested for two second-line drugs. The concerning cluster of cases in Tugela Ferry clearly
showed the limitations of Shah’s database-based study in terms of accurately reflecting the
global rates of drug-resistant tuberculosis that is even more drug-resistant than MDR-TB.

As discussed in chapter 1, Dr. Shah first presented the global survey of XDR-TB in
October 2005 in Paris at the World meeting of the Union against TB and Lung Disease (the
“Union meeting”), thus publicly establishing the CDC’s definition of XDR-TB as MDR-TB plus
resistance to three or more second-line drugs. The Tugela Ferry group had hoped to present
its own research on highly drug-resistant tuberculosis at the same meeting, but the abstract
that had been submitted for the group in July 2005 as a late-breaker submission was not
included in the conference program. Instead, the first public presentation of the drug
resistant tuberculosis cases in Tugela Ferry occurred in a poster session at the Conference
on Retroviruses and Opportunistic Infections (CROI) in Denver in February 2006. Since
Tugela Ferry’s TB cases were only known to be resistant to two second-line drugs, they
were not called XDR-TB but instead were called highly drug resistant tuberculosis, or HDR-
TB. The title of the group’s poster - Identification of a Multi-Drug Resistant Tuberculosis
Cluster as a Cause of Death among HIV Coinfected Patients in Rural South Africa - did not
emphasize the heightened level of drug resistance in their patients, but rather highlighted
the many cases of MDR-TB seen in Tugela Ferry. The poster specifically highlighted the
fact that MDR-TB had previously been missed as a cause of death with HIV and TB
coinfection. In the absence of antiretrovirals (and even after their introduction), such deaths

---

304 Anthony Moll et al., “Identification of a Multi-Drug Resistant Tuberculosis Cluster as a Cause of
Death Among Coinfected Patients in Rural South Africa” (presented at the Conference on
Retroviruses and Opportunistic Infections (CROI), Denver, 2006).
were still likely to be attributed to "end-stage AIDS" disease.\textsuperscript{305} Now that antiretrovirals were increasingly being used for AIDS patients in South Africa, the impact of untreatable (or merely untreated) tuberculosis would become more apparent.

The data in their presentation was alarming. By this point Moll, Gandhi and colleagues had documented 50 cases of highly drug-resistant tuberculosis in Tugela Ferry, which they called HDR-TB. Forty-four of them had already died, giving this form of tuberculosis a mortality rate of 84%. According to most reports the poster did not cause much of a stir. Dr. Graeme Meintjes, a Cape-Town based tuberculosis physician and researcher, remembers meeting Dr. Moll at the CROI meeting in Denver and being immediately impressed with the findings emerging from the research in Tugela Ferry, however. Referring to Moll's poster, Dr. Meintjes recalled that "anybody working in a developing world situation working with TB knew that this was a staggering finding."\textsuperscript{306} He was particularly impressed by the high rates of MDR-TB and what they told him about the apparent failures of South Africa's standardized management of TB and MDR-TB. "This was happening in South Africa, but because we were only testing for MDR and had adopted a policy of just treating MDR with a fixed regimen and not looking for further resistance."\textsuperscript{307} For him, the poster showed that South African tuberculosis specialists "were all ostriches with our heads in the ground as a result of the national policy to do away with second line drug testing."\textsuperscript{308} He also observed, however, that most conference attendees did not pay close attention to the poster.\textsuperscript{309}

Dr. Shah, who had been following her husband Neel Gandhi's study's progress and knew how it related to her own work, believed that the results from Tugela Ferry warranted

\textsuperscript{305} Ibid.
\textsuperscript{306} Graeme Meintjes, interview by author, 14 May 2010, Cape Town, South Africa.
\textsuperscript{307} Ibid.
\textsuperscript{308} Ibid.
\textsuperscript{309} Ibid.
a much greater response and that “nobody cared as much as they should have.”\textsuperscript{310} In part, she attributed this to the fact that the researchers did not use the term “XDR-TB” to describe their highly resistant tuberculosis cases. As we have already seen in chapter 2, the reaction was very different when similar data was presented again six months later at the International AIDS Conference in Toronto.

Meanwhile, the CDC’s survey of XDR-TB was published in \textit{Morbidity and Mortality Weekly Report} at the end of March 2006, and Dr. Shah’s work received some public attention. In May 2006, the PARTNERS TB Control Program gathered in Atlanta for the five-year review of their MDR-TB treatment projects.\textsuperscript{311} Dr. Shah was asked to present the data of the XDR-TB survey at the final review meeting of the project. She chose to share her 10 minutes of allocated presentation time with Dr. Gandhi, who described the findings from Tugela Ferry, South Africa. The groups represented at this meeting included the World Health Organization (WHO), the American CDC, the US Agency for International Development (USAID), Partners in Health, Harvard University and the Peruvian government, among others. They were all very concerned and agreed that global XDR-TB and the highly drug-resistant cases of tuberculosis in Tugela Ferry demanded an active response. Dr. Ernesto Jaramillo, of the STOP TB department of the World Health Organization, remembers this meeting as falling into an important transition period, as the Bill & Melinda Gates Foundation was ending its financial support for the WHO MDR-TB

\textsuperscript{310} Shah, interview by author, 2007.
\textsuperscript{311} PARTNERS stands for Partnership Against Resistant Tuberculosis: A Network for Equity and Resource Strengthening. “The PARTNERS TB Control Program is an international consortium of organizations addressing MDR-TB. This five-year program, funded by the Bill & Melinda Gates Foundation, focuses on the control of MDR-TB in Peru and in a prison population in Russia with a goal of developing an integrated program model that can be used in other resource-poor countries”. http://www.taskforce.org/tb.asp, last accessed 4/30/2007. According to the Partners in Health (PIH) website, the program received $44.7 million from the Bill and Melinda Gates Foundation. “Partners In Health History” pih.org, accessed February 29, 2012, http://www.pih.org/pages/partners-in-health-history/.
Working Group and the Green Light Committee. Over the five years of Gates funding it had become clear that public concern over MDR-TB was an effective tool with which to advocate for better tuberculosis control in general. But now that MDR-TB related programs were losing an important source of funding, what would “be the way to do advocacy for MDR-TB?” When Dr. Shah presented the CDC’s findings on XDR-TB worldwide along with Dr. Gandhi’s cases in Tugela Ferry, it became clear to many present that XDR-TB provided an opportunity for public health advocacy that would in turn highlight MDR-TB.

According to Dr. Jaramillo, the audience of tuberculosis experts was at first shocked into silence by Dr. Gandhi’s findings, until the chair of the session, Dr. Jim Kim, stated that he couldn’t believe that nobody was saying anything. But in Jaramillo’s view the group immediately realized that XDR-TB provided a great opportunity to help people understand that MDR-TB is in fact a reflection of a failure of the whole health care system. Dr. Jaramillo (like many other public health experts I interviewed) explicitly resisted characterizing XDR-TB as a crisis engineered by the WHO or CDC, yet he readily admitted that our current understanding of XDR-TB resulted from a serendipitous “convergence” of events, whereby “some people [were] offering something that others were in need of,” and that as a result XDR-TB became a major issue which was heavily supported and promoted by the WHO and the STOP TB department. The CDC (especially Dr. Kenneth Castro and Dr. Charles Wells) also felt it was important to remain a part of the discussion. Dr. Kenneth Castro put it more diplomatically than Dr. Jaramillo: “As this came about there was growing concern that

---

312 Ernesto Jaramillo, interview by author, 12 November 2010, Berlin, Germany.
313 Ibid.
314 Ibid.
315 Physician-anthropologist Dr. Jim Kim was cofounder of Partners in Health with Paul Farmer. He has since then been director of WHO’s HIV/AIDS department, president of Dartmouth College, and is now president of the World Bank.
316 Jaramillo, interview by author, 2010.
the world was uncovering the existence of a group of individuals with MDR who were virtually untreatable with the available drugs and many of us who were part of the global STOP-TB partnership came together and said, you know, it would be irresponsible to sit on this without prompt action."\footnote{Castro, interview by author, 2010.}

Those present at the Atlanta meeting decided to convene an expert consultation meeting on XDR-TB in the following months, and scheduled it to take place in South Africa in September 2006. In the meantime, however, Dr. Gandhi was encouraged to submit the findings from Tugela Ferry as a late-breaker abstract to the International AIDS Conference that was soon to take place in Toronto, in August 2006. This biennial AIDS conference is the unrivaled highlight of the HIV/AIDS conference cycle. In light of the meager response that Dr. Moll’s poster from Tugela Ferry had received at the CROI meeting in February, Dr. Cegielski and Dr. Shah suggested that it would make sense for the Tugela Ferry team to call their strain of highly drug-resistant tuberculosis \textit{XDR-TB} in their submission to the conference, even though their cases did not, strictly speaking, fit the CDC’s definition for XDR-TB.\footnote{Shah, interview by author, 2007.}

According to Dr. Shah this was quite possibly justified scientifically. The reason that Tugela Ferry's cases had not been called XDR-TB until that point was that the lab in Durban had only demonstrated that they were resistant to two second-line anti-TB drugs, while the CDC definition of XDR-TB required strains to be resistant to at least three second-line drugs. Yet the CDC had analyzed tuberculosis cases known to be resistant to two second-line drugs and found that they frequently were also resistant to a third or fourth drug. Thus, it could be argued that the cases in Tugela Ferry were likely to be resistant to a third second-line drug that hadn’t been tested for. More importantly, perhaps, it was clear that patients in Tugela
Ferry who had this increased level of drug-resistance were dying at an alarming rate.

Whether or not they fit the CDC’s definition, these cases were highly concerning and could be highlighted by using the term XDR-TB, which connected them both to the CDC’s March publication in *Morbidity and Mortality Weekly Report*, as well as to other work which had been done as a result of that publication.320

This change in terminology apparently paid off. Dr. Gandhi submitted his group’s research as a late-breaking abstract to the 2006 International AIDS Conference and it was selected for an oral presentation during the high profile late-breaker session, which was attended by several thousand people. At the session, Dr. Gandhi gave a clear and engaging ten-minute power-point presentation that focused on the most dramatic aspects of the Tugela Ferry findings. He stressed just how high the rates of MDR-TB and XDR-TB were in Tugela Ferry compared to other areas in the world and described XDR-TB as “rapidly and nearly completely fatal.” Instead of defining XDR-TB, he consistently spoke of cases with “resistance to all second-line drugs tested” without ever specifying the drugs actually tested, thus obscuring the difference between his use of “XDR” and the CDC/WHO definition published in March 2006. He ended his talk with policy recommendations, pointing out that MDR-TB was jeopardizing the gains in HIV mortality brought by antiretroviral therapy and stressing that an increase in resources was required to strengthen necessary tuberculosis programs.321

When Dr. Gandhi sat down after giving his ten-minute talk, there was no time for questions, (eighteen speakers were scheduled in what some termed a marathon session that ran through the lunch break), and he wasn’t sure if people in the room had even heard

what he had said.\textsuperscript{322} In the end, his presentation generated a very large response, however, became one of the items picked up by the scientific and lay media covering the conference,\textsuperscript{323} including NPR's \textit{All Things Considered},\textsuperscript{324} the \textit{New York Times},\textsuperscript{325} and \textit{Science} magazine.\textsuperscript{326} Scientists and global health experts who became aware of the XDR-TB problem through the conference were interested in attending the XDR-TB expert consultation meeting that had already been scheduled to take place in Johannesburg in September.\textsuperscript{327}

Soon after the conference, the editor of the prestigious British medical journal \textit{Lancet} contacted Dr. Gerald Friedland, who was the principle investigator on the study, expressing the journal's interest in publishing the XDR-TB results as a "fast track" article. The \textit{Lancet} considered XDR-TB important and topical enough to be published as quickly as possible – fast track articles are published within a month of submission, which is a very short time considering the more common turn around time of months to years for biomedical articles in such a prominent journal.\textsuperscript{328} Dr. Salim Abdool Karim, a prominent South African HIV and TB researcher who attended the AIDS conference, remembered chatting with \textit{Lancet}'s editor, Richard Horton, at a social function related to the

\footnotesize
\begin{enumerate}
\item Some people thought of this meeting as an emergency meeting that resulted directly from the attention at the International AIDS conference, but it had in fact been decided on at the earlier PARTNERS meeting. (Shah, interview by author, 2007.)
\item This conference generates many articles in the mainstream press worldwide every year.
\item Shah, interview by author, 2007.
\item Dr. Friedland was excited at the prospect of publishing the work in \textit{Lancet}: "So they had understood the importance of it and of course you always want to get something in Lancet. It's widely read, it's a major medical journal, it's read internationally, probably more than other journals, so that this information would be widely disseminated. So of course we agreed to do it and we very quickly wrote the paper." Gerald Friedland, interview by author, 27 March, 2007, New Haven, CT.
\end{enumerate}
conference. Abdool Karim himself was not impressed by the results from Tugela Ferry, yet “[Richard Horton] thought this was the biggest thing ever. […] He was just saying, this is amazing, look at these problems. […] And it was the Lancet actually that gave it the high profile. The same thing, you know, in some small journal might not have even got much play.”

In truth, by the time the Lancet article went to press, readers of many leading scientific journals had already heard about XDR-TB in South Africa through news-briefs and conference summaries. Dr. Gandhi’s ten-minute presentation on XDR-TB in South Africa at the Toronto AIDS conference rapidly led to a broad reaction and further exposure among the professional HIV/AIDS community, in public health circles, among biomedical scientists, as well as in the lay media and culminated in publication in the Lancet in November 2006. For Dr. Moll and his department of health colleagues and superiors in South Africa, the repercussions were almost immediate: “After Toronto there was an amazing press interest and I didn’t know what I was coming home to, but when I came home I was just bombarded with telephone calls, with requests for interviews, all this kind of thing. And the department of health [was] also bombarded. And this basically took the lid off everything. And people across the country, across the world, were informed about XDR and about the challenges and the dangers.”

Thus the response to the deaths in Tugela Ferry was dramatically different than it had been when they were presented at Conference on Retrovirals and Opportunistic Infections (CROI) in Denver, only six months earlier. The intellectual content of the two

---

329 Salim Abdool Karim, interview by author, 1 April 2010, Durban, South Africa. The exact phrase he used was “we were on one of those boat things where they have these dinners.”


presentations was very similar. Thus I do not believe it was not the data per se that did or did not precipitate an international reaction. I will take a little time here to consider some of the reasons that this second presentation elicited such a response.

Some of the differences between the two presentations were rather banal. At CROI the group’s abstract was selected for a poster-session, while at the AIDS conference Dr. Gandhi had the opportunity to give an oral presentation to a large audience. Posters often take a back stage at conferences compared to oral presentations, and dedicated poster-time in a conference schedule can easily turn into break-time, networking-time or general milling-about time. Even a compelling poster might easily be overlooked. A late-breaker oral presentation session at the International AIDS Conference, on the other hand, is likely to attract a large audience that includes members of the press who are looking for their obligatory news story from the conference. In addition, presentations from much of the AIDS conference were broadcast on the internet and were summarized through numerous AIDS-related websites and news outlets, such as thebody.com. The presentation from Tugela Ferry was briefly previewed on the first day of the conference in the opening issue of the daily in-conference newspaper as one of several promising late-breaker abstracts worth attending. The presentation was also highlighted in the plenary on the last day of the conference when one of the conference rapporteurs, Dr. James McIntyre (himself from South Africa), included a slide from Dr. Gandhi’s talk in his summary of the findings of scientific Track B - Clinical Research, Treatment and Care. After giving a thirty-second summary of Dr. Gandhi’s talk with an emphasis on the high rates of XDR-TB in Tugela Ferry

---

332 There were differences: the AIDS 2006 presentation included a few more XDR-TB cases (53 vs 50), and a higher mortality rate (98% vs 84%) than the CROI poster.
333 Thebody.com also summarizes research findings from CROI but there is more information about the AIDS conference broadly available in more sources.
and its high and rapid mortality, Dr. McIntyre stated that “drug-resistant TB and HIV coinfection are challenges that go with us as we leave this conference and require much more research, and much more commitment, and much more funding.” Overall, the AIDS conference provided more, higher-profile exposure of XDR-TB than CROI did (though CROI also is a large, professional conference).

Graeme Meintjes, a South African physician who had been impressed by Dr. Moll’s poster at CROI, attributed the biggest difference between the conferences to the role of journalists in spreading the news about XDR-TB in South Africa. Meintjes pointed out that scientifically speaking, the group in Tugela Ferry had essentially performed observational epidemiology, which usually does not itself attract much attention. The scientific methodology was not innovative (or particularly rigorous), researchers had not developed a new drug or diagnostic test, and there was no commercial entity that would market the results to the medical community. Instead, it was journalists who generated the conversation and debate that generated a communal sense of shock among biomedical experts as well as the broader public. “Often what happens nowadays is [...] somebody, a scientist or a medical academic, will speak to [a journalist] and say ‘this is a major story.’ And when [XDR-TB] hit the news, that was when people really started speaking about it. I guess it’s just a critical mass. Because individually, I’m sure a lot of people found it shocking.


336 It’s worth pointing out that the first author of the poster at CROI was Dr. Moll, a non-academic South African physician at a rural hospital, and at the AIDS meeting the first author was listed as Dr. Gandhi (who was a striving young academic physician from the US). I don’t know how this change in authorship was negotiated but it is probably significant.
But you know, it kind of took six months for people to speak to each other, and I think that step of medical journalists highlighting it is what really [brought] it to the fore."\(^{337}\)

While this is a much simplified view of how scientists and the journalists who report on them relate, Meintjes’ explanation hints at how important mass media were not only for communicating the importance of XDR-TB to the lay public, including potential global health funders and policy makers, but also to expert tuberculosis scientists, AIDS researchers, public health specialists and clinicians who themselves shaped TB research. Sociologists of science have argued that lay representations and popularizations of science play a key role in diffusing scientific concepts within and across disciplinary boundaries, allowing the acceleration of scientific communication, setting the tone of scientific debates, and supporting or undermining the authority of individual researchers and their work.\(^{338}\) As Bruce Lewenstein puts it: “science communication is not a linear process from field or lab to certified "science” published in journals, and only then followed by public communication. Rather, science communication is a “web” of interactions among different actors and formats.”\(^{339}\)

Media coverage of science is rarely simply the result of a casual conversation between scientists and journalists. Rather, the coverage is often very actively sought by scientists and other researchers – often using formal and professional public relations strategies – as a tool with which to promote careers and scientific work. For example, Jerome Singh, a South African bioethicist who co-authored an influential opinion-piece on

\(^{337}\) Meintjes, interview by author, 14 May 2010.
XDR-TB in the biomedical journal *PLoS Med* in January 2007, about half a year after the AIDS conference, felt that much of the international interest in XDR-TB was in fact generated and sustained by coverage of his paper. He explained to me that his Canadian coauthor had hired a public relations professional (a “press liaison officer”) through his academic institution. This person was tasked with promoting the paper, scheduling media appearances and documenting how much media coverage the paper received. The reports he generated compared the amount of coverage received with the amount of money that would have been required to pay for that same coverage in form of advertising. As Singh remembered it, the value of the coverage quoted to him around two or three weeks after his article was first published “worked out to something like $7.5 million dollars. [...] So it was quite phenomenal.”

Major (and minor) biomedical conferences like the International AIDS conference not only have paper presentations and plenary lectures which pass-carrying journalists are welcome to attend, but also feature press conferences where paper presenters and their collaborators make themselves available for questions from the media, especially if broad interest is anticipated. Sometimes these press conferences take place in the more nebulous form of conference calls or online web-chats. Once findings are about to be published, major journals also issue press statements and organize conference calls. It is at events like these that journalists often get quotes from experts who summarize the salient features of the issue at hand. Most early reports about Neel Gandhi’s presentation at the International AIDS Conference, for example, contained quotes from Dr. Gerald Friedland regarding the dangers of XDR-TB in South Africa. In the case of XDR-TB, the high-profile placement of Gandhi’s talk, the dramatic nature of the results (including the mortality rate of 98%), the broad

---

341 Jerome Amir Singh, interview by author, 19 May 2011, Durban, South Africa.
interest of the AIDS community in the location of South Africa and successful use of PR strategies combined to generate a strong response from the media. It also helped that multiple agency's representatives (including WHO and CDC) were available for comment at the same conferences, as is evident in some of the press coverage.

**Emergency expert consultation meeting**

The response to Dr. Gandhi’s presentation in Toronto was impressive, but it could be argued that it wasn’t until later that the extensive interest in XDR-TB truly became apparent. At the AIDS conference, those who were interested in learning more were directed to a global expert consultation on XDR-TB that was scheduled to take place in Johannesburg, South Africa on September 7-8 2006. This expert consultation (also called an emergency consultation by some sources) was hosted by the South African Medical Research Council (MRC) in Johannesburg and was funded mostly by the CDC, who had a long-standing relationship with tuberculosis researchers at the MRC. As Dr. Kenneth Castro, director of the Division of Tuberculosis (TB) Elimination in the National Center for HIV, STD, and TB Prevention at the CDC, explained, “we had the linkages [in South Africa] with Karin Weyer who was there as the lead laboratorian [sic], so by the time this whole thing happened, we were able to agree, [that] we can’t wait long. [...] The classic scenario that we see in federal government is that at the end of the year you end up finding some unobligated dollars that had been appropriated but hadn’t been spent for whatever reason, and so I said, oh, I can contribute. So we ended up transferring to them $50,000 to pull this meeting together, and recruiting a bunch of us who flew there to be a part of that” meeting to provide technical expertise.\(^{342}\)

Many of the people who attended this meeting described it as an intense, even frenzied experience. While some of the international and South African participants already

---

\(^{342}\) Castro, interview by author, 2010.
knew each other from past collaborations and conference interactions, it also became an opportunity for individuals who had not been as involved in existing US-South African tuberculosis research networks to make their presence known. This is where Dr. Holtz (who worked for the CDC and had been engaged in TB research projects in South Africa, but not in KwaZulu-Natal) met Prof. Sturm (who was a leading figure in academia and tuberculosis research in KwaZulu-Natal), for example. As Holtz recalled: “We had this emergency meeting in September, by which we pulled together a lot of global experts to talk about the problem in South Africa. [...] It was then that we really got to meet some of the other important players in the issue, particularly a guy named Willem Sturm who is a [...] pretty high up administrator in the medical school. [...] He’s also a force to be reckoned with. He really wanted to take charge of the microbiologic issues surrounding the strain that he had since looked at in Tugela Ferry, and he’s done a lot of genotyping work in his laboratory and started calling it the KwaZulu-Natal strain without really talking to anybody. [...] It was the first time we all met him.”343

This last comment provides a clue regarding the contested power to name diseases and molecular entities and the importance of generating a consensus around such new names. Dr. Holtz had himself just recently named XDR-TB, though he certainly would not describe himself as having done it “without really talking to anybody.” As described in chapter 1, he had been involved in a series of meetings and consultations with numerous experts and stakeholders before the name and definition of XDR-TB was finally solidified. Yet among the initial responses to the publication of the first paper on the global XDR-TB survey there were some who expressed some discontent at not having themselves been consulted in the generation of this new disease entity. Researchers from Spain, Norway and Iran wrote brief papers pointing out their own studies in which they had found similar

343 Holtz, interview by author, 2010.
cases; letters to the editorial sections of scientific journals asked what the utility of the new definition was. Dr. Abdool Karim recalled that “interestingly a whole lot of people thought the use of X in the XDR was like a hype. In that it should be EDR not XDR!” The power of the CDC and the WHO to name, define, and endorse such a disease was not really in doubt, however.

Back in Johannesburg, the expert consultation meeting on XDR-TB turned out to be a political tight rope act for Dr. Karin Weyer, of the South African Medical Research council (MRC). She was the "head laboratorian" Castro mentioned who organized the meeting. The WHO’s HIV/TB department’s Paul Nunn who attended from Geneva described her as having organized the event somewhat “in the teeth” of the South African department of health, who, according to another MRC researcher were “very upset that MRC held that meeting.”

According to Dr. Weyer, the MRC had been aware of the MDR-TB problem in Tugela Ferry for about a year before the September 2006 meeting. In fact, the department of health of KwaZulu-Natal had asked the MRC (which is not itself a government agency, but had taken a lot of responsibility for the South African tuberculosis program in the past) to help the province in investigating the Tugela Ferry outbreak. The MRC had suggested working together with the CDC under an existing cooperative agreement, yet the province of KwaZulu-Natal insisted instead that involving the CDC in this case required an additional formal invitation from the national department of health to the CDC. In the meantime, the CDC and WHO asked Dr. Weyer to organize an expert consultation meeting, and the MRC

345 Dr. Weyer played a leading role in the MRC in introducing and studying MDR-TB treatment programs in South Africa. She now works for the WHO as the Coordinator of the WHO Stop TB Unit for Laboratory Strengthening.
346 Paul Nunn, interview by author, 27 May 2010, Durban, South Africa.
347 Karen Shean, interview by author, 7 May 2010, Cape Town.
348 This is the same cooperative agreement mentioned from the CDC perspective on page 4.
was among the groups encouraging the researchers in Tugela Ferry to present their findings at international conferences and publish them. According to Dr. Weyer, she (and by implication the department of health) was kept informed of the upcoming presentation at the International AIDS Conference: "We knew this was coming."\footnote{Weyer, interview by author, 2010.}

For the September 2006 expert consultation, Dr. Weyer invited representatives from all nine South African provincial departments of health, as well as the managers of the South African National TB Program and their supervisors.\footnote{"National TB Program" is standardized language used by the WHO to describe just that; it is usually abbreviated "NTP."} In addition to CDC and WHO colleagues, representatives from other Southern African Development Community (SADC) countries were also included.\footnote{Member states of the Southern African Development Community include Angola, Botswana*, Democratic Republic of Congo, Lesotho*, Malawi*, Mauritius, Mozambique*, Namibia*, Seychelles, South Africa, Swaziland*, Tanzania, Zambia, Zimbabwe*). Seven of these (followed by *) are direct neighbors of South Africa.} The participation of the South African national department of health was confirmed until two days before the meeting, when the office of the Minister of Health requested via the National TB Program that the expert consultation be canceled. By this time, the press had already started reacting to Dr. Gandhi’s presentation that had occurred on August 17, only two weeks before, so it may be that the government was trying to shut down a press reaction that they would be unable to control. Since it was too short notice to cancel the meeting, Dr. Weyer decided to proceed anyway. Interestingly, representatives from all nine South African provinces still attended the meeting, even though the national department of health was not represented at a high level. Dr. Weyer saw this as evidence that the provincial departments were very concerned about XDR-TB and were not willing to ignore it.\footnote{Weyer, interview by author, 2010.}
The real surprise, however, was the degree of interest that the press showed in this particular meeting. According to Dr. Weyer, the MRC put out a press advisory about the event the day before, as it usually would. The organizers had booked a room for twelve journalists for half an hour. In fact, more than 40 journalists, including some from major international media outlets like CNN and BBC appeared for the press conference, which lasted an hour and a half. The department of health had not allowed the press to visit the TB program in Tugela Ferry, making the journalists even more eager, and making the absence of the national department of health (and of the Minister of Health or her representative, specifically) from this press conference even more apparent. It seemed that the initial press coverage after the International AIDS Conference combined with the South African department of health’s inclination towards secrecy made XDR-TB even more interesting to local and international media outlets.

The WHO representatives who attended the meeting were keenly aware of the potential political sensitivity of this meeting, especially considering MDR-TB’s (and by extension XDR-TB’s) status as a WHO indicator of public health system failure. In light of the absence of high level national level South African department of health representatives at the meeting, Paul Nunn, the coordinator of TB/HIV activities at WHO in Geneva, decided to have his subordinate, Ernesto Jaramillo, represent him at the event’s official press conference. The meeting achieved significant coverage in the scientific and lay press.

Timothy Holtz remembered Paul Nunn “running around all day doing interviews... with the BBC, on CNN, and it was just kind of a surreal situation. [...] I remember going over to the TV station and Paul Nunn was being interviewed by the BBC in this small little media room, and I just remember it just seemed like non-stop. The attention, it just kept going on and on and on

---

353 Anthony Moll, interview by author, 13 May 2011, Tugela Ferry, South Africa.
354 Jaramillo, interview by author, 2010.
355 Jaramillo, interview by author, 2010.
on everyday there was someone else who wanted to talk to us about this problem. And that’s when I think we all realized that this really was something that we could harness and benefit from, call attention to the problem of drug resistance and try to get more resources for the fight against drug resistant tuberculosis.”

Though the press conference and interviews were not the only events at this two-day meeting, they did help fulfill some of the aims of the consultation as they were stated afterwards in a brief report generated by the WHO. According to the report, the WHO aimed to “call attention to the problem of TB drug resistance in SADC countries” and “call attention to the WHO Guidelines for Programmatic Management of TB Drug Resistance, launched in May 2006,” – both of these goals benefitted from publicity. In addition, formal presentations and discussions on the topics of “epidemiology and surveillance of drug-resistant TB, programmatic management of such patients, drug-resistant TB outbreaks, and infection control measures needed within the context of high-burden HIV settings” helped to achieve other stated aims. These were to “define the gaps in surveillance of TB drug resistance in the region;” “define essential components of TB infection control, particularly in high-HIV prevalence settings;” and “identify the steps necessary for SADC countries to effectively address the problem of drug-resistant TB.”

Interestingly, the meeting’s published aims attempted to spread the attention across countries of the Southern African Development Community (SADC) generally, rather than place the onus directly on South Africa. Despite the WHO’s attempts to be sensitive and not single out South Africa as the source of the XDR-TB problem, however, it seemed that the South African government’s strategy to avoid controversy had backfired. According to Dr.

358 Ibid.
359 Ibid.
Weyer the expert consultation and the extensive press coverage which emerged from it opened up the National Department of Health for criticism, and the department was accused of “trying to hide the problem and not paying enough attention as was warranted.” In response to this criticism, “the national department of health organized another consultation with the SADC countries as well as the nine provinces one month later,” this time in Pretoria. Once again, the MRC, CDC and WHO attended.

In an effort to appear proactive, the Johannesburg meeting had issued a 7-point action plan. The seven proposed actions included the conduction of epidemiological surveys, the enhancement of laboratory capacity, the improvement of the technical skills of public health managers, the implementation of infection control measures, increased research for anti-TB drug development, increased research for diagnostic test development, and improved access to HIV and TB drugs in joint programs. In the short term, especially the points about increasing anti-TB drug and diagnostics research seemed unrealistically ambitious and beyond the control of those attending the meeting. The plan showed the imprint of the scientific and technical experts at the meeting by focusing almost entirely on technical, knowledge-based interventions. The report resulting from the meeting did not reflect any consideration of the reasons why South Africa and Tugela Ferry suffered from such high rates of tuberculosis to begin with, and did not engage with the fact that

---

361 Ibid.
364 In hindsight the progress made in these domains on a global level is actually quite impressive and include the development of novel diagnostic techniques, new drugs which are currently in clinical trials, and new insights into effective infection control measures.
tuberculosis is well known to be a disease which thrives in conditions of poverty and deprivation and which responds well to improved living conditions.\textsuperscript{365}

The WHO task-force on XDR-TB

The most concrete outcome of the meeting in Johannesburg was the convening of another meeting: the global WHO task-force on XDR-TB met at WHO headquarters in Geneva, Switzerland (more politically neutral territory than South Africa) on October 9-10, 2006 to deal with specific epidemiology, policy, and advocacy questions regarding XDR-TB. According to the \textit{Report of the meeting of the WHO global task force on XDR-TB}, “more than 110 participants representing the most affected countries attended the meeting, together with global experts in TB control and MDR-TB management; HIV prevention, care and control; infection control and occupational health; communicable disease preparedness and response; advocacy, communication and social mobilization (ACSM); and representatives from bilateral and multilateral agencies and organizations.”\textsuperscript{366}

The September meeting in Johannesburg, South Africa and the October meeting in Geneva, Switzerland demonstrated that the WHO and CDC, among others, had decided to take on XDR-TB as an important issue which had momentum that could be built on relatively quickly. An emphasis was placed on urgency. The stated goal of the task-force meeting in Geneva was to “define key issues, make recommendations and propose urgent actions required in the next three to six months.”\textsuperscript{367} People attending the meeting (some of whom had been involved in the discussions about XDR-TB from the very beginning, while others were only just being introduced to the concept) were brought on the same page with

presentations by key players, including Sarita Shah (CDC), Paul Nunn (WHO), Tony Moll (Tugela Ferry), and Ernesto Jaramillo (WHO), among others. These speakers set the stage for framing XDR-TB as a global crisis that affected the broader, global public health community, and the global AIDS community, in particular. Geographically, the emphasis of the background presentations at the meeting was on Estonia, Latvia, Peru and the Philippines. These countries had in previous times been the focus of MDR-TB concerns in global discussions and were now seen as model countries for the management of MDR-TB. In addition, three Southern African countries (Lesotho, South African and Swaziland) were now introduced as the new loci of concern with regards to drug resistant tuberculosis. While the reports from South Africa were the main motivator for this meeting, the focus was again diffused in part onto its neighboring countries.368

For parts of the XDR-TB taskforce meeting participants were split into groups to address the different topics of XDR-TB management and surveillance, infection control, the protection of health workers; advocacy, communication and social mobilization, as well as the laboratory definition of XDR-TB. The WHO had taken an active role in the past of increasing the epidemiological surveillance of tuberculosis (the use of Supranational Reference Laboratories to keep track of drug-resistant tuberculosis is one such example) and in issuing policy recommendations for the operational and clinical management of tuberculosis (with DOTS, in particular, being the WHO’s flagships TB program). The WHO also has a long history of involvement in standardizing biomedical terminology.369 Thus, the key domains of discussion identified for this taskforce meeting were in keeping with the WHO’s traditional roles in shaping action around disease.

368 WHO, *Report of the Meeting of the WHO Global Task Force on XDR-TB.*
The definition of XDR-TB – once again, a problem

The most significant decision at the XDR-TB taskforce meeting emerged from the group that discussed the laboratory definition of XDR-TB. Laboratory specialists, researchers and policy makers had started to think of the existing definition for XDR-TB as a problem. As we have seen, the standing definition for XDR-TB had been solidified, after much negotiation, around Dr. Shah and Dr. Holtz’s research (under the leadership of Dr. Peter Cegielski), and was published in Morbidity and Mortality Weekly Report (MMWR) in March 2006 as *MDR-TB plus resistance to 3 out of 6 classes of second line anti-TB drugs.* Yet by October 2006 this definition was no longer satisfactory. Some of the reasons for this were related to the techniques of laboratory science: few labs in the world actually tested for three or more second-line drugs, rendering the conditions for XDR-TB un-fulfillable, and thus useless. Some of the six second-line drug classes were more effective than others, making some resistance patterns that were included under the rubric of XDR-TB much more difficult to treat than others. Several experts, including CDC’s Dr. Kenneth Castro, connected the review of the definition of XDR-TB with the need for a standardized definition which would mean the same thing everywhere in the world: “One of the key components of case definitions is to facilitate consistent and universal reporting so that if you live in China and you call this XDR it’s pretty much consistent with what we in the US call XDR. Whereas if you have a case definition that [is] ... well I’ll use the scientific term "mushy"... then you don’t quite know if the cases reported in China are indeed similar to the ones reported in the States. [...] And in this we were trying to find a sweet spot that was both sensitive and specific.”

---

Castro’s ironic use of the surely not scientific term “mushy” highlights two things. First, the fact that the definition of XDR-TB used by Shah and Holtz was “mushy” was initially more of an asset than a drawback, since it allowed tuberculosis samples that were obtained and tested in different settings, using different standards, by different laboratories and for different research purposes to be collected under an umbrella term and definition as “XDR-TB.” The need for resistance to “3 out of 6 classes of second-line drugs” to fill the definition was both restrictive and capacious, since the exact combination of drugs classes was not pre-determined, and there was no hierarchy of second-line drugs – they all equally contributed to the XDR-TB diagnosis.

The “mushy” quality of such a capacious definition, however, became problematic in part because laboratory and clinical specialists came to the conclusion that there should be a hierarchy of second-line drugs. Some cases of XDR-TB by the original definition were apparently more difficult to treat than others, and some laboratory studies were more difficult to conduct accurately than others, leading to Castro’s hypothetical scenario that Chinese and American cases of “XDR-TB” could be based on quite different physical realities as far as the condition of actual patients, and actual threat to public health was concerned.

Other motivations to revisit the definition of XDR-TB were more explicitly political. The highly drug-resistant tuberculosis cases from Tugela Ferry were being called XDR-TB ever since Neel Gandhi’s presentation at the AIDS conference in Toronto in August 2006. Yet strictly speaking, these cases did not fit the original XDR-TB definition published by the CDC and WHO in March 2006.\(^{372}\) While this discrepancy may have gone unnoticed (or unremarked upon) at Neel Gandhi’s oral presentation for the Toronto AIDS conference, it

\(^{372}\) As explained earlier, the original definition required XDR-TB cases to be resistant to at least (any) 3 classes of second-line drugs. The microbiology laboratory in Durban, South Africa only tested for resistance to 2 classes of second-line drugs. (These tests are expensive and not readily available.) As a result, even a “proper” case of XDR-TB could never be identified by the Durban lab as such.
became a point of resistance in later discussions. When Dr. Moll presented his group’s findings at the WHO task-force meeting in Geneva, for example, South African department of health representative Professor Ronald Green-Thompson,\textsuperscript{373} immediately challenged his “abuse of this term XDR-TB.”\textsuperscript{374} As Dr. Moll remembered the exchange, Green-Thompson argued that Dr. Moll and his collaborators “were not using the definition scientifically.”\textsuperscript{375} What he meant by this was that Dr. Moll and his colleagues were incorrectly claiming to have identified XDR-TB cases in Tugela Ferry, even though the laboratory tests they had done merely demonstrated that they had cases that were resistant to all four first-line anti-tuberculosis drugs, as well as two second-line drugs (not three). As a representative of the South African national department of health, Green-Thompson implied that Moll’s group was blowing cases of drug-resistant tuberculosis out of proportion and ignoring scientifically established categories in order to gain attention.

In Dr. Moll’s view, Green-Thompson was all the while clouding the issue that “boy, there’s a problem here, we need a national response to it. [...] Forget the definition.”\textsuperscript{376} Professor Green-Thompson’s critique was in line with the KwaZulu-Natal provincial Health Minister’s statement that the department of health already had programs in place for multi-drug resistant tuberculosis, and was thus already dealing with the problems in Tugela Ferry. Dr. Moll meanwhile did not really care about whether or not his patients’ versions of tuberculosis fit any particular definition, but was invested in applying the terminology required to get the government and private response that the patients required.

Professor Green-Thompson was not the only person who balked at the use of the

\textsuperscript{373} Professor Green-Thompson had been secretary general for the KwaZulu Natal provincial department of health when Tugela Ferry first identified the highly drug-resistant cases of TB. At this point he was an advisor to the national department of health in South Africa.

\textsuperscript{374} Moll, interview by author, 2007.

\textsuperscript{375} \textit{Ibid.}

\textsuperscript{376} Moll, interview by author, 2007.
term XDR-TB. Some tuberculosis scientists and clinicians from other regions of the world also resisted the XDR-TB terminology, especially if they had been dealing with advanced forms of MDR-TB for quite some time. This resistance was partially motivated by the pragmatic fact that in clinical settings the case-definition was less important than assessing and appropriately treating the specific drug-resistance patterns present in individual tuberculosis patients. Especially scientists from the former Soviet Union were not too convinced of the need for the XDR-TB term. Some scientists and clinicians who worked in areas with low HIV prevalence also worried that the focus on XDR-TB as a byproduct of a massive HIV-epidemic in South Africa would pull attention and resources away from their own MDR and XDR-TB problems. Still other scientists seemed a bit miffed that scientists working on XDR-TB in Tugela Ferry were getting the attention they were by being imprecise in their embrace of a new term, even though others had in fact identified very resistant forms of tuberculosis much earlier, and employed more rigorous epidemiological and scientific criteria to do so, without an equivalent response. Finally, the discrepancy between the Tugela Ferry cases and the “official” definition of XDR-TB needed to be resolved one way or another before Dr. Friedland, Dr. Gandhi, Dr. Moll and colleagues could publish their results in a peer-reviewed, prestigious journal, such as the Lancet. There was some urgency to this question, as well, since the Lancet had agreed to publish the results in a fast-track paper and wanted Friedland’s group to submit the final draft of their publication on XDR-TB in Tugela Ferry with a clarified definition of their cases’ degree of drug resistance by mid October.

Thus, there were several potential reasons to reconsider the definition of XDR-TB. Karin Weyer (the South African laboratory-based tuberculosis expert who had organized the expert consultation meeting in Johannesburg) had been given the task of reviewing the literature and writing a discussion document suggesting a new definition for XDR-TB that was based more solidly on a technical laboratory foundation than the existing definition. Her paper sought a “pragmatic working definition” which would be relevant in an operational setting, taking into account the limited availability of second-line anti-tuberculosis drugs, the global lack of laboratory capacity to diagnose second-line drug-resistance, and the highly limited treatment options available for XDR-TB.\textsuperscript{381}

Weyer’s document focused on the laboratory. The main problem, as her discussion document formulated it, lay in the technical limitations of second-line drug resistance testing. These limitations included the lack of international standards for many of these tests, the poor reproducibility of results for some drugs, the unclear relationship between lab-based resistance findings and the degree of resistance seen clinically, and the fact that some of the tests have not been systematically verified or can only be conducted in developed countries.

In addition, Weyer organized all the available anti-tuberculosis drugs in a hierarchy of efficacy (based on WHO TB treatment guidelines). Unlike the Dr. Shah’s paper in Morbidity and Mortality Weekly Report (MMWR), which categorized second-line anti-tuberculosis drugs into six classes (based on chemical properties) which were treated equally in terms of their ability to activate the XDR-TB definition,\textsuperscript{382} Weyer’s hierarchy identified four groups of second-line drugs, including injectables, fluoroquinolones, “oral

\textsuperscript{381} Karin Weyer, “Revised Definition for Extensively Resistant Tuberculosis (XDR-TB),” October 10, 2006.

bacteriostatic 2nd line drugs” (which included several different types of drugs which have been shown to be somewhat effective against tuberculosis) and a group of “unclear efficacy,” which mostly included drugs that had been tried in patients where there were no other options, but seemed to have some effect.383

This newly-constructed drug-hierarchy, as well as evidence from Latvia “which shows that the rate of successful treatment outcomes precipitously falls as resistance to the key [second line drugs] increases”384 logically and successfully led to the proposal that from then on, XDR-TB should be defined as "the occurrence of TB in persons whose M. tuberculosis isolates are resistant to isoniazid and rifampin plus resistant to any fluoroquinolone and at least one of three injectable second-line drugs (i.e. amikacin, kanamycin, or capreomycin).”385 This new definition also allowed the neat inclusion of the cases from Tugela Ferry in the category of XDR-TB, though this is not mentioned in Dr. Weyer's discussion document.386 The definition for XDR-TB was revised just days before the final version of the fast-tracked Lancet paper reporting the findings from Tugela Ferry was submitted to the publisher. The 53 cases of tuberculosis resistant to all first and second-line drugs tested reported at the 2006 International AIDS Conference could still be called XDR-TB, and the Lancet paper discussing them could use the term XDR-TB.387

Interestingly, the 53 cases in the Lancet paper now more than fulfilled the definition of XDR-TB because they displayed resistance to all four first-line drugs, not merely isoniazid and rifampin. A re-analysis of the same dataset using the new definition meant that Tugela

383 Weyer, “Revised Definition for Extensively Resistant Tuberculosis (XDR-TB).”
384 Ibid.
386 Weyer, “Revised Definition for Extensively Resistant Tuberculosis (XDR-TB).”
Ferry could have claimed even more XDR-TB cases at the time, though the authors chose to publish their original analysis. It is worth pointing out that though these Tugela Ferry cases could now be included in the global tally, this did not automatically mean that there was an increase in documented XDR-TB cases worldwide. When Shah’s data from the global XDR-TB survey was reanalyzed according to the new definition, the number of detected XDR-TB cases decreased from 347 to 234. This no longer hurt the case for the importance of XDR-TB, however.

Judging by the retrospective musings of several of the leading tuberculosis experts who were involved in suggesting and deciding the change in XDR-TB definition, it was in fact a rather uncontroversial decision to make the change. Once the change had been decided upon and published, there was soon a general consensus around the new definition, to the extent that even people who were intimately involved in the discussions around XDR-TB in mid 2006 seemed almost to forget that there ever was a different definition than there is now. As Dr. Holtz explained: “When it was published in November [2006] there [were] various dissenting letters and people asking [...] ‘do you think this is really the best definition?’ But there has really been no strong counterargument why we need to go back or change anything. Since November of 2006 the name has stuck and the entity has stuck and now there have been growing numbers of papers that have been published looking at XDR.”

Those most intimately involved in the decision-making deny that the need to include Tugela Ferry’s cases in the definition (be it in order to have a high-profile publication on XDR-TB in the Lancet, or in order to be able to put pressure on the South African department of health) was a significant factor in the decision (or a factor at all).

There was some awareness of the fact that the new definition had such advantages, but most of the participants in the laboratory definition breakout group at the task-force meeting were laboratory specialists who had no difficulty arguing for the change in microbiological terms.

In 2007, Dr. Friedland stressed the clinical aspects of the revised definition:

"Prognostically, the important resistance in second-line drugs is to the fluoroquinolones and an injectable. In terms of clinical meaning it makes sense to actually define it with those two classes of drugs rather than any three classes of drugs."390 Some of the players closest to the policy-making process were relatively open about the political dimensions of the definitional change, as well. In a CDC podcast, Dr. Cegielski stated that the definition was changed "partly for microbiological reasons, partly for political reasons."391 Dr. Shah apologetically stated: "I wish I could say it was the clinical and the lab parameters, but there was also a large political component to it."392 Dr. Moll, the one person present at all these meetings who was also an almost daily witness to the suffering and death brought by tuberculosis and HIV in Tugela Ferry, agreed that the term XDR-TB had political power, but also emphasized that compared to MDR-TB – or even the first definition of XDR-TB – the newly defined XDR-TB "was a different disease with a different outcome and different treatment challenges. That’s what we as physicians felt here [in Tugela Ferry]. That married very well with technical aspects of the definition in terms of being able to reliably reproduce it across the world. [...] The injectables and the fluoroquinolones were the next after rifampicin and INH [as] the most potent TB drugs.393 And if you take them out together with

393 Rifampicin is an alternative name for rifampin; INH is the commonly used abbreviation for isoniazid, the most powerful anti-TB drug.
INH and rifampicin you are now in a treatment dilemma. So the new definition XDR-TB accommodated that very well. So take away all the press hype, etc. It is to me a totally logical scientific conclusion to come to. [...] What the new definition very nicely did was to package fluoroquinolones and injectables exclusively into the definition and that really took the disease into a treatment dilemma.”

Thus, in Dr. Moll’s view, the change in definition reflected the material reality of a more acute and desperate clinical situation that meant that patients were worse off, and that those who were trying to take care of them were left with very few options. Dr. Moll himself had actively pursued media involvement in order to put pressure on his superiors in the South African department of health, and had discounted the importance of the definition of XDR-TB (and whether or not it was “scientific” according to Dr. Green-Thompson of the Department of Health). He did, however, support a definition that highlighted the clinical and human devastation that could be caused by drug-resistant tuberculosis and emphasized its scientific, and thus moral validity.

The publication of the research from Tugela Ferry in the Lancet in November 2006 brought closure to the process of naming and defining of XDR-TB, while also clearly anchoring XDR-TB in a specific place. The article supported a narrative in which XDR-TB could claim clinical and political meaning in the context of HIV/AIDS, emerging infectious diseases and global health research in resource-limited settings. In South Africa, activating the term XDR-TB for use in Tugela Ferry and elsewhere had the potential to allow clinicians within the South African health system to make increased claims on government agencies, holding them accountable for the citizens in their care.

In part two of the dissertation I transition away from the international making of XDR-TB to focus more closely on South African responses to this new disease entity. As we will see in chapter four South African government health agencies initially responded

ambivalently as they both resisted and worked together with researchers and clinicians to study and address the extent of drug-resistance that had been uncovered. Nurses, research assistants, logbooks, databases and rural landscapes are the subject matter of chapter five which further examines the complex relationship between international and South African expertise, research, and clinical intervention around drug-resistant tuberculosis.
CHAPTER 4: Dealing with a Time Bomb – At the Interface Between Government Health Departments and Global Health Research

“You could be sitting on a time bomb you don’t even know.” – Bruce Margot, TB Program Manager for KwaZulu-Natal.

“I knew it would be a bombshell, should it break.” – Dr. Anthony Moll, physician at Church of Scotland Hospital in Tugela Ferry.

“We were saying, you know, that something’s going to happen. [...] You know, saying we’re just sitting on a bomb. We’re waiting for this bomb, and that was it.” – Karen Shean, South African nurse-researcher.

“No one came up to actually alert [the district office] that we are going towards the time bomb.” - Jabulani Mndebele, Umzinyathi District Manager.

According to most early accounts, the immediate official South African response to the discovery of highly drug-resistant tuberculosis in Tugela Ferry appeared half-hearted. Prof. Sturm came to Tugela Ferry from Durban to discuss infection control and he made his laboratory available to test all tuberculosis samples from Tugela Ferry for drug resistance (with backing from the department of health). Beyond this, however, Dr. Moll and his colleagues struggled to get their department of health superiors to respond with a true sense of urgency. The number of MDR-TB and XDR-TB patients was overwhelming, and the doctors in Tugela Ferry needed the department to make a plan to get their patients access to appropriate medications and care. Dr. Moll described himself as shouting until his voice was hoarse, and his colleague Dr. van der Merwe similarly recalled that getting the department of health on board was a challenge.\(^{395}\) Dr. Moll tried to convince the department

\(^{395}\) Anthony Moll, interview by author, 13 May 2011, Tugela Ferry, South Africa; Theo van der Merwe, interview by author, 19 June 2011, Tugela Ferry, South Africa.
that it was in their best interest to be proactive and remembered warning "the provincial public health relations person, begging him to leak the information about MDR and XDR because I knew it would be a bombshell, should it break."396 As late as mid 2007, after the news about XDR-TB had already received a broad, international audience, Dr. Nesri Padayatchi, a South African doctor and tuberculosis researcher in Durban, lamented that "the whole world is concerned about MDR and XDR-TB except us. And really, you know, the department of health is really not coming to the party."397

By 2010, however, assessments of the South African government’s response to MDR-TB and XDR-TB were much more generous. Dr. Padayatchi was more optimistic and was able to list a number of tuberculosis programs supported by the department of health: "In terms of comparing what’s happened since 2007, yes, we are moving in leaps and bounds."398 In the meantime there had been a change in the South African presidency and in the leadership of the department of health, and scientists and physicians were feeling much more positive about the future of public medicine in South Africa.

Though many people still described South Africa’s public health system as difficult to work with or even dysfunctional, several people I spoke to emphasized that the government employees responsible for tuberculosis in the province of KwaZulu-Natal and the district of Umzinyathi (the administrative district in which Tugela Ferry is located), in particular, were admirably attentive and proactive in addressing drug-resistant tuberculosis. Physicians and researchers in Tugela Ferry had developed a functional working relationship with district and provincial tuberculosis program offices. International and local researchers, clinicians, administrators and policy makers had worked together to design and implement new, innovative public health programs to deal

396 Moll, interview by author, 2011.
397 Nesri Padayatchi, interview by author, 13 July 2007, Durban, South Africa.
398 Nesri Padayatchi, interview by author, 6 April 2010, Durban, South Africa.

This chapter highlights the important contributions made by district and provincial government employees to tuberculosis control in Tugela Ferry while taking seriously the critiques that the South African government was slow to respond to XDR-TB. I argue that department of health workers, including administrators and nurses, played a greater role in responding to the “outbreak” of drug-resistant tuberculosis in Tugela Ferry than common conceptions of global health research and intervention might predict, even as international researchers, foreign development agencies (including the Italian Cooperation and USAID), transnational health agencies and health consulting companies were all involved in the response to XDR-TB.

The chapter is based in part on interviews conducted in 2011 with local department of health officials from the Umzinyathi district, which oversees four sub-districts, including the Msinga sub-district, where the town of Tugela Ferry and its Church of Scotland Hospital are located. From these officials’ perspectives the discovery of XDR-TB in Tugela Ferry triggered a significant and relatively rapid response, not only from the international community and the media, but also from parts of the South African government bureaucracy. In the short term, the Umzinyathi health district shuffled its own resources and worked together with representatives from the Italian Cooperation (Italy’s aid agency)
and Philanjalo to gather epidemiological data and to actively pursue cases of drug-resistant tuberculosis. In the long term, tuberculosis management in Msinga was transformed by a new paradigm of community-based management and by the addition of over a dozen government-funded nurses, drivers and data managers to Tugela Ferry’s previously small tuberculosis office. In addition, increased supervision and support of designated tuberculosis nurses in outlying clinics was initiated. In 2008 the Umzinyathi district opened a dedicated MDR-TB hospital and clinic where MDR-TB patients from Tugela Ferry and other parts of the district could be treated. Systems were put in place to coordinate TB, MDR-TB, and XDR-TB patients’ care between sub-district, district, and province level to ensure that acceptable care was available.

South African government support for drug-resistant tuberculosis programs was not a straightforward answer to international pressure, however. Government actors simultaneously demanded, resisted, and reluctantly embraced international expertise and interventions in efforts to assert their own authority over the drug-resistant tuberculosis problem. There was an awareness among South African officials that even as outside tuberculosis researchers provided skills and expertise and attempted to work together with local officials, they also used South African resources (both in the form of patient access and uncompensated laboratory testing) to build their own careers and gain prestige. Government officials did not always consider outsiders’ (or even South African researchers’) help benign, and tried to control the form that such help took. The correct response to MDR-TB and XDR-TB in South Africa was an open question that South African

---

experts and administrators grappled with seriously while under close scrutiny from WHO officials, international researchers, humanitarian medical organizations, well-connected human rights activists and investigative journalists. South African tuberculosis experts and administrators used a variety of strategies both to contain and harness the attention, energy and potential resources which came with the high profile of XDR-TB and the at times overwhelming international interest.

This chapter is organized chronologically, showing a progression in research, clinical, and government responses to the knowledge that Tugela Ferry had a serious problem with drug-resistant tuberculosis, from fact gathering and consternation, to program development and management. After documenting the initial shock of discovery, this chapter discusses how district and provincial TB managers related to international expertise and used international experts to help gather and interpret information about the causes of XDR-TB in Tugela Ferry and the province as a whole. The chapter culminates in a discussion of the choices that led to the placement of Umzinyathi’s MDR-TB hospital in Greytown, only 45 kilometers from Tugela Ferry, but not in Tugela Ferry, a choice that I argue simultaneously expressed some resistance against international authority and maverick physicians while allowing the province to continue to benefit from the resources provided by these experts and physicians.

The tip of a deadly iceberg?

As we have seen, Lynn Roux’s revelation to Dr. Moll in May 2005 that she had identified at least ten cases of highly drug-resistant tuberculosis opened a wide range of questions for the staff at the Church of Scotland Hospital in Tugela Ferry. Where did the severe drug-resistance come from? How deadly was it? Were the discovered cases just the
tip of an iceberg of a widespread epidemic? On a personal level, Dr. Moll and everyone else working in the hospital had reason to be concerned for their own safety in the face of this air-borne disease, and it was unclear what protective measures would be feasible and effective. This was highlighted by the fact that the first cluster of documented XDR-TB cases included several health workers who were employed at the hospital, as well as hospital workers’ relatives.

In the absence of a robust government response Dr. Moll and his colleagues turned to American research collaborator Dr. Gerald Friedland, his colleague Neel Gandhi and their extensive international network around infectious diseases research and policy for support. Early research efforts focused on quantifying the extent and lethality of the apparent outbreak of drug-resistant tuberculosis. This work led to presentations at the 2006 Conference on Retroviruses and Opportunistic Infections (CROI) and the 2006 conference of the International AIDS Society, as well as the 2006 Lancet paper that made Tugela Ferry famous, as discussed in previous chapters.

Dr. Moll was able to travel to Denver, Colorado to formally present the tuberculosis cases from Tugela Ferry at the Conference on Retroviruses and Opportunistic Infections in February 2006. He was amazed at the intensity of the feedback he received from international experts: “This allowed me to come home thinking that if it really is so serious, why is it that in South Africa we’re not jumping or doing anything about it? I [was] starting to get embarrassed that the international community was saying, oh, this is serious, and in South Africa we’re saying, sorry about that, it’s just another problem and we’ll get around to it some time.” This feeling was only further enhanced by the interest in XDR-TB generated at the International AIDS Society conference a few months later. Moll was

402 Anthony Moll, interview by author, 23 July 2007, Tugela Ferry, South Africa; Kristina Wallengren, interview by author, 23 September 2010, Durban, South Africa.
encouraged to demand further action against drug-resistant tuberculosis from his superiors in the South African department of health.404

South African officials, meanwhile, had reason to feel embarrassed by the presentations about drug-resistant tuberculosis made at these large international conferences. Observers privy to meetings at the national level indicated that the department of health felt attacked by the Tugela Ferry research group’s public presentation of unflattering statistics without fully involving them. This in part explained early official government responses of denying the severity of the problem and attempting to block media access to information about XDR-TB. At one point Dr. Moll was even informed that as a government employee he did not have permission to speak about XDR-TB at another conference that he had been scheduled to attend.405

According to other sources, however, government offices had in fact been regularly updated about research developments in Tugela Ferry. Bruce Margot, TB program manager for the province of KwaZulu-Natal, remembers being aware of the elevated drug-resistance rates in Tugela Ferry by May 2005, not long after Dr. Moll discovered the problem. According to Margot, the WHO was conducting a review of South Africa’s TB program that year, and he invited WHO and national TB program representatives to visit Tugela Ferry as part of that review. The extent of the problem had not yet been fully documented at the point, however, and “no-one” – neither the WHO nor the national TB program – got “overly excited at that stage.”406 As we have seen, Margot’s office also asked the South African Medical Research Council for assistance in assessing MDR-TB in KwaZulu-Natal. He and

404 In 2006 Dr. Moll was not the only South African health worker embarrassed about the inadequacy of South Africa’s response to a pressing public health issue. At the 2006 International AIDS Society meeting, for example, the official South African display booth made international headlines for featuring garlic, beetroot and lemons as treatment for AIDS, but no HIV medication, enraging South African physicians and activists.
406 Bruce Margot, interview by author, 18 April 2010, Pietermaritzburg, South Africa.
other government representatives at national and provincial level had also been invited to
attend the upcoming September expert consultation on XDR-TB organized by the South
African Medical Research Council and the American CDC. The department did not anticipate
the extent of media interest in XDR-TB that followed the AIDS conference in Toronto in
August 2006, however, and was “caught with their pants off,” as one doctor put it, after the
presence of XDR-TB in Tugela Ferry was announced at the conference. They “were totally
unprepared for the media onslaught that took place,” according to one observer. One issue
clearly was a lack of effective communication between different levels and branches of the
department of health itself.

Government health administrators for the Umzinyathi district (in which Msinga and
Tugela Ferry are located) agree that the media storm around XDR-TB caught them by
surprise. Some administrators and hospital staff in Tugela Ferry claimed that it was from
these sensationalist news reports that they first heard about the XDR-TB problem in their
midst. Others remembered learning about it in meetings at the hospital. Sister Msomi, the
TB coordinator for Msinga and head of the clinical TB DOTS office at the hospital in Tugela
Ferry recalls attending a presentation by Dr. Moll and being surprised about what was being
reported: “I wasn’t aware that we were having a crisis.” She was miffed that her office had
not been more closely involved in investigating drug-resistant tuberculosis cases from the
start. Referring to the “snapshot” study which first revealed the extent of highly drug-
resistant tuberculosis in Tugela Ferry she stated: “In fact Dr. Moll was doing a study through
Philanjalo [the AIDS NGO founded by Dr. Moll through which HIV/TB research was
channeled] and they didn’t involve us [at] DOTS. They were just doing their own thing.”

---

407 Nonhlanhla Msomi, interview by author, 10 December 2010, Tugela Ferry, South Africa.
408 Ibid.
Zanele Radebe, the senior technical advisor for tuberculosis for the Umzinyathi district (the district’s “TB coordinator”) explained that before the XDR-TB outbreak became known, the district was already aware of the fact that their tuberculosis program required strengthening.409 Umzinyathi district (like many South African districts) was not meeting the WHO-prescribed cure rate target of 85%, and the province of KwaZulu-Natal had been encouraging its districts to improve their statistics, in part as the result of a meeting of WHO Afro in Maputo in 2005 (before XDR-TB was discovered), in which tuberculosis was established as a priority disease.410 But when Church of Scotland Hospital CEO Hans Human reported the discovery of drug-resistant tuberculosis in Tugela Ferry at one of Umzinyathi district’s regular executive committee meetings, Radebe was alarmed. Immediate action was required. As Radebe recalled: “First thing the following day I was on the road to Church of Scotland to look at the infection control. The clients that have been detected that they’ve got MDR. Have they been traced? What is going on? They must go to King George [hospital in Durban] to get treatment, you know? Just a nightmare.”411

Fikile Ngema, then the Umzinyathi deputy district manager for the department of health412 in charge of 17 priority health programs (including TB, HIV/AIDS, and maternal and child health) remembered being doubtful when she first heard about Tugela Ferry’s cases of multi-drug resistant (MDR) tuberculosis: “It was very rare to hear that there is an MDR case. MDR, here! [...] We could not believe. [...] We were horrified.”413 Ngema admitted that there was some initial denial on the part of her department, and that she had been

409 Zanele Radebe, interview by author, 19 April 2011, Greytown, South Africa.
410 TB had been declared a priority at a meeting in Maputo, Mozambique in 2005, before the MDR/XDR-TB cluster in Tugela Ferry was even known. This had led to a series of activities around TB in KwaZulu-Natal, including the declaration of “crisis districts” that received additional funding for tuberculosis control. Umzinyathi district was not originally one of these crisis districts, but the district was later added due to XDR-TB. Margot, interview by author, 2010.
411 Radebe, interview by author, 2011.
412 Ngema later became director of Philanjalo.
413 Fikile Ngema, interview by author, 13 October, Tugela Ferry, South Africa.
tempted to question the researchers’ motives. She wondered: “Where are they getting those patients? Are these people looking for funding?” She was impressed by the media response. “The story just blew out of proportion. The news, the papers. And as a district office [...] we were frustrated because we were receiving calls from all over. All the radio stations.” In the shadow of the press coverage there was a sense of urgency, and Ngema traveled frequently from district headquarters in Dundee to Tugela Ferry, over an hour away. Her efforts also immediately benefitted from the resources and interest of Philanjalo, the affiliated American HIV/TB researchers, as well as Italian development assistance. “We had to stay here at COSH [Church of Scotland Hospital] most of the time, checking, what is happening, the infection control. We involved other people. Philanjalo was involved full time, the Italian Cooperation was there, we had to try and do something, set up teams, trace. And during that time, most of the patients were... by the time they were discovered some were dead.”

Overall, Umzinyathi district employees indicated that their first reaction to hearing about the high rates of drug-resistant tuberculosis was one of surprise and consternation, while their second reaction was one of frenzied action. In 2011 Church of Scotland Hospital CEO Hans Human explained that the official reaction could not be considered slow in government terms: “I think that in the context of working for government things happened quite fast, for me. Because really it’s very, very slow, because we’ve got the financial year and in that financial year you must [have] a budget allocation, adjustments, and money must come from somewhere that’s not been allocated this financial year, and create more staff, and create more post levels, [...] and create office space and get extra budget for your extractor fans, to find the money. You’ve got all of these in-house protocols, politics, procedures, systems that you have to overcome.”

415 Hans Human, interview by author, 14 January 2011, Tugela Ferry, South Africa.
The news media featured heavily in administrators’ accounts of how they came to understand the importance of drug-resistant tuberculosis in Msinga. This lends some credence to claims that a strong response to drug-resistant tuberculosis in Tugela Ferry took place only after higher level officials had been embarrassed by critical and alarmist reports in the South African and international media. Mr. Jabulani Mndebele, the Umzinyathi district manager, in particular, asserted that he learned about XDR-TB from the news.416 In his view, any government delay in response to drug-resistant tuberculosis in Tugela Ferry was not related to his department’s denial or incompetence, but was due to the fact that researchers had not followed the correct reporting hierarchy. “They never alerted anyone to say we are now going in explosion. So people started using different routes to actually make the problem be known all over. And that was not going to help it, because only [we – the district office] were responsible to solve that problem.”417 I interpret this to mean that he had information about a problem with drug-resistant tuberculosis in his district but had not seen the urgency of the situation or of XDR-TB, per se, until he saw alarmist, international media reports.

In the context of media pressure, Mndebele called the different stakeholders who were involved in the response to XDR-TB together for a meeting so that they could “come and present: what it is that you are talking about, what is that XDR, how did you find it? What exactly needs to happen in order for us to try to actually minimize and turn this cycle around?”418 According to one of the American researchers present, the visiting tuberculosis researchers anticipated resistance from the district manager and worried about the future of their research. To their surprise, the district manager expressed a desire to see the work continue. He requested that they do a better job of communicating their research to the

---

416 This contradicts some accounts from other sources.
417 Jabulani Mndebele, interview by author, 10 March 2011, Tugela Ferry, South Africa.
418 Ibid.
district leadership and of more explicitly coordinating visiting researchers through appropriate government authorization processes. Seeking official permissions for tuberculosis research in Tugela Ferry was not just an official hurdle. It allowed government officials to be apprised of research occurring at their public hospital and be informed about interesting results. It also potentially enabled research efforts to be more evenly distributed across hospital sites – district manager Mndebele argued, for example, that he encouraged new applicants who wanted to do research on tuberculosis to look beyond Tugela Ferry and set up projects in one of the other three hospitals in his district. Finally, it was implied to me by several people that researchers affiliated with the original research team in Tugela Ferry (specifically Dr. Moll and his American collaborators Dr. Friedland and Dr. Gandhi) were more likely to receive research permission for work in Tugela Ferry than new research teams. This guaranteed that the original research group had continued access to the research site and discouraged competition from other interested institutions. It also fostered the building of friendly relationships between researchers and government representatives. In fact, the increased inclusion of district and provincial government employees as authors on research papers and as presenters at meetings may well be an indicator of improving mutual relationships between the two groups over time.

Regular meetings between researchers, physicians, TB coordinators and the district manager were set up to review and improve the tuberculosis program. One priority was to find and bring into care the patients whose laboratory results had shown that they had drug-resistant tuberculosis. Another included improving tuberculosis infection control in order to protect staff and patients. Finally, dramatic changes needed to be made to the organization of tuberculosis care in order to give patients timely access to treatment for MDR-TB and XDR-TB.

Umzinyathi TB coordinator Zanele Radebe recalls tracing the newly identified MDR-
TB patients: “So first what we did is to organize teams so that they go out and trace, these teams. It just took us plus-minus three months to do the whole exercise. And there were more than 100 clients that were just roaming around in the community, not on treatment and we were not aware whether they died, or they are still alive.”

Patients were dispersed across the extensive hospital catchment area; many of them lived in remote settings, far from main roads, and without regular (or known) phone access. Philanjalo was able to make community health workers, research workers, vehicles and fuel available, while the Umzinyathi district reallocated some of its vehicles. Existing hospital resources were also focused on tracing these patients. Sister Msomi who oversaw the teams stated: “Many patients needed to be traced, so our teams were going out on a daily basis looking for these contacts. And newly diagnosed patients were dying like flies.” She emphasized that her hospital-based DOTS staff worked together with non-government Philanjalo employees that were provided to help her: “We were very busy. We were working hand in hand to identify suspects.”

Later, Zanele Radebe oversaw the hiring of dedicated TB nurses at each outlying primary health care clinic and, with help from the Italian Cooperation, introduced TB diaries with which the nurses could keep better track of their patients. The simple provision of improved stationery paired with hospital-based tracer teams who sought out patients who had not made it to their clinic appointments improved patients’ ability to complete their treatment and the nurses’ ability to hold them accountable. The supervision

---

419 Radebe, interview by author, 2011.
421 Ibid.
422 The TB diary is a simple ring-bound calendar that allows nurses to see each day which patients are due to come in to receive their treatment and which patients have not come. It was mentioned several times to me (including by clinic nurses) as a major improvement in how they managed their patients.
and support of nurses who were stationed at remote clinics was strengthened, as well, though retention and ongoing support of these nurses remained a challenge.423

The risk of infection

Next to identifying patients and bringing them in to the hospital for evaluation and treatment, another priority was to protect hospital staff, researchers, patients and visitors from infection with drug-resistant tuberculosis. When nurses, therapists, research assistants, technicians and physicians first heard about the presence of the deadly, airborne, treatment-resistant disease in their midst many of them understandably reacted with panic. Msinga TB coordinator Sister Msomi recalled that one newspaper hyperbolically claimed that if “you come to Msinga within six hours you’ll be dead,” and that some hospital physicians and nurses stopped coming to work.424 One HIV counselor said that she was shocked when she first heard about MDR-TB on the radio, and her relatives asked her if she was bringing a deadly disease home with her. It was not until shortly thereafter that information about the disease was cascaded to her through the ranks in the hospital through meetings and workshops. Many South African newspaper articles emphasized the individual patients who did not take their treatment correctly, thereby causing drug-resistant tuberculosis, as well as the risks that arose at facilities that housed such patients.425 Nurses, HIV counselors and technicians were nervous about working with sick, coughing patients who could potentially expose them to a deadly illness. Several health workers framed their fear in terms of HIV, the disease that had so dramatically increased their workload and increased the stakes of working in medicine over the previous decade.

423 Radebe, interview by author, 2011.
As one technician explained: “I don’t have a problem with an HIV positive person and I’m not afraid of him. I can even nurse him. But I’m very afraid of MDR-TB.”

The district, with assistance from the Italian Cooperation, Philanjalo, and a South African health consulting organization called Health Systems Trust, conducted workshops to train the hospital staff on TB infection control. One individual-based line of defense against tuberculosis infection is to wear a protective mask called an N95 mask that seals tightly over nose and mouth. These masks are different from standard surgical masks and were not readily available through the government hospital at first, but they were supplied by the University of KwaZulu-Natal and through international research sources.\(^{426}\) Later, they were supplied through government procurement sources. Consistent mask-wearing could be very difficult to maintain, however. Eugene Meyer, a missionary from Cape Town, was working as a data manager for Philanjalo’s TB/HIV cotreatment study and remembers that the discovery of highly drug-resistant tuberculosis in Tugela Ferry “just changed my life.”\(^{427}\) He spent many hours each week interacting with TB and HIV patients as they arrived in clinic, and he sought ways to protect himself, but found masks were very cumbersome to wear, especially in hot weather: “The problem was wearing a mask.”\(^{428}\)

Many of the other health care workers I spoke to agreed.

In the hospital, the masks were not only uncomfortable, but were the first indicator for some staff, patients, and visitors that something very concerning was happening. They gave some nurses and staff sense of security, while others wondered what the point was, considering that they had relatives, friends and neighbors with HIV and TB and they did not wear masks at home. Health workers learned in infection-control workshops that healthy, well-fed bodies with strong immune systems (unencumbered by HIV/AIDS, old-age, stress,
or systemic diseases) were less likely to become ill with tuberculosis. Many of the nurses and auxiliary staff I spoke to concluded that they must never be hungry or tired when seeing patients. Thus for some the consumption of snacks and lunch during well-timed breaks became an existential matter more important than the masks.

Many health workers relied on their faith in God to safely get them through days filled with potentially risky encounters with contagious patients. Others resigned themselves to their fates and decided that their odds of infection were not so high to make their jobs unacceptable. Sheila Bamber, a white South African physician in her 70s who had treated tuberculosis patients for four decades, took her chances and never wore a mask, even when sitting in a room with several known MDR-TB patients. She pointed out that she had lived a long life and laughed at the other physicians and students who started the day wearing masks around their faces but soon found them hanging around their necks (or arms, or elbows, or in their pockets).429 Several other physicians I spoke to had an air of invulnerability to them and seemed to reassure themselves that the social distance from their patients, their good health, and their avoidance of disease until now would protect them. Some doctors pointed out that the mask was incompatible with their chosen facial hairstyle and found that explanation enough for opting out of wearing one. One nurse said he always wore a mask when at work, including when going on home visits. But other practitioners had a more selective approach. Another nurse explained that she wore the mask if she knew that the patient might have drug-resistant tuberculosis, but not when dealing with all patients. But how could she know for sure? Yet another nurse explained that she tried to wear the mask at the hospital but became discouraged when she took public transportation to go home, because she couldn’t know what she was exposed to there.

429 Sheila Bamber, interview by author, 26 August 2010, Tugela Ferry, South Africa.
Not only health-care workers but also patients were at risk of infection in the hospital. The Church of Scotland Hospital in Tugela Ferry, like most South African hospitals, had large, open wards, and only minimal ability to isolate individual patients suspected to harbor dangerous diseases. Before the discovery of XDR-TB the TB wards were often filled beyond capacity, with patients sleeping on “floor beds” – mattresses placed between the formal beds. In retrospect many people, including the CEO of the Church of Scotland Hospital, acknowledged that this was a predictable recipe for the rapid spread of an illness like XDR-TB. As CEO Hans Human put it: “From an environmental perspective, the more patients you’ve got in the TB ward the more risk of spread. It doesn’t matter where in the hospital you are, because you’ve got bad germs and because everybody is coming here sick with some kind of illness. So actually the hospital is a very dangerous place to be and it’s better to discharged as soon as possible.” Until XDR-TB made itself known, however, patients’ need for compassionate care, including nursing, medication, and regular meals, took precedence, especially for the core group of physicians who had been administering to the impoverished community in Msinga for many years.

Once the MDR/XDR problem became evident in the wards, Moll and his colleagues started clamoring for extraction fans to be installed in order to remove the TB bacillus from the hospital air and help protect patients and staff. The department of health eventually installed such a system in the tuberculosis wards though no corresponding investment in the maintenance of the system was made. Small side-wards were made available for people with known MDR-TB or XDR-TB. Yet considering the slow diagnostics for drug-resistant tuberculosis, patients with drug-resistant tuberculosis could lie together with dozens of other patients for days to weeks before their status as MDR patients was known. Formal studies eventually confirmed the suspicion that prolonged stays at the Church of Scotland

Hospital were in fact a key contributor to the spread of MDR-TB and XDR-TB in the Msinga region.431

Interestingly, closer evaluation of tuberculosis infection control techniques indicated that old-fashioned or low-tech methods of infection control could potentially be as effective as high-cost extraction systems, negative pressure isolation rooms, or ultraviolet lamps (which are used to kill the TB bacillus).432 Systemic strategies that could lower the likelihood of hospital-based spread of tuberculosis included keeping windows in hospital wards open at all times for cross-ventilation (and providing blankets in cold weather), conducting sputum collection in the open air and in sunlight in order avoid the spread of germs in a closed space, as well as implementing changes in waiting-room policies. Researchers used mathematical modeling studies to argue for a comprehensive package of low and high-tech interventions.433 Increasingly, funders and government agencies perhaps had reason to feel justified in resisting the purchase of expensive infection control equipment.

In Tugela Ferry American researchers, working together with an infection control nurse hired by the department of health, surveyed hospital staff to determine barriers to effective infection control and implemented education sessions and policies with the goal of preventing infections at the hospital.434 International visitors working for Philanjalo also assembled educational materials and visual aids to explain XDR-TB and infection control to

staff and patients. New outpatient department policies called for coughing patients to be screened upon arrival and to be given simple surgical masks to prevent droplet formation in the waiting room. These patients were also to be seen ahead of others so that their time in the waiting room (spreading potential infection) could be minimized. These and other "low-tech" interventions were frequently re-emphasized and re-affirmed. Infection control was a crucial yet surprisingly complicated issue that demanded a high level of motivation and institutional will in order to be successful. It was clear that repeated re-evaluation and input from outsiders (especially outsiders who were themselves wary about the risks of infection in their new environment) helped local staff maintain (and periodically re-introduce) effective infection control practices.435

**Getting people into care: introducing community-based management of MDR-TB**

As we have seen, early efforts to deal with the news of MDR-TB and XDR-TB in Tugela Ferry focused on identifying the patients with positive laboratory tests and finding them in the “real world.” This was a challenging task made worse by the fact that many of the patients were already dead by the time hospital staff found them, or were in desperate need of effective treatment. As Fikile Ngema recounted years later: “More than half of them were dead, and we realized that this problem was discovered late. Because when you got to the families they were saying no, the father died six months ago, had the same symptoms, was working in Jo-burg…”436 The new practice of testing all tuberculosis patients for drug-resistant pathogens at the start of their treatment course led to a further increase of the number of patients with drug resistant tuberculosis who were identified. Yet in 2006 the South African health system had little to offer these patients.

---

435 Author’s field notes.
One of the biggest structural limitations to an effective response to XDR-TB in Tugela Ferry was the fact that King George V Hospital (KGV), the government referral hospital in Durban that was responsible for treating MDR-TB cases in KwaZulu-Natal, was clearly not equipped to take care of all cases of MDR-TB and XDR-TB across the province. In the 1980s King George V hospital had primarily been the hospital for complicated tuberculosis cases, such as TB meningitis and tuberculosis of the bones and joints, for the wider Durban region. As outpatient therapy according to DOTS became standard practice in the mid 1990s, the tuberculosis hospital in Durban reduced its number of beds and focused on MDR-TB cases. Following WHO recommendations, KwaZulu-Natal designated King George V hospital as the center of excellence for MDR-TB treatment for the entire province. The reduction of the number of beds, a dramatic increase in the rate of tuberculosis in the province, and the fact that MDR-TB patients require very long treatment courses (at least a year) meant that the Durban hospital became increasingly overwhelmed by the patient load over the course of the 1990s and 2000s. In 2005, when Tugela Ferry discovered its MDR-TB and XDR-TB problem, King George V hospital was quickly full with the referred patients and its waiting list was months long.

This left the Church of Scotland Hospital in Tugela Ferry with dozens of patients who had been identified as having MDR-TB or XDR-TB, but who did not have access to appropriate treatment or care for their drug-resistant strain of tuberculosis. Tugela Ferry's tuberculosis program was able to dispense first-line tuberculosis drugs, but these would not significantly help people with drug-resistant tuberculosis. Sister Msomi remembered the

438 Iqbal Master, interview by author, 30 April 2010, Durban, South Africa.
patients who died waiting: “They had to book a bed at King George [V hospital] and they had to wait at home until there is a bed. So the time would go and you would find that the patient is dead. It was bad. Bad. […] Really, many patients died while they were waiting for a bed.”

The hospital had the option of admitting patients with drug-resistant tuberculosis in Tugela Ferry and giving them supportive therapy as best they could. This, however, came with a significant risk of transmitting drug-resistant tuberculosis to other patients and staff. Sending people home without any tuberculosis treatment after they had been diagnosed with MDR-TB or XDR-TB was also highly unpalatable, but seemed to be a better option, since the waiting list at King George V hospital remained long, even as the hospital prioritized XDR-TB patients from Tugela Ferry. Faced with these unacceptable scenarios, physicians and researchers in Tugela Ferry decided they needed to find a way to treat patients in Msinga.

Physicians, administrators, and nurses in Tugela Ferry, with the cooperation of their counterparts in Durban, cobbled together a pragmatic solution to this treatment dilemma. When doctors in Tugela Ferry identified patients as having MDR-TB or XDR-TB, they notified the doctors at King George V hospital and sent stable patients to Durban for an outpatient clinic appointment. They were then sent back to Tugela Ferry with a supply of medications for drug-resistant tuberculosis, including medications that needed to be injected by a nurse. Once the patients were back home, teams of nurses from Tugela Ferry regularly visited them to provide the injections required for MDR-TB and XDR-TB treatment in addition to their pills. These nurses could also check for side-effects and other problems. This solution freed up beds at the TB hospital in Durban and allowed patients with drug-resistant tuberculosis to access treatment close to home in Msinga.

This home treatment program required a significant investment of resources on the part of the Church of Scotland Hospital’s TB program and the Umzinyathi district. The human resources and transport capacity that was required for such intense outreach was initially facilitated and funded by Philanjalo and the Italian Cooperation and later expanded with public government funds. Tugela Ferry’s hospital-based DOTS office was greatly expanded with tracer teams, injection teams and vehicles in order to provide this home-based service and was moved to larger quarters within the hospital. By mid 2008 the DOTS office had expanded from a handful of office-based staff to at least thirteen field teams of about two people each, and at least five dedicated hospital vehicles, in addition to office based nurses, technicians and data capturers.

Tugela Ferry’s move towards treating people with MDR and XDR-TB at home was not uncontroversial and harked back to the debates of the 1990s about the best ways to manage MDR-TB. While some public health experts viewed this approach as an innovative and positive strategy for dealing with an MDR-TB epidemic, others preferred inpatient treatment of drug-resistant tuberculosis and felt that not putting patients under quarantine was irresponsible.441 Managing MDR-TB in the community raised many questions about the risks of sending people with tuberculosis back home, where they might infect family and community members with their drug-resistant strains. One the other hand, hospitals are themselves places that tend to facilitate the spread of airborne diseases among its patients. Some experts argued that it was more efficient to monitor people’s treatment course in the hospital, and believed that it was unrealistic in the long run to provide nurses with vehicles who drive to patients’ homes every day to give them their treatment injections. Some

patients, nurses and physicians argued that especially poor patients found it easier to take treatment in an inpatient facility, where meals and nursing care were provided and the hunger caused by the healing body was not an existential problem.

WHO experts did not immediately support community-based management, but instead advocated for an expansion of hospitals specialized in treating MDR-TB. Even the organization Doctors without Borders (MSF), which had started to treat MDR-TB and XDR-TB patients in a community-based program in Khayelitsha (in the Cape Town area) and had advocated for patient-centered integration of HIV and TB management in its own work, was initially weary about endorsing outpatient treatment of MDR-TB and XDR-TB too strongly. Doctors without Borders’ Eric Goemaere explained that he wanted to be sure that community-based MDR-TB and XDR-TB treatment was the best option before promoting it, since some government agencies were perhaps prematurely enthusiastic when they realized it was cheaper and less permanent than building and staffing new tuberculosis hospitals.\footnote{Eric Goemaere, interview by author, 17 May 2010, Khayelitsha, South Africa.}

The organization Partners in Health, on the other hand, actively advocated for community-based management of MDR-TB and XDR-TB from the onset and soon entered the conversation around XDR-TB in Southern Africa by initiating a pilot program for community-based treatment in Lesotho.\footnote{“Studies confirm XDR-TB can be cured,” Partners in Health (blog), PIH.org, August 1, 2008, http://www.pih.org/blog/studies-confirm-xdr-tb-can-be-cured#disqus_thread.}

The KwaZulu-Natal provincial TB office, the Umzinyathi district office and the Church of Scotland Hospital administration at first tacitly and then actively supported the home-based approach to MDR-TB and XDR-TB treatment that was developing in Tugela Ferry under the steam of Dr. Moll and his South African and international colleagues. The national department of health appeared to withhold judgment for several years, and other South African provinces chose to act differently. The Western and Eastern Cape provinces, for example, enforced long-term hospitalization of XDR-TB patients, and tried to prevent patients from leaving fenced-in hospital compounds. The escape of several patients with drug-resistant tuberculosis from a hospital in the Eastern Cape gained considerable media attention in South Africa, and was even reported in the *New York Times*.445 In the Western Cape, the burden of XDR-TB was low enough that an expert panel could convene to discuss the options for each individual case.446 In KwaZulu-Natal, however, the tuberculosis hospital was so overwhelmed by XDR-TB and MDR-TB that community-based management seemed like the only possible option, next to not treating patients at all.

Researchers and clinicians working in Tugela Ferry argued that community-based management was not simply the most expedient option for improving TB treatment outcomes, but the best option. Infection control studies had showed that MDR-TB patients were most infectious when they were not being treated at all, before they were diagnosed, and the investigation of families with clusters of TB patients did not show significant transmission of MDR-TB between family members.447 Thus returning patients home once they had started appropriate treatment (after appropriate lead-time) should not

446 Karen Shean, interview by author, 7 May 2010, Cape Town, South Africa.
significantly increase the risk of infecting family members and neighbors, and would hopefully improve their chances at completing treatment. Mathematical modeling exercises supported the claim that community-based management of MDR-TB would be more effective than hospital-based care. American researchers in the Tugela Ferry research network designed a study protocol with which to assess the effectiveness of the community-based model.

In the aftermath of the discovery of XDR-TB in Tugela Ferry, South African physicians and administrators from the Church of Scotland Hospital and from the Umzinyathi district (including district TB coordinator Zanele Radebe) had the opportunity to visit Partners in Health’s MDR-TB program in Lesotho. The Msinga treatment program was partially modeled after this and other Partners in Health treatment programs that emphasized the importance of supporting patients’ basic needs and providing treatment support in the form of paid community health workers. In keeping with the model, Philanjalo and the South African department of health found ways to pay many (though not all) community health workers in Msinga a stipend for their work with MDR-TB and XDR-TB patients. It was also decided that all people on MDR-TB treatment in Msinga should be assisted in obtaining a government-funded disability grant for the duration of their treatment.

One difference between the programs in Lesotho and Msinga was that in South

---

450 The South African government’s social benefits system relies on a series of modest monthly grants including disability grants (for people with chronic illnesses and disabilities), child support grants and foster grants (for people caring for children under a qualifying age) and old age grants (pensions for people above a qualifying age). In an age of high AIDS rates among economically productive age groups as well as high unemployment rates many poor South Africans depend on AIDS-related disability grants, older relatives’ pensions and younger relatives’ child care grants for financial survival.
Africa injections had to be given by nurses. While community health workers in Lesotho helped give shots this was not considered an option in South Africa’s highly professionalized and regulated nursing environment.

From provincial headquarters in Pietermaritzburg KwaZulu-Natal’s TB coordinator, Bruce Margot, instigated further changes to the TB program that went well beyond the reach of Tugela Ferry and Msinga’s surrounding areas. Faced with the lack of capacity at the central tuberculosis hospital in Durban he distributed the hospital care for MDR-TB in the province to four hospitals located in different parts of KwaZulu-Natal, essentially decentralizing the management of MDR-TB instead of expanding the Durban TB hospital. His plans were also informed by the MDR-TB treatment models promoted by Partners in Health. Karen Wallengren, a WHO technical advisor working with Margot on MDR-TB and XDR-TB, helped design the decentralized, community-based MDR-TB program at the provincial level. She, in turn, sought advice from a friend and colleague who worked for Partners in Health in Peru.451

One of the four decentralized MDR-TB hospitals in the province was placed in the town of Greytown in Umzinyathi district, 45 kilometers (and 45 minutes drive) from Tugela Ferry. When the MDR-TB hospital in Greytown was opened in 2008, this meant that MDR-TB patients identified in Tugela Ferry could be treated more locally and no longer needed to travel to the overburdened hospital in Durban. They were admitted to the hospital in Greytown for initial medical stabilization and education on MDR-TB treatment and management. If they were well enough they were then sent home to be managed on an outpatient basis with regular visits from DOTS nurses as well as a community health worker. Once a week, the facility in Greytown hosted an outpatient MDR-TB clinic where nurses and physicians monitored the progress of MDR-TB patients living in Umzinyathi on a

King George V hospital in Durban continued to be responsible for caring for XDR-TB patients who required hospitalization, though Greytown could house XDR-TB patients for brief periods of time, as well.

Even as more decentralized structures for managing MDR-TB and worse drug-resistant tuberculosis were put in place the treatment of XDR-TB remained extremely difficult. Activists and physicians had successfully advocated for the introduction of third-line drugs to treat XDR-TB, including capreomycin and PAS, and they were available at King George V hospital in Durban by December 2006. But XDR-TB treatment requires patients to take these medications that have significant potential side-effects for several years, and even then a cure is not guaranteed. Known possible adverse effects from these drugs include loss of hearing, loss of normal vision, serious psychiatric effects, and fatal electrolyte disturbances. Furthermore, even as Tugela Ferry and the district of Umzinyathi reorganized their TB treatment structures and improved their methods for reaching patients in their own homes, King George V hospital in Durban had a much weaker outpatient and community presence and struggled to keep patients in care once they left the four walls of the hospital.

Indeed, it appears that Umzinyathi’s tuberculosis program specifically benefitted from administrators, researchers and clinicians who understood how to capitalize on the spotlight that had been focused on them and Tugela Ferry’s XDR-TB “outbreak.” According to Fikile Ngema the attention towards XDR-TB and MDR-TB helped Msinga sub-district and Umzinyathi district strengthen many aspects of its overall TB program (for all kinds of tuberculosis). At the onset this required proactive reshuffling of the government district’s resources and the willingness to work closely with outside partners. “We tried to reorganize ourselves, using available resources. [...] We had to take stock of the vehicles that were”

---

available, and identify those that [could] be dedicated to tracer teams.” The district also allowed the Church of Scotland Hospital to redistribute existing posts in order to address the tuberculosis problem, and to let the hospital advertise posts that hadn't been filled due to budget constraints. “We allowed them to overspend. [...] We had to write some motivations to say ‘we are going to overspend, because of this.’” Ngema also claimed that many of these efforts originated in her administrative district, not in the province or at the national level. She argued that by the time the province of KwaZulu-Natal made funds available to districts to hire additional TB coordinators, for example, the Umzinyathi district already had those people in place.

Marian Loveday, a researcher who studied the establishment of decentralized treatment programs for MDR-TB across the province of KwaZulu-Natal, confirmed that Umzinyathi’s district leadership seemed particularly proactive and effective. When Umzinyathi started offering treatment for MDR-TB at Greytown hospital in 2008, for example, the district procured audiology equipment in order to monitor the adverse effects MDR-TB drugs could have on patients’ hearing. By the time the province offered funding to its decentralized MDR-TB programs with which to buy such equipment, Umzinyathi’s machine was already in place. At the same time, Loveday and most other sources acknowledged that Bruce Margot’s provincial TB office was very supportive and actively funneled resources and personnel to TB programs in distress when they were brought to his attention. Intriguingly, despite the XDR-TB outbreak in Umzinyathi, the Umzinyathi district was one of the better performing districts in the province in terms of TB program indicators.

Mr. Human, the CEO of Tugela Ferry's Church of Scotland Hospital, credited Dr. Moll’s leadership, in particular, with the hospital’s success in uncovering and responding to its drug-resistant tuberculosis problem, and for embracing the opportunities that were provided by “his friends from America.”\textsuperscript{455} He counted Dr. Moll as one of a larger group of people who were crucial, however, including his colleague Dr. van der Merwe, “people from the district,” and Bruce Margot from the provincial head office of the department of health. Human saw himself as the man who passed the “wish-list” to the higher-ups, asking for more staff, more vehicles and a bigger budget, while Dr. Moll provided plans, results, and projections which motivated further projects and actions. From Human’s perspective his hospital’s involvement in research allowed Dr. Moll, and with him the administrative district of Umzinyathi, to be at the leading edge of tuberculosis research and policy, having a say in new global policy development, and influencing decisions about new laboratory technology.\textsuperscript{456}

\textbf{Why Tugela Ferry?}

Earlier in this chapter I stated that the response to the high rates of MDR-TB and XDR-TB in Tugela Ferry took place in the context of many open questions concerning the causes, extent, and lethality of the discovered epidemic. Why did XDR-TB come to Tugela Ferry, and how bad was it? As Dr. Moll recounted later: “we felt we were looking through a keyhole and we were seeing just a little bit of the province through the keyhole but having no clue what was happening in the rest of the province. [...] That was the question on the table. And there was no quick way of answering it.”\textsuperscript{457} We have seen that WHO and CDC experts were as uncertain about the answer to this question as the clinicians in Tugela Ferry. Public health experts in the South African department of health, in academia, and in

\textsuperscript{455} Human, interview by author, 2011.
\textsuperscript{456} \textit{Ibid.}
\textsuperscript{457} Moll, interview by author, 2007.
public policy circles across the world clamored for more epidemiological data. The first expert consultation on XDR-TB in South Africa in September in 2006 focused heavily on the lack of diagnostic capacity for drug-resistant tuberculosis in Africa, “because you could be sitting on a time bomb and you don’t even know.”\(^{458}\) Put in the context of the existing WHO recommendations it dawned on global TB experts that “we were so busy watching smear positive [drug-susceptible] TB that no one was watching what was going on with MDR and XDR. [...] It was quite an hysterical conference.”\(^{459}\)

XDR-TB in Tugela Ferry did not arise in a total data vacuum, however. Laboratories in Durban had been conducting TB drug-susceptibility tests on various kinds of samples and collecting the data in dispersed databases and files during the decade preceding the discovery of the XDR-TB despite WHO guidelines that recommended against it. There was no single source that could provide the answer to the origins of XDR-TB in Tugela Ferry or project its future, but it seemed that the information might not be completely elusive.

At the time when international alarm about XDR-TB was at its peak, the WHO offered to provide technical assistance to South Africa around XDR-TB. The provincial TB manager in KwaZulu-Natal requested someone who could help him assemble the disparate data on drug-resistant tuberculosis that existed across the province and conduct a “situational analysis” of the origins and causes of XDR-TB in Tugela Ferry. (South Africa was apparently more open to take up such an offer from the WHO than from the American CDC.) Understanding the root causes and progression of XDR-TB in the province could potentially direct the department of health towards reasonable solutions. According to another observer an additional, important effect of requesting this help was the fact that a WHO presence in KwaZulu-Natal was mirrored by the placement of a WHO representative in the

\(^{458}\) Margot, interview by author, 2010.  
\(^{459}\) Ibid.
national TB program office. This encouraged increased communication and accountability between provincial and national departments. It also kept the WHO involved with South Africa's attempts to address the XDR-TB problem, so the WHO could not argue that South Africa’s problems were due to the country’s resistance to expertise.

Kristina Wallengren, a Harvard-trained public health specialist from Sweden, was hired by the WHO as the technical expert to assist the KwaZulu-Natal TB program in its analysis of the XDR-TB outbreak in Tugela Ferry and KwaZulu-Natal. She was given the task of collecting, compiling and cleaning data on drug-resistant tuberculosis from disparate excel sheets, clinical databases, and laboratory computers in numerous locations across the province. None of them had been designed to provide information in a format that made sense for this project. Wallengren started her work in 2006, and due to the dispersed data it took her over a year to complete the analysis. The results of her study were only published in abbreviated form several years after that, though she presented her work in various forms at conferences and meetings. Publication was initially delayed because the South African department of health was not entirely comfortable sharing the results publicly; later scientific journals were perhaps not as interested in such a report as they might have been closer to the original report of the outbreak.

There were many theories in circulation in South African and international scientific and lay circles regarding the causes of the XDR-TB outbreak in Tugela Ferry. One theory that I encountered frequently was that the long-term mismanagement of MDR-TB patients at King George V hospital in Durban had caused XDR-TB to arise in a patient in Durban, who later was released from hospital and returned home to Msinga, causing an outbreak there.

---

460 Margot, interview by author, 2010; Wallengren, interview by author, 2010.
No specific “patient zero” who had spread the disease in this way was ever identified, however, and molecular and epidemiological data showed that the extent of XDR-TB in Tugela Ferry could not be fully explained by such a mechanism.

Another common theory, especially among nurses and other hospital staff members in Tugela Ferry, was that the extent of XDR-TB in the Msinga region was a direct result of poverty and lack of education. The argument played out in two different ways. Firstly, some argued that poverty, poor nutrition, overcrowding, and a lack of education regarding health risks made the population of Msinga fundamentally susceptible to infectious diseases like XDR-TB. This is in keeping with conventional readings of tuberculosis as a fundamentally social disease. The second version of this argument was less conventional. Some hospital staff essentially argued that they did not believe that Tugela Ferry had more XDR-TB cases than anywhere else, but that the poverty and lack of education in the district prevented individuals from keeping their illness a secret by keeping up the appearances of health through increased nutrition and expensive clothing. One person also argued that wealthier South Africans escaped being captured by government statistics because they avoided public hospitals and sought treatment from private doctors, while poor patients like those who lived in Msinga showed up in the numbers. This argument did not mesh with the epidemiological evidence available. However, this view effectively pointed out that the experiences of illness and the options for projecting an image of well-being in South Africa were profoundly different depending on the means of the sick persons and their families.

Several laboratory-based tuberculosis experts in South Africa, including Professor Sturm at the University of KwaZulu-Natal, blamed the WHO's TB-related policy
recommendations from the 1990s for the rise of XDR-TB in KwaZulu-Natal.\textsuperscript{463} Before DOTS was introduced to the South African public health system in 1996, each province had its own tuberculosis treatment policies. Tuberculosis physicians in KwaZulu-Natal could use TB drug sensitivity testing (DST) to help guide treatment decisions, even in first-time TB patients. The 1996 national TB policy eliminated routine drug sensitivity screening and introduced standardized first-time treatment regimens for all tuberculosis patients. KwaZulu-Natal effectively ignored this new policy and continued to provide DST until 2001, when KwaZulu-Natal aligned its practices with the rest of the country. Prof. Sturm (whose laboratory performed DST for much of the province) has argued that it was this switch that allowed XDR-TB to rise unhindered.

Several tuberculosis researchers in Cape Town and Stellenbosch also argued that the cause for the rise of MDR and XDR-TB in South Africa was primarily programmatic. For example, Robert Warren and his research group used molecular and genetic studies to argue that the standardized sequence of anti-tuberculosis drugs followed by the South African TB program led to the amplification of a particular resistance-favoring mutation among South African patients.\textsuperscript{464} His team also believed that the standardized TB treatment program did not sufficiently distinguish between “retreatment” patients who had been infected multiple times (by different strains of TB) and patients who had never cleared their previous TB infection.\textsuperscript{465} Karen Shean, a nurse who had worked on drug-resistant tuberculosis government TB programs in the Western and Eastern Cape and later for several research projects (including a collaboration with the American CDC to assess MDR-

TB in parts of South Africa) argued that imperfect treatment programs that lacked a strategy to deal with treatment defaulters led to increases in levels of drug-resistance.\(^{466}\) In addition she saw that South African MDR-TB treatment staff were increasingly overwhelmed by the burden of increasing numbers of patients. “DOTS is only as good as the clinic you start in. Because if you don’t have motivated staff that are actually going to make it work, forget it. […] You got nurses that are completely overwhelmed by HIV, by the primary health care they have to do. […] We know that nurses’ attitudes have a lot to do with defaulting.”\(^{467}\) Difficult conditions also led to high turnover of new physicians who were not sufficiently familiar with the side-effects of the drugs they were prescribing.\(^{468}\)

Finally, one Durban based physician I spoke to blamed the outbreak of XDR-TB in Tugela Ferry on a combination of backwards, though compassionate, rural doctors and the dangerous mixing of HIV and TB patients caused by the American HIV/TB treatment intervention. Based on circulating theories, rumors, and hallway conversations with people who had seen provincial data (but not first-hand information), this person argued that Tugela Ferry had a poor tuberculosis program to begin with, which was exacerbated by “very caring” Christian physicians who admitted everyone to the hospital who was very sick. Patients with AIDS, many of whom had severe diarrhea, were treated with fluoroquinolones (a type of antibiotic) in an attempt to get the diarrhea under control. In his theory, this exposure to fluoroquinolones could have caused patients who also had tuberculosis to develop tuberculosis that was resistant to fluoroquinolones (a drug also used to treat MDR-TB). The final factor that was rumored to have caused high rates of XDR-TB, however, was the fact the Yale/Philanjalo HIV/TB cotreatment program put people with


\(^{467}\) Karen Shean, interview by author, 7 May 2010, Cape Town, South Africa.

\(^{468}\) Ibid.
tuberculosis and AIDS in close proximity with each other, without putting in place appropriate infection control measures. This way, he argued, what may have started as a single case of XDR-TB could easily spread to a cohort of immune-suppressed people.

Kristina Wallengren’s official situational analysis of MDR-TB and XDR-TB in KwaZulu-Natal was not immediately published, yet the results of the study circulated, both as formal presentations at TB meetings and conferences, as well as through one-on-one conversations. Her full, unpublished report more diplomatically confirmed some of the above source’s impressions. Wallengren concluded that while XDR-TB was present in small numbers throughout the province of KwaZulu-Natal, large numbers were mostly limited to Umzinyathi (the district which includes the Msinga subdistrict). In her analysis, the spread of XDR-TB through the province had not (up to that point) been facilitated by patients who had stayed at King George V hospital in Durban for their tuberculosis treatment.469

Wallengren noted that the Church of Scotland Hospital in Tugela Ferry had cared for HIV patients with enthusiasm and commitment and had admitted these patients to the hospital on a regular basis even before antiretroviral therapy was available. She compared this practice to other institutions around the province, whose HIV clinics “were rather half hearted efforts [where] HIV patients were treated as outpatients.”470 Her report noted that it was common at the Church of Scotland Hospital to use a two-week course of ciprofloxacin (a fluoroquinolone471) to treat HIV patients who had diarrhea. She also pointed out the hospital’s proactive efforts in integrating HIV and TB care and in educating HIV and TB patients about antiretrovirals prior to the public rollout of antiretroviral drugs.

Interestingly, she did not explicitly mention the Yale/Philanjalo treatment study that was

471 Fluoroquinolones are a class of drugs which is used to treat MDR-TB.
the reason Tugela Ferry was engaged in TB/HIV integration and antiretroviral education. Wallengren emphasized that tuberculosis infection control measures remained very poor in most of the province even after the XDR-TB scare.\footnote{Kristina Wallengren, \textit{Tuberculosis Drug-Resistance in KwaZulu-Natal Situational Analysis}, May 7, 2008.}

Wallengren was also able to exclude several theories why XDR-TB had become such a problem in Tugela Ferry. She pointed out that HIV rates in Umzinyathi district are not higher than elsewhere in the province; that the poor performance of the TB program was not to blame (compared to other districts), though the provision of six months of TB treatment at a time may have been a problem. She did point out that no matter how XDR-TB first took hold at in Tugela Ferry, “mixing the susceptible HIV population with infectious TB cases transpired to be very efficient at COSH [Church of Scotland Hospital]. Mixing occurred in congregate settings such as hospital wards, HIV literacy classes and waiting rooms. A higher throughput of HIV and TB patients in these settings occurred at COSH due to HIV patients being hospitalised more frequently (compared to treated as out-patients in other settings), COSH made particular efforts to integrate TB and HIV programmes (compared to poor programme integration elsewhere), and the practice of HIV literacy classes prior to the ARV rollout (compared to no pre-ARV training). Due to non-existent infection control for TB, these well intended efforts may have created the conditions suitable for an epidemic to expand.”\footnote{Kristina Wallengren, \textit{Tuberculosis Drug-Resistance in KwaZulu-Natal Situational Analysis}, May 7, 2008, 27.}

Though Wallengren was very careful not to lay blame on the clinicians and researchers in Tugela Ferry when she gave public presentations at TB conferences, her report implicitly concludes that some of the very conditions that made Tugela Ferry an appealing place for Dr. Friedland to attempt his HIV/TB cotreatment study (in particular the
enthusiasm and commitment on the part of physicians and nurses in treating HIV), as well as his cotreatment study itself, appear to have inadvertently created a fertile ground for XDR-TB in Tugela Ferry. This was not the dominant narrative in the world of tuberculosis experts, however. Overall the research and treatment work conducted in Tugela Ferry is much admired and outsiders are impressed with the interventions put in place once MDR-TB and XDR-TB in Tugela Ferry were discovered.

Medical personnel at the Church of Scotland Hospital and their international collaborators led the charge in responding to XDR-TB in Tugela Ferry. American physician-researcher Dr. James Brust, who is based at Albert Einstein College of Medicine and worked together with Dr. Neel Gandhi (who himself worked with Dr. Gerald Friedland) listed on his website that he “designed and implemented a novel, home-based treatment program for patients co-infected with HIV and MDR TB” in rural KwaZulu-Natal, South Africa.\(^{474}\) Sarita Shah, who was hired by Einstein College of Medicine and began to research MDR-TB and XDR-TB in Tugela Ferry after she left the CDC, used the pronoun “we” when describing the improvements in the MDR-TB program in Umzinyathi in an interview in 2010: “The other thing we’ve done in KwaZulu-Natal is, in the district where Tugela Ferry is located, we’re treating MDR patients in their community, at their homes.”\(^{475}\) But it was department of health employees at the clinic, hospital, district, provincial and eventually national level who enacted, institutionalized and to a large extent funded improvements to the tuberculosis program in Tugela Ferry and beyond. Others can also take partial credit for the development of the decentralized, community-based management of MDR-TB in the


province, including WHO consultants and advisors from other countries’ TB programs who provided and sought expertise. Government officials did not simply enact outside recommendations (which were inconsistent), but took their own initiative and heavily influenced the possibilities available to researchers and clinicians. In the following section I look more closely at an event that illustrates how government offices attempted to simultaneously engage in international research partnership and demonstrate the independence and authority of the local public health system: the placement of an MDR-TB hospital and clinic in Greytown.

**From Tugela Ferry to Greytown and back**

The enmeshed relationship between government public health programs, research, and clinical practice around MDR-TB in South Africa was strikingly demonstrated to me soon after I moved to Tugela Ferry to conduct fieldwork. On a Wednesday morning I accompanied two doctors – one a government physician at the Church of Scotland Hospital, one a physician hired by Philanjalo to live in Tugela Ferry take care of patients at Philanjalo's hospice as well as to help with MDR-TB related research projects – on their weekly trip to the MDR-TB clinic at the Greytown MDR-TB hospital. We met at the front gate of the Church of Scotland Hospital and made our way to Greytown, a 45 minute drive towards the southern boundary of the Umzinyathi district, in a department of health vehicle. That first week I rode in the back of the car contemplating the view as it transitioned from the dry, rocky, desolate landscape of Msinga to the fertile agricultural land of Greytown. The doctors up front talked about the happenings of the week and discussed recently admitted MDR-TB patients they were worried about.

When we arrived at the MDR-TB hospital and adjoining clinic in Greytown we were greeted by two Greytown-based department of health nurses who provided the list of patients to be seen for the day. Some patients had already arrived for the MDR-TB clinic and
were forming lines to see an adherence counselor, to get blood drawn by a nurse, to get X-rays, to give sputum (assisted by a physical therapist) and to have their hearing evaluated by an audiologist. In addition the patients were waiting to being seen by a doctor and receive the next month’s medications from the pharmacist.

At the clinic the two doctors I had come with were joined by two more physicians, one of whom was another government physician from Tugela Ferry (who had come in his own vehicle), and the other was a government physician who worked at the main hospital in Greytown in addition to overseeing the medical care at the MDR-TB hospital. (In other weeks a young visiting American physician might also join the fray.) The Greytown-based doctor was the most recent addition to the team; until recently all of the doctors had commuted in from Tugela Ferry. The four doctors got to work in a single, moderately-sized room with one exam table and four desks, at which the doctors sat and saw patients. In addition to the four doctors (who were all over 45; 2 white males, 1 white female and one black male) there were several young black Zulu women sitting at tables and moving about the room carrying stacks of files and paperwork. As I learned later, these women were research assistants hired for the US-based research project evaluating the outcomes of community-based treatment of MDR-TB in Msinga. They sat with the doctors filling out forms that documented the clinical encounters taking place. They also translated between Zulu and English when this was needed. At the end of each encounter they would point out parts of the form that still needed to be completed and hand them to the physician to quickly finish. These research assistants, like the doctors, had traveled from Tugela Ferry to Greytown. They had traveled in a Philanjalo-funded vehicle together with a Philanjalo-funded nurse who was also worked for the American study. The researchers were in Greytown to make sure that the visits of patients enrolled in a study assessing MDR-TB treatment outcomes in Msinga were properly conducted and documented. They were also
engaged in many other activities that day (and throughout the week) that helped clinic run smoothly.

In Greytown, MDR-TB patients from all four subdistricts of Umzinyathi were evaluated and placed onto treatment. The majority of patients who were seen at the outpatient clinic in Greytown each week, however, were from Msinga (one of those subdistricts). Every week, dozens of MDR-TB patients assembled at the Church of Scotland Hospital in Tugela Ferry, Msinga in the early morning to be transported to the Greytown MDR-TB hospital in a department of health vehicle (usual a bus or minivan), accompanied by a driver and a nurse who worked for the TB-DOTS office in Tugela Ferry. This particular transport was easily recognizable when it left Tugela Ferry by the fact that all the patients in the bus as well as the driver wore masks for the trip.

I found it somehow comical that physicians, nurses, researchers and most of the patients all traveled (in separate vehicles) from Tugela Ferry to Greytown in the morning and all had to travel back again in the afternoon. This seemed like a highly inefficient way of dealing with a problem that was well known to be most severe in Tugela Ferry and the surrounding region of Msinga. Even for the Umzinyathi district as a whole, Greytown was not the most logical geographical location for the MDR-TB clinic and hospital, since Tugela Ferry is more central to the whole district than Greytown, and patients from another hospital had to pass through Tugela Ferry to get to Greytown. Despite the fact that not everyone came from Tugela Ferry – the Greytown hospital provided nurses, pharmacists, an adherence counselor, an X-ray technician, a physiotherapist and a data capturer, for example – these circumstances demanded an explanation.

When I asked why Greytown was selected as the location for the MDR-TB clinic and hospital most people simply pointed out that Greytown had a suitable building readily

---

476 During part of my research the audiologist also made this trip.
available, while Tugela Ferry did not. As a result of South Africa’s apartheid past, Greytown had a government-owned hospital building that was underutilized and could be repurposed as the MDR-TB hospital. The structure that is now the MDR-TB hospital used to be Greytown’s “white” hospital during apartheid, when health services, like everything else, were segregated by race, even in small towns like Greytown. (As a Zulu friend from Durban once said to me: “I hear that Greytown is so small, that you can easily walk from the [black] location into [white] town.”) After 1994, hospital services in Greytown for all people were moved to the formerly “black” hospital. For a while, private physicians in Greytown still used the white hospital as a sort of semi-private hospital that they could admit their patients to directly (thus partially replicating apartheid divisions by race and income).

Given the facility’s ambiguous status, both the province and the district were happy to repurpose the property as an MDR-TB hospital.477

Yet, according to some sources the availability of underutilized space was not the only issue. Rather, Greytown was consciously selected as a location that was relatively close to Tugela Ferry and the majority of patients in KwaZulu-Natal who required MDR-TB treatment, but not in Tugela Ferry. Tugela Ferry had become closely associated with XDR-TB in international public health circles, and the research that took place in Tugela Ferry had played a significant role both in ensuring that HIV and TB would be treated in Msinga, as well as in uncovering a devastating epidemic of drug-resistant tuberculosis. As the research in Tugela Ferry expanded, however, some people in the department of health felt that the department had lost control of hospital activities and the use of resources in Tugela Ferry. American researchers had brought significant attention to Tugela Ferry, much of which was negative – putting department of health officials in a difficult position. The researchers’ propensity to presenting and promoting their work also had the potential of

477 Mndebele, interview by author, 2011; Margot, interview by author, 2010.
creating momentum for interventions that the department of health could not control. As importantly, however, Americans had used South African resources and samples to collect the data they needed to conduct their research – research that was used to a large extent to boost American careers. As one source put it: “All these Americans using South African money to conduct their research. Order this test, that test, the next test. It’s the only way I’m maintaining some control. So [moving MDR-TB treatment to Greytown] was a political decision.” Wallengren’s analysis of the events leading up to the rise of XDR-TB in Tugela Ferry (which partially implicated the HIV/TB research efforts) also may have motivated attempts to reduce the American research influence on MDR-TB and XDR-TB care in Tugela Ferry.

For the most part, however, this resistance to American research influence was not overt – only one person I interviewed brought up the issue of excessive influence of American researchers and their potentially inappropriate use of South African resources unprompted. Others carefully assented that this was a concern when I brought it up, and still others explicitly stated that they disagreed with the notion that the international researchers were a nuisance or potentially exploitative, and affirmed that as a rule American researchers and clinicians have been helpful and a wonderful asset.

Not only South African versus international dynamics were at play. I believe the placement of the MDR-TB hospital in Greytown could also be interpreted as a way of a post-apartheid bureaucracy resisting the idiosyncratic methods of the three long-time, white, Afrikaans-speaking physicians working in Tugela Ferry. Dr. Moll, Dr. van der Merwe and their equally passionate colleague Dr. Eksteen were driven by compassion and missionary zeal (like many rural doctors in South Africa) and they often felt justified in using unorthodox treatment strategies if they were convinced that their patients would benefit. They were highly valued by the community in Tugela Ferry. But they were also well known
by the department of health and by their colleagues for their independent streaks that allowed them to follow their convictions rather than department of health policy. This was demonstrated both by their refusal to allow abortions to be performed by anyone at the Church of Scotland Hospital (despite the fact that they are legal in South Africa), as well as their early, inspirational work in the field of HIV in the face of department of health reluctance. We have seen that the doctors in Tugela Ferry admitted AIDS patients who were very ill, and aggressively treated their diarrhea with ciprofloxacin (a fluoroquinolone) – a relatively expensive drug used in South Africa primarily for the treatment of sexually transmitted infections.

Tugela Ferry’s physicians’ independence expressed itself in the sometimes-idiosyncratic – though not incorrect – ways they prescribed tuberculosis treatment, as well. Confronted with a high percentage of MDR-TB cases the doctors in Tugela Ferry were sometimes willing to treat patients for MDR-TB empirically when they suspected that a patient was not responding to treatment, even if they did not have a definitive laboratory confirmation of the diagnosis. They did this despite the potentially severe side effects of MDR-TB medications. They also modified standardized treatment regimens according to their own individual (though well-informed) judgment. The physicians’ willingness to overrule guidelines could frustrate administrators, protocol-bound nurses and protocol-

---


480 The potential danger of empirical treatment became clear to me when I encountered Z, a patient who had symptoms consistent with tuberculosis but had not responded well to first-line anti-tuberculosis drugs. His TB sputum test had been inconclusive. When I met him he was in the process of being evaluated to start MDR-TB treatment. What he had not told the doctors in Tugela Ferry, however, was that a private doctor in another town had (correctly) diagnosed him with lymphoma (one of several diseases that can sometimes be mistaken for tuberculosis). In Tugela Ferry it makes sense to first think TB (a common, treatable disease) before thinking lymphoma. But MDR-TB treatment was not likely to help this particular patient.
loving researchers alike. Department of health officials may have been trying to rein in some of these practices even as they desperately relied on those passionate physicians to see MDR-TB patients and provide their expertise.

Considering that physicians from Tugela Ferry still traveled to Greytown every week to see their MDR-TB patients, and that American researchers still had studies running through the Greytown clinic and hospital, the attempt to remove MDR-TB from Tugela Ferry's influence clearly did not succeed. Doctors and researchers working in Tugela Ferry instead became mobile and traveled with their patients to the new treatment location. American researchers and their South African employees continued to document the outcomes of the MDR-TB patients treated through the program in Umzinyathi. This happened in part because the department of health was initially unable to find a physician to staff the MDR-TB hospital, and because physicians from Tugela Ferry – very experienced with MDR-TB by 2008 – took an interest in ensuring that their patients from Tugela Ferry were taken care of. Physicians, nurses and researchers from Tugela Ferry worked together with the full-time nurses at the Greytown MDR-TB hospital and department of health officials to put together a functioning MDR-TB treatment program, and American researchers documented the outcomes of this program, as it related to patients from Tugela Ferry, in particular. The extra research staff funded by American research grants helped make sure that the MDR-TB clinic ran smoothly, and that people from Msinga made it to Greytown each week for care. The main nurses in Greytown who were in charge of the clinic clearly enjoyed the interaction with the Tugela Ferry-based clinicians who were passionate about their tuberculosis subject-matter, and they engaged with enthusiasm with the
researchers. Yet one Pietermaritzburg-based observer remained wary and noted: "things have gone so wrong up there, that department needs to monitor things quite carefully."\textsuperscript{481}

**The presence and absence of government in global health – a South African perspective**

I argued earlier that government involvement in the management of XDR-TB in Tugela Ferry ended up being greater than I might have anticipated. This statement reflects my own experiences and the biases that I developed over the course of a decade of engaging with global HIV/AIDS activism, research and clinical care. At the start of this project my own expectations for the South African government's pro-active involvement in the expansion of tuberculosis programs in KwaZulu-Natal were low. My impression of South African government action on matters of deadly infectious diseases had been formed during the presidency of Thabo Mbeki, who openly doubted that HIV caused AIDS and, together with his Minister of Health Manto Tshabalala-Msimang had actively and vocally resisted providing effective treatment for HIV/AIDS in public hospitals. The early HIV programs that I witnessed as an AIDS activists and HIV laboratory scientist in South Africa between 2002 and 2004 relied heavily on funding that did not come from the South African government, and were in some cases actively hindered by high-level government action.

News reports in 2006 and 2007 that the South African government was not sufficiently paying attention to drug-resistant tuberculosis were consistent with this narrative. South African scientists and physicians themselves seemed surprised that the South African government eventually took ownership of MDR-TB and XDR-TB as health problems it needed to address. Interviews I conducted with South African researchers in 2007 and 2010 reveal a noticeable shift in their stances regarding what they could expect from the South African Department of Health.

\textsuperscript{481} Loveday, interview by author, 2010.
Another reason I was surprised by the degree of South African government involvement in addressing XDR-TB was that I had an incomplete idea about what global health research programs “do.” My experience in early HIV treatment research in South Africa led me to conclude that in order to do responsible and publishable research as part of a global health project most of the resources used – both for the intervention being studied, and for the study itself – would have to come from external grant funding. Possible funding sources included entities like the National Institutes of Health (NIH) or the Doris Duke Foundation, the Global Fund to Fight AIDS, Malaria, and Tuberculosis (“Global Fund”), the Presidential Emergency Plan for AIDS Relief (PEPFAR), the US Agency for International Development (USAID) or the Bill and Melinda Gates foundation. Early international HIV treatment research programs not only provided expensive HIV medications (antiretrovirals), but had to put in place all the structures of HIV care: laboratories that could perform diagnostic testing and monitoring, clinicians who were comfortable administering HIV medications, educational materials for patients and nurses, and statistical documentation capacities.

In some international HIV treatment projects, research was a sub-component of a humanitarian intervention. When the organization Doctors without Borders (MSF) started their HIV treatment program in Khayelitsha, outside Cape Town, for example, the primary objectives were humanitarian and political, but the organization documented outcomes and published the results in respected biomedical journals. For other HIV projects,

---


research was the primary reason for putting in place clinical, laboratory, and HIV treatment structures and the fact that people gained new access to life-saving drugs was a humanitarian bonus that could be used to help justify the research.\textsuperscript{484} Finally, there were HIV treatment projects that were designed as research, but whose investigators had consciously set up their programs so that they could access research funds to provide expensive, life-saving HIV drugs to people who would not have had HIV treatment otherwise.\textsuperscript{485} Some of this research was also consciously used to support pro-treatment arguments in the ongoing debates around the feasibility of HIV treatment in Africa.

The question of how people access care for a life-threatening or chronic illness in the setting of insufficient financial resources and an \textit{essentially absent state} has occupied many medical anthropologists in the past decade, especially in the context of HIV/AIDS in Africa. Vinh-Kim Nguyen, Joao Biehl, Susan Reynolds-Whyte, Hansjörg Dilger and Ippolitos Kalofonos have documented how non-governmental organizations (both local and international) and faith based organizations have found ways of assisting people in their time of existential medical need – some more effectively than others.\textsuperscript{486} Access to support requires a declaration of belonging, however. Nguyen uses the concept of “therapeutic citizenship” to describe the ways some HIV positive individuals were able to trade their ability to openly “disclose” their HIV positive status for access to medical care and jobs with

\textsuperscript{484} Much of the research I was engaged in while working in Sharon Cassol’s molecular virology laboratory at the Africa Centre belonged in this category. See, for example, the following studies: Edana Cassol et al., “Therapeutic Response of HIV-1 Subtype C in African Patients Coinfected with Either Mycobacterium Tuberculosis or Human Herpesvirus-8,” \textit{The Journal of Infectious Diseases} 191, no. 3 (2005): 324–332; Anisa Mosam et al., “Generic Antiretroviral Efficacy in AIDS-associated Kaposi’s Sarcoma in sub-Saharan Africa,” \textit{AIDS} 19, no. 4 (2005): 441–443.

\textsuperscript{485} Dr. Friedland and Dr. Moll’s HIV/TB cotreatment study in Tugela Ferry appears to belong in this category.

AIDS NGOs. In the rather different setting of Ukraine after the nuclear power plant accident in Chernobyl, Adriana Petryna shows that identifying as a Chernobyl sufferer brought with it the ability to claim support from the Ukrainian state – also often facilitated by NGOs – at a time when the state was unable to fulfill its broader obligations toward its citizens.487

In Tugela Ferry in the 1990s and early 2000s clinical research and non-governmental organizations did indeed play an important role in filling the large gaps left by a state which had not managed to provide well for its poor citizens, and which ignored the pressing needs of HIV positive individuals. When the Yale/Philanjalo research collaboration on HIV/TB (Sizonqoba) started in 2002/2003, this carefully monitored and documented treatment intervention with a total study population of 125 people – described by Friedland as “operational research” – was the only way to access HIV treatment in Msinga. The uncertainty being studied was not a new drug with incompletely known properties, but instead lay in the operational possibilities of using a particular protocol to successfully treat a particular set of comorbidities (TB and HIV) in a particular location (Msinga).

Not all global health research takes place in the absence of appropriate state-sponsored care, however. By the time Dr. Friedland’s research group uncovered XDR-TB in 2005 the participation in research was no longer a condition of survival for HIV positive people in Msinga. The South African state had started funding HIV medication and rolling it out to its citizens in 2004. Meanwhile, research on tuberculosis in South Africa, unlike early research on HIV and AIDS, plugged into pre-existing, nurse-driven tuberculosis program structures that were maintained by the South African department of health and supported by organizations like the South African Medical Research Council and Health Systems Trust.

The government had been providing free treatment for tuberculosis – including multi-drug resistant tuberculosis – since the 1990s. Though the quality of TB program was highly variable, and often poor, the DOTS office in Msinga – like DOTS offices in many districts in KwaZulu-Natal – provided free anti-TB drugs, basic TB diagnostic testing on site, drug-resistance testing via a laboratory in Durban, and the ability to refer drug-resistant tuberculosis cases to King George V hospital in Durban, “only” 2.5 hours drive away. Many components of tuberculosis programs were weak, and researchers studying them supplemented staffing and provided resources that improved program quality and the ability to document outcomes. Unlike research on HIV, however, tuberculosis research did not involve putting in place the entire TB program, including TB drugs, TB clinic staff and TB laboratory services and providing the funding for it.

When Dr. Moll and Dr. Friedland designed their study of the co-treatment of HIV and TB in Tugela Ferry they designed the HIV treatment component from scratch. The tuberculosis treatment component of the study, however, was adapted to existing tuberculosis treatment structures and employed existing treatment regimens and diagnostic laboratory protocols that were paid for and regulated by the government health system. Thus it would be difficult to argue that international TB research in Tugela Ferry stepped into a true absence of care and treatment. Yet it was through the act of careful looking and documenting of TB outcomes that international HIV/TB researchers “discovered” XDR-TB – or rather, made XDR-TB visible, and with that also revealed a dangerous gap in government-sponsored health care demanding a response.

**From worst-case scenario to best practice**

By the time I moved to Tugela Ferry in 2011 the town was making the transition from being internationally known as the site of the worst-case scenario for drug-resistant tuberculosis to being seen as the site of a best-practice model for combatting MDR-TB and
XDR-TB in a patient-centered, effective manner. Rates of new XDR-TB cases in Msinga had fallen significantly – so much so that one American research study evaluating XDR-TB transmission in Msinga had to expand its catchment area to the entire province of KwaZulu-Natal in order to capture the required number of study patients. Dr. Moll, who had facilitated the research on MDR-TB and XDR-TB in Tugela Ferry, felt that it was time to “shift from that sort of hard-core research to the next phase, which will be technical assistance to the rest of the country in terms of establishing MDR best practices in terms of community management of MDR-TB.” In fact, in 2011 Philanjalo had received a grant with which to set up a center of excellence for MDR-TB treatment and promote the community-based model around the country, including in skeptical provinces and districts.

Even as researchers and forward-thinking clinicians moved on, however, the everyday challenge of managing a staggering number of MDR-TB patients in Umzinyathi (and the province as a whole) remained. Nurses in the TB-DOTS office in Tugela Ferry, together with doctors and other staff at the hospital, under the direction of the local department of health had to find ways to cope with a new category of patient which had unexpectedly been uncovered and for whom an obvious plan of treatment had not yet been developed. Using the existing public health structure designed for regular tuberculosis patients, individuals with drug-resistant tuberculosis had to be identified, traced, referred, and treated, and their care needed to be documented. The following chapter focuses on the labor of the nurses and researchers whose daily job it was to engage in these tasks.
CHAPTER 5: Finding Data in a Global Landscape

The centerpiece of Tugela Ferry’s response to the high prevalence of drug-resistant tuberculosis was the decentralized, community-based (or home-based) treatment of MDR-TB.\textsuperscript{488} In this innovative and somewhat controversial program MDR-TB patients were only briefly hospitalized in Greytown (ideally two weeks or less, if stable) and they received most of their treatment (including injections) in their own homes. Tugela Ferry’s MDR-TB patients attended the MDR-TB clinic in Greytown only once a month to be evaluated and to receive the next month’s medication. During the initial intensive phase of treatment (usually the first six months) TB nurses visited patients in their homes every day to administer the injections that were part of MDR-TB treatment (in addition to pills) as well as to monitor potential side-effects and to provide treatment support. Additional support was provided by lay community health workers. XDR-TB patients were treated in a similar manner, though their hospitalizations took place in Durban and were often longer. As we have seen, this program was made possible in part by the fact that the province of KwaZulu-Natal opened a "decentralized" hospital and clinic for MDR-TB in Greytown, about 45 minutes drive from Tugela Ferry, so that patients with MDR-TB no longer had to be sent to Durban. In Greytown patients were seen by doctors, nurses, and research staff based in Tugela Ferry and Greytown. In addition, the number of staff in Tugela Ferry’s outpatient tuberculosis program was greatly expanded, and vehicles were procured so that nurses and other community outreach workers could reach tuberculosis patients in their homes throughout Msinga, the catchment area for the Church of Scotland Hospital in Tugela Ferry.

Researchers, government employees and clinicians began sharing news of this community-based model of care at scientific meetings and workshops not long after the

program was initiated. Tugela Ferry’s efforts to combat drug-resistant tuberculosis were also featured in news-articles and television documentaries, including a South African investigative reporting program and a documentary for BBC television. According to research presentations in 2010 and beyond the program was innovative; the rate of successful treatment outcomes was high; the risk of infection to family members was low; and the relationship between different levels of government of administration and researchers was productive.

A key feature in presentations both for the lay public and the scientific audience was the Msinga landscape. Conference presentations on MDR-TB and XDR-TB in Tugela Ferry almost always included compelling photographs of four-by-four vehicles negotiating rugged rural terrain. They featured striking views of ragged cliffs, traditional Zulu round houses with thatched or tin roofs, poor patients (sometimes in traditional attire), and uniformed nurses with syringes poised. Images of rural Msinga and its heroic healthworkers offered a picturesque backdrop for more focused discussions of treatment program outcomes, adverse event statistics, and infection control concerns. Yet the images and conditions of rural Msinga were not incidental to these discussions. Difficult terrain, resilient health care workers, and patients in difficult circumstances who needed to be met halfway helped conveyed the structural challenges of providing effective tuberculosis care in South Africa. They shaped the meaning and communicated the significance of work on drug-resistant tuberculosis for global public health and for biomedical science.

Other MDR-TB and XDR-TB treatment programs similarly employed visual evidence

---


to underline these challenges. At the South African TB conference in 2010 researchers
working for MSF (Doctors without Borders) in Khayelitsha – a large, black township outside
of Cape-Town known for tin shacks, bustling commerce, and high rates of crime – presented
a video of a young, outspoken community worker going from door to door, visiting grannies
in cramped, run-down shacks in order to convince them to keep taking their medicines. The
images from both urban and rural South Africa resonated with common tropes of “real
Africa,” which I will discuss later in this chapter. It was easy to imagine nurses and
community health workers suffering through adverse conditions in order to make a
personal connection with their poor, suffering patients.

This chapter deals with three types of activities: the work of providing community-
based MDR-TB treatment in Msinga, and the tasks of documenting and representing this
work. I consider the challenges of translating the repetitive and dull tasks of maintaining an
effective public health treatment program into exciting, publishable science and cutting-
edge global health. In the following sections I follow nurses as they go about their daily
business – signing out cars, driving up hillsides, finding patients at their houses, providing
injections and reporting back at the office any problems encountered. I watch doctors as
they see patient after patient, review X-ray after X-ray and prescribe similar treatment
courses for each. I also detail the ways research workers, data capturers and academics
capture this (everything but?) routine work and convert it into data. The nurses’ physical
environment, the landscape that surrounds them, and the hardships of their patients
necessarily shape their daily experience, in the same way, perhaps, that uncomfortable
office chairs and demanding clients impact an urban, office-based customer-service
representative. The landscape becomes an important actor in itself, however, when the
work is presented and explained to an outside audience. South African and American
representatives alike demonstrated a strong need to explain the location of Msinga in
addition to providing quantitative evidence for the needs and successes of MDR-TB treatment. This was particularly evident in less formal powerpoint presentations that could easily make use of photographs as well as in colorful publicity materials summarizing the research work being done in Tugela Ferry. But it was also apparent in formal, published scientific papers where stunning photographs were replaced with brief, elliptical descriptions (like “rural”) and laden words (like “traditional,” and “resource-poor”) that coded Msinga as a site of global health intervention.491 The core content of these papers, however, was based on a comprehensive accounting of patients’ treatment course, laboratory values, radiologic findings, and health status. Great effort was exerted to acquire this information. I argue that it is in part this combination of public health intervention, solid quantitative documentation and the context of an “othering” landscape that make the community-based treatment of MDR-TB in Tugela Ferry a model “global health” project.

Controlling an Epidemic with Paperwork

“We had a DOT [Directly Observed Tuberculosis Treatment] team in the hospital. In fact the DOT team was one professional nurse - a nursing sister - and a staff nurse. And at any one time they would be looking after about 700 TB patients in the community, right, but without wheels and basically just grounded in the hospital, using paper registers to try and control these patients coming in and out.”

- Dr. Moll (in 2007), speaking about tuberculosis treatment before 2005. 492


492 Anthony Moll, interview by author, 12 July 2007, Tugela Ferry, South Africa.
Before the discovery of XDR-TB in Tugela Ferry tuberculosis control was essentially “grounded in the hospital.” Dr. Moll’s quote above evokes the jarring – perhaps comical – image of two lonely nurses staving off a tide of infectious disease with paperwork. He elaborated: “Now these two ladies would be sitting in the office, basically, when a patient is diagnosed with TB in the hospital, whether from the wards or the outpatients department, they would go via the DOT office, be registered, their names would be filled in all the different stationary that’s used for TB. There’s a carrier card, there’s a register [...] The patients would be given brief health education, given their tablets and sent home with a come back date.”

By 2010, five years after the discovery of XDR-TB, Tugela Ferry's tuberculosis office’s ability to reach out to patients in the community and to follow-up their care through community workers, injection teams and tracer teams had expanded considerably. The TB office was still trying to fight tuberculosis with paperwork, however. During my fieldwork I spent many days sitting in the tuberculosis office observing tuberculosis management in action. Each morning, after injection nurses and tracers had left for their work in the surrounding area, two or three office-based nurses sat at a large table in the tuberculosis office, managing the flow of tuberculosis patients by writing on paper. As each patient came in the nurses started diligently writing down the patient’s information on the many documents required. Each person with drug-susceptible tuberculosis generated at least six hand-written entries (not including carbon copies) onto color coded cards, files, and registers.

The records produced in the TB office reflected – to varying degrees – the needs of clinical care, public health bureaucracy, funder reporting requirements and academic research. The centerpiece of official TB documentation was the tuberculosis register, which

---

493 Anthony Moll, interview by author, 12 July 2007, Tugela Ferry, South Africa.
was required by the South African tuberculosis program. It is a long booklet (that opens up to about a meter in length) that lists every tuberculosis patient (ten per page) and captures over 35 key facts about each patient and their treatment course. The register attempted to represent each standardized treatment decision as a tick box or entry. In theory, it fulfilled an important function in ensuring the compliance of both patients and nurses with national tuberculosis protocol and provided a tool for epidemiological surveillance. In addition, the content of the register was of potential interest to researchers studying tuberculosis epidemiology and treatment.494

According to TB nurses in Tugela Ferry the primary purpose of the tuberculosis register was “for stats,” or statistical reports for the department of health. The register constituted the basis for the reporting of Msinga sub-district level TB program statistics to the Umzinyathi district level and upward, eventually reaching the national tuberculosis program. Every tuberculosis case that was diagnosed and treated via the Church of Scotland Hospital was listed in the register (except for tuberculosis cases identified at the HIV clinic, which had its own TB register). Information from registers at outlying clinics in the catchment area was also compiled at the hospital’s TB office. Each page of the register generated three color-coded carbon copies that were submitted at key times in order to produce data on important reporting items. These included the total number of tuberculosis patients enrolled in treatment, the number of patients who had “sputum conversions”495 and the number of patients who completed treatment. In combination with other registers in the country, the register generated the raw data for the official statistics of the South


495 Patients who experience “sputum conversion” are patients with positive TB sputum results at the beginning of treatment who later have a negative sputum result. Ideally this indicates successful treatment. This is a poor measure to rely on, however, since patients can be sputum negative despite having TB, especially in the context of HIV/AIDS.
African tuberculosis programs that were reported to the WHO and its STOP-TB program.

Despite the Tuberculosis Register’s apparent utility for statistical reporting, however, many clinicians, administrators and researchers (ranging from Tugela Ferry’s nurses to Durban-based scientists, to WHO experts) found the register inherently problematic. The paper register alone did not really facilitate clinical care and inflexibly constrained nurses in their clinical decision-making by assuming a standard treatment algorithm. Sputum samples were to be taken at 3 months and 6 months of treatment, for example, and sent to the laboratory for a smear (with direct microscopy), not culture (and drug sensitivity). But if, for some reason, an extra sputum sample was taken at 4 months, there was no place to write it down. Similarly, if, for some reason, a patient received a sputum culture and drug-sensitivity testing at an “inappropriate” time, there would be no space to account for this. Such gaps potentially allowed failing treatment and drug-resistance to go undocumented (and thus “unnoticed”).

Clinically, it was problematic that patients in the tuberculosis register were listed in sequence of their registration date at the TB office. This could make finding a particular patient by name very tedious, though identifying a patient by date of encounter was not difficult. The paper-based register also meant that analysis and distribution of information required multiple entries and re-entries, which was labor-intensive and error-prone. In one attempt at simplifying data compilation, the national tuberculosis program created an electronic database that allowed the computer-based entry of the data. Yet, as one clinician explained to me, the database “sucked away” the data, not leaving the local TB office an

496 By the time I observed work in the TB office in Tugela Ferry in 2010, the standard tuberculosis register had space to enter some information about drug-resistance; information that previously had only been located only in the patient’s chart. Separate MDR-TB registers had been designed for the MDR-TB hospitals in KwaZulu-Natal, including the one in Greytown which MDR-TB patients from Tugela Ferry were referred to.
electronic record to reference or manipulate. Thus, the motivation on the part of local clinicians to fill out this database (in addition to the paper register) was low, since it did not improve their ability to care for their patients. One South African operational researcher encouraged nurses to prioritize more helpful forms of documentation.\footnote{Loveday, interview by author, 2007.}

Originally, TB registers assumed every patient had drug-susceptible tuberculosis. KwaZulu-Natal’s provincial tuberculosis coordinator Bruce Margot explained that MDR-TB reporting and recording systems were poor, both globally and locally: “There was nothing, really. No decent[ly] designed paper systems, and no software systems to support your analysis. So with no official reporting and recording system for MDR-TB in the country you had little bits of information lying all over the place. Most of it lying in clinical files.”\footnote{Bruce Margot, interview by author, 18 April 2010, Pietermaritzburg, South Africa.}

Accessing these clinical files meant going to file rooms, sorting through irrelevant charts to find patients of interest and manually browsing their files for information that may or may not have been documented.

As interest in HIV/AIDS research in South Africa increased, so did the interest in tuberculosis statistics from public health officials, international agencies, and academic researchers. The interest – especially in drug-resistant tuberculosis – became more pronounced once Tugela Ferry’s XDR-TB cases were publicized. Physicians at the King George V hospital, the specialized tuberculosis hospital in Durban, started receiving increasingly frequent requests for data from outside researchers. Tuberculosis physician Sheila Bamber recalled: “For a long time, when TB started being interesting, people used to come and say, oh, have you got stats? I’d say ’we don’t keep stats here.’ […] It was very embarrassing. So I actually recruited a colleague and we set up a database.”\footnote{Sheila Bamber, interview by author, 26 August 2010, Tugela Ferry, South Africa.} A laboratory worker at the hospital also set up his own database based on the diagnostic tests he
oversaw.\textsuperscript{500} Another clinical and laboratory database was located at Inkosi Albert Luthuli Central Hospital, the modern academic teaching hospital in Durban where the government tuberculosis laboratory was located. However, this database was proprietary and very difficult to work with. According to Bruce Margot, “whoever designed it had never heard of TB, so it was very difficult to extract the information.”\textsuperscript{501} When Kristina Wallengren was hired by the WHO to investigate MDR and XDR-TB epidemiology in KwaZulu-Natal, a large part of her job was to find the various ad-hoc local systems for documentation of TB cases that were scattered across the province and to compile and clean the data that emerged from them.\textsuperscript{502}

Though tuberculosis registers could not answer many of the researchers’ and public health officials’ questions, they were part of a public health surveillance effort that sought to bureaucratically capture people with tuberculosis and count them as part of a local, provincial, national and global program of tuberculosis therapy. A patient’s entry in the tuberculosis register was not envisioned as a once-off data point: tools existed to account for patients’ movements from one health facility to another, and out of one health district into another. In theory (though not necessarily in practice), a patient’s movements could be traced through a series of tuberculosis registers in different health centers and hospitals, as long as a patient transferred out of one tuberculosis program and transferred into another. Appointments missed, medications not taken, and laboratory results received could all theoretically be found in registers and accompanying documentation. Yet gathering the traces of any particular patient from these disparate sources could be daunting, if not impossible. It required physical travel from one TB register to the next, and assumed that

\textsuperscript{500} Kristina Wallengren, interview by author, 23 September 2010, Durban, South Africa.
\textsuperscript{501} Margot, interview by author, 2007.
documentation closely represented clinical reality. While in Tugela Ferry I witnessed one such data-tracing attempt by South African tuberculosis researchers based in Cape Town trying to piece together missing information on a group of patients they were studying. They found themselves travelling across the country, to Greytown and to Tugela Ferry, among other places, spending their days visiting TB offices, paging through old tuberculosis registers half-forgotten in the back of filing cabinets.

Perhaps it is not surprising, then, that it was not through the paper documentation of the TB office in Tugela Ferry that the MDR-TB and XDR-TB outbreak in Tugela Ferry was identified. As we have seen this, instead, was accomplished by physicians and researchers who overrode the government protocol and conducted additional screening for drug-resistant tuberculosis in the context of the unexpected deaths of research participants.503 Retrospective chart-reviews partially helped the researchers piece together patients’ treatment course leading up to diagnosis. Close evaluation of the published research paper that resulted from this work shows that this ad hoc method left several gaps in the data, as well.504

**Foraging for information: The essential role of data managers**

The official bureaucratic method for keeping track of patients at the TB office in Tugela Ferry remained the bound, paper tuberculosis register, however. Once the MDR-TB and XDR-TB problem in Tugela Ferry became known, researchers sought more comprehensive ways to prospectively capture cases, evaluate their impact and assess interventions that were introduced in response. The tangible and intangible value of this data on the global health research market has been made clearly visible: Dr. Sarita Shah and

---

503 See Chapter 2 for a description of the way Dr. Moll and his colleagues became aware of the high rates of drug-resistance at the hospital in Tugela Ferry.  
Dr. Neel Gandhi, for example, both obtained large grants from the National Institutes of Health (NIH) to study XDR-TB in KwaZuluNatal; Dr. Sheela Shenoi received funding from USAID to study the impact of intensified case-finding for XDR-TB in Msinga, and several American medical students obtained fellowships that allowed them to engage in TB research in Tugela Ferry, among others. The Howard Hughes Medical Institute, inspired in part by the findings from Msinga, built a multi-million dollar basic science facility in Durban for the study of HIV and TB and provided funds for housing and research buildings in Tugela Ferry. Researchers with the South African Medical Research Council sought access to research infrastructure in Tugela Ferry and built collaborations with the American researchers who worked there. The MDR-TB and XDR-TB data at the specialized MDR-TB hospital in Durban was also in high demand, and young physician-scientists such as Dr. Max O’Donnell built careers analyzing KwaZulu-Natal’s drug-resistance problem from the Durban perspective. In some cases, data was freely given to those who showed an interest in it; in others case hurdles were set, permissions were required, or favors were asked for in exchange.

Assessing the community-based treatment of MDR-TB (from outside the community)

When I arrived in Tugela Ferry in 2010 researchers under the leadership of Dr.

---


508 Iqbal Master, interview by author, 30 April 2010, Durban, South Africa.
James Brust and Dr. Neel Gandhi (then both based at Albert Einstein College of Medicine) were evaluating the outcomes of the community-based management of MDR-TB in order to determine the impact of injection nurses, tracers, and the new MDR-TB clinic and hospital in Greytown. Patients moved between local Msinga clinics, the TB office in Tugela Ferry and the MDR-TB clinic in Greytown. Laboratory results were generated in Tugela Ferry, Greytown, and Durban. Thus a successful study required patient information from all these places. At this point the government tuberculosis program was happy to work together with (some) external experts, but existing forms of documentation did not accommodate researchers’ needs. Valuable information about MDR-TB in Tugela Ferry was inscribed in patients’ medical charts as well as numerous registers, binders, print-outs and computer files in many locations, from hospital registration rooms, to radiologists’ shelves, to clinic desks to patient pockets. Information was not easily extractable for an internationally residing researcher. Certainly, data from registers and clinical charts would have to be converted into an electronic format before it would be useful.

Negotiations over access to and content of medical records and other kinds of health data are a crucial part of the interactions between public health, research, and humanitarian interventions. As anthropologist Ramah McKay’s work in a busy public health center in Mozambique has shown, medical files are contested objects used and shaped not only by the clinical requirements of doctors, nurses, and patients, but also by the research, reporting and technical evaluation needs of international non-governmental organizations, researchers and funders. Different stakeholders are interested in different information and seek ways to make sure that the data they need is captured during the course of clinical encounters. McKay argues that “medical documents are multiple, simultaneously enacting

---

and articulating a range of ethical, bureaucratic, and knowledge-producing activities,” and that through “documentary practices, authority itself is made multiple.”

In South African TB work, as well, academic careers, government allocations, and donor funding were in part determined by the successful collection, compilation, and interpretation of such medical information. The TB office in Tugela Ferry, the MDR-TB clinic and hospital in Greytown, and other sites of MDR-TB treatment and assessment were very busy places, however. Health care workers were kept occupied with the task at hand: diagnosing and evaluating patients and providing them with appropriate medical treatment. It was an additional step to translate the diverse and complex clinical contributions of nurses, doctors and other health workers treating drug-resistant tuberculosis into a coherent narrative – populated by authoritative numbers and assessments of outcomes – worthy of public and scientific presentations. The following section looks at some of the ways researchers not only ensured access to existing clinical information about the treatment of MDR-TB, but inserted themselves into its production at both a bureaucratic and clinical level, thus improving completeness of the variables the researchers were most interested in and improving patients’ ability to behave in ways that were in keeping with research protocols.

One way outside researchers gained access to public health information that they were not directly in charge of was by employing computer-literate data-capturers and lending them to offices and laboratories where data was generated. In the TB office in Tugela Ferry, for example, an employee of Philanjalo (the research and care organization through which most tuberculosis research in Tugela Ferry was channeled) spent each morning copying the previous day’s entries from the tuberculosis register into an excel spreadsheet which had been designed to mimic the register. When I first saw this electronic

---

file I imagined that it might be clinically useful for the tuberculosis nurses. Yet over the course of several months in the TB office I only witnessed one occasion when nurses (unsuccessfully) looked for a patient entry on the computer register after an extensive, unsuccessful search of the hand-written tuberculosis registers. Once the register was copied into electronic form, however, it was available to researchers, who could generate their own statistics and conduct their own analyses independent from the statistics generated by the TB office for the national tuberculosis program. The head of the TB office was aware that the data was shared in this way and benefitted from the presence of an extra person in her office – when he was not busy recreating the register she gave him other tasks to do.

Outside researchers had no authority over the government TB office staff who could have filled out the electronic spreadsheet themselves, but instead provided an extra pair of hands who was at the disposal of the TB office once his own work for the research program was done, allowing him to unobtrusively extract useful data as it was generated, hopefully in accurate form, and without impacting ongoing clinical operations or baseline data collection.

Such data-collectors were present in other departments in the hospital in Tugela Ferry, as well. Researchers paid for a laboratory technician who assisted with data entry in the hospital's diagnostics laboratory after they encountered difficulties in accessing the data from the central diagnostic database; researchers also paid someone to laboriously scan hundreds of chest X-ray films of tuberculosis patients onto a computer and load them onto a server which could be accessed by researchers based in the US. These data scavengers entered into every-day operations and worked around the often-inflexible workflows and documentation methods of government workers, quietly duplicating and siphoning off the information that was of interest, converting it into a research-friendly format. Clinical and laboratory departments accepted the help of additional data-capturers in part because they
gained free man-power for tedious and repetitive tasks, which they traded for a much reduced capacity to firmly withhold information. As Johanna Crane has shown on the example of HIV patient databases in Uganda, the ownership of clinical databases shared between local clinical programs and international researchers can become a highly contentious issue. The above strategies helped work around such conflict and allowed the duplication of local databases in exchange for the labor of this duplication.

**Improving the data**

A second strategy used by researchers to improve access to quality research data around the community-based treatment of MDR-TB involved strengthening the program itself by supplying qualified clinical staff to help oversee patient care. These clinicians paid close attention to the production of standardized clinical documents and data collection tools. This served two functions – on the one hand the MDR-TB program itself was improved through the activities of staff dedicated to the research project; on the other hand, the data was improved by ensuring that forms were accurately completed and that the public health and research protocols were followed and documented.

As we saw in the previous chapter, doctors, nurses, and other clinical staff at the MDR-TB clinic in Greytown were joined each week by a cadre of research assistants and a research nurse who helped the clinic run smoothly by assisting with the flow of patients, charts, and other materials. During the week the research nurse, Sister Makhubu, was based in Tugela Ferry’s TB office and helped prepare the MDR-TB patients of Msinga for their upcoming MDR-TB clinic appointments in Greytown. Officially, managing Msinga’s MDR-TB patients fell to government nurses based at the Tugela Ferry TB office and at outlying

---

Yet Sister Makhubu made sure that clinical details were not overlooked and did not become too onerous. For example, MDR-TB patients had their blood drawn on the Monday before their monthly Greytown clinic appointment (on Wednesday) so that the blood results would be available when clinic doctors saw their patients. Sister Makhubu reminded patients of their upcoming blood draws and clinic appointments by calling them from her research-funded cell-phone. Patients could conveniently go to their closest clinic to have the blood draws done. Sister Makhubu left little up to chance, and she filled out all the paperwork needed for the blood draws, labeled the blood tubes, and placed them in specimen bags for every MDR-TB patient in the region. She then gave these tubes to the TB office tracers so that they could distribute them to the appropriate outlying primary care clinic nurses. The clinic nurses merely had to draw their patients’ blood and send the samples back to the hospital via an established system.

This pro-active approach in which the burden of ensuring that each step took place was on clinicians rather than the patients was not typical of public health programs in South Africa that I have witnessed. By making the work required from patients and outlying nurses as easy as possible Sister Makhubu and the research project she represented helped ensure that clinical care was successful. She also ensured that sample collection required for the production of complete and convincing quantitative data occurred. Patients and researchers benefited from the individualized attention of a dedicated nurse. Blood results were available on time, and according to the research protocol. Several possible hurdles that could undermine the successful acquisition of data and lead to gaps, such as missing or incorrectly filled out paperwork, transport problems or missing blood tubes were minimized.

---

512 Sister Makhubu left the research project towards the end of my fieldwork stay and this task reverted back to the TB office nurses when she departed.
The research project made its presence known in other ways, as well. In the MDR-TB clinic in Greytown three or four study-funded research assistants sat together with physicians (most of whom were funded by the department of health) with folders, filled with carefully designed forms whose templates reflected the information needed for the study protocol. While the doctors and nurses talked to the patients and filled out the standard government MDR-TB treatment forms and clinical charts, the research assistants followed along and filled out research forms which for the most part duplicated information from the clinical interaction in a more explicit and detailed format. The study forms included reminders about the types of information that should be sought at each visit, including lab tests, X-ray studies, and questions about medication side-effects. The research assistants filled out large proportion of the study forms on their own, while listening to clinical interactions. Occasionally they came across parts that only the physician could complete. Then the research assistant simply handed over the page in question, compelling the doctor to complete it. These forms and their keepers disciplined clinicians to ensure that the needs of the study were met, even when the actual clinical interaction did not require the same level of documentation. During the week the standardized charts were entered into electronic databases by the research assistants. This way all the information that the researchers were interested in analyzing was already available in standardized and complete form and did not have to be retroactively abstracted from the free-flowing clinical charts that were more typically used in clinical encounters.

Not all patients who were seen at the MDR-TB clinic in Greytown were from Msinga. Those from neighboring sub-districts were not enrolled in the study of community-based management of MDR-TB (which had arisen specifically out of the interest in the outbreak in Tugela Ferry). Though the same doctors and nurses attended to all MDR-TB patients at the clinic and the research assistants translated clinical interactions for these patients, too, their
care was not managed with the help of research forms. That level of documentation was not considered necessary for the sake of the clinical encounter itself or for the sake of government program reporting. Thus, even as researchers sought to document the impact of a government-run program for the treatment of MDR-TB, this documentary research added both steps and resources to the clinical encounter that would not have been present in the absence of the research effort. The main aim of these extra resources, then, was to improve data; yet it most likely improved the nature of care, as well.

**Traversing the landscape: the banal nature of heroic and innovative work**

While successful research on MDR-TB management in Tugela Ferry required the successful acquisition of clinical and public health data, the successful implementation of the community-based treatment of MDR-TB itself relied heavily on nurses’ and community health workers’ capacity to trace the actual patients – finding them in their homes and providing them with treatment. The strategy of fighting tuberculosis with paperwork was ineffective until it was paired with intense, pro-active outreach and educational activities of TB workers who spent their days seeking out patients. Some patients were easy to find and engage in treatment, while others lived in particularly remote or challenging circumstances, or actively resisted being found. Just as MDR-TB researchers worked around official bureaucratic practices to gain access to information they were most interested in, TB nurses in the office and the field developed strategies which enhanced the official tools of TB documentation in order to better do their jobs and serve their patients.

As we have seen, fieldwork was the most visually impressive component of the community-based-management of MDR-TB. Injection nurses and tracer teams in action drove across the Msinga landscape to reach patients who lived on remote hillsides, often in rustic-looking traditional round-huts located well beyond the end of a gravel road. Nurses
drove into the community every day to find 8-15 patients at home and give them injections while TB tracers drove across the Msinga landscape to notify new patients who had just been diagnosed by the lab, to survey patients' households to determine if family members had been infected, and to find patients who had stopped coming to clinic visits. Routines of bureaucratic documentation, patient visits, and clinical protocol were broken up by meal breaks, car washes, road-side flirtation, and the entertainment of visitors, including myself, who arrived to “see” MDR-TB management in Msinga in action.

The following section is compiled from the field-notes I wrote after several “ride-alongs” with TB office staff between August 2010 and June 2011. I rode with several different nurses as they traveled across Msinga to give their MDR-TB and XDR-TB patients injections of TB medication and I accompanied tracers as they notified patients in their homes of their drug-resistant TB and looked for patients who had stopped reporting to their clinic appointments. I employ a series of vignettes to describe the actual day-to-day activities entailed in “community-based management” of drug-resistant tuberculosis and to illustrate some of the strategies used by nurses to keep track of their patients. These stories demonstrate the importance of TB nurses to the success of a global health research endeavor even as their contributions may be constrained by the parameters of their mandate and their actions minimized (or at least anonymized) in the research record. I also consider my own experience as a visitor riding along to see patients in order to portray the ambivalent romanticism of rural poverty for a global health worker – a romanticism which I believe forms the foundation of the global health enterprise. The chapter ends with a reflection on the significance of Msinga – a place that evokes complex connotations in many South Africans and well-read visitors to the area – as a global health site.

The nurses also visit “retreatment” patients who have failed the standard TB regimen and are now being treated with the injectable streptomycin, though they have not been diagnosed as having drug-resistant tuberculosis.
Going “out into the community”

One day in August 2010 I went “out into the community” with NF, a TB injection nurse. I waited for her in the TB office for an hour while she filled out paper work to sign out her hospital vehicle and she collected her supplies, including syringes, alcohol swabs, vials of streptomycin, blue patient charts, and a cooler box. We set out in a battered yellow bakkie (pick-up truck) marked on the door with the insignia of the KwaZulu-Natal Department of Health. Before we left the commercial crossroads of Tugela Ferry, however, we filled up on petrol at the chaotic Tugela Ferry petrol (gas) station, waiting for several minutes in a disorderly line along with several other department of health bakkies, as well as bakkies belonging to other government departments and to the local non-government organization, Philanjalo. We then stopped at the car wash across from the hospital to clean off the dust of the previous days’ journeys. As we were waiting, we went to a small shop to buy provisions for the road – coke, chips and apples to keep us going.

We spent hours driving through the hilly, dry landscape to places without any obvious nearby water source or easy access to food or commerce. In some places there was evidence of agricultural activity and small-scale gardening, but in most areas I could not help imagining that isolated huts had been dropped on vast fields of stones and thorns, or that in some freak phenomenon it had rained rocks instead of water. On occasion we were slowed down as we passed small herds of cattle lying in the middle of the road. NF would chuckle as she told me we needed to wait for the “robots” (this is the South African word for traffic lights). The cows reluctantly got up and we would continue our journey. On some of the roads (marked Zibambele, which means “doing it for ourselves”) we passed older women wearing orange vests over their clothing and big floppy hats to protect themselves from the sun. They were working at the side of the road, clearing out drainage ditches and cutting brush as part of a public employment program.
Over the course of the day, we visited eight patients in six hours. Several of NF’s patients were evidently living in dire conditions. One client appeared to be squatting in an abandoned compound surrounded by dust – her home was in a cluster of 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 round room was covered with an intact sheet-metal roof.\textsuperscript{514}

Each encounter was slightly different. We drove to a patient’s house, waited a few seconds to be invited in, and then entered the patient’s room, where the she handed NF her treatment card, and lowered her pants for the injection. NF ticked off the date on the card to show that she had come, while the patient rubbed the painful injection site with a swab. In another case, we rode up to an area and then dramatically honked the truck’s horn. We waited a few minutes until a gaunt figure emerged in the distance. Only partially hidden from view, he received the injection leaning against the door of the truck. Next, we met a gogo (local vernacular for elderly woman) and her TB-patient husband on a clearing that was littered with several dozen alcohol swabs – the evidence of months of daily injections. Another patient met our vehicle under a pre-designated tree, away from neighbors who might see the clearly marked government vehicle. One patient had given up waiting for NF when she arrived later than usual and had gone to the shops in the next town. No matter, NF 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. NF was surprised and she promised his mother she would look into it when she got back to the hospital.

Most of these encounters were cordial but brief. There was a friendly conversation

\textsuperscript{514} I was later reminded of this place when a nurse I interviewed stated that it didn’t matter whether or not we ever found the cure for AIDS since the people were already dead and the houses were already abandoned and decaying.
here, a moment of support there, but as the day got longer, the goal seemed to be to get back to home base soon. 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 move on. Injections were provided for tuberculosis patients who needed them. It was strange to realize that this was the foundation of internationally celebrated public health program with the evocative word “community” in the title. While injection teams performed necessary, even interesting work, there was little glory in chasing down patients and giving them injections. Our vehicle apparently had no suspension to speak of, and after we had spent a day driving through the Msinga countryside on roads that ranged from tarred, to dirt, to rocky ruts covered in mud, I was completely exhausted. My back was aching and my shoulders were stiff, and I was suffering from a headache. Had the conference presentations on the community-based management of MDR-TB in Tugela Ferry oversold something that was not more than an injection service? Is this what community meant?

**Moments of tenderness, care, and concern**

Not all injection work was rushed business as usual. On another day I watched another nurse, NC, carefully touch the left butt-cheek of an XDR-patient who had been receiving injections from her for well over a year. She was looking for a patch of flesh 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 with her sharp needle. NC was concerned about this patient, since she was soon scheduled to finish injections but wasn’t really looking any better than when she had started treatment.

Another nurse, RB, and I saw a patient with bright red, painful eyes and shingles in his face. The nurse expressed grave concern for his well being and mentioned his case in the nurses’ meeting the next morning. A few weeks later NF found a patient lying on a dirty mattress in a very untidy room that had not been cleaned recently. NF called in the patient’s
sister-in-law and informed her in no uncertain terms that it was her responsibility to keep the patient’s room clean. She implied that if the patient didn’t get better, it might be the sister-in-law’s fault for not giving the medication a chance to work.

Several patients clearly appreciated the convenience of receiving injections at home, while others enjoyed the opportunity to chat and learn about what was happening in town. Sometimes injection nurses would come with food packages and news about other patients they had seen at the monthly clinic. In one case, an injection visit revealed one MDR-TB patient to another neighbor with MDR-TB and they asked their injection nurse if she could arrange for their monthly MDR-TB clinic in Greytown to be coordinated onto the same schedule so that they could travel together. Neighbors not receiving tuberculosis care occasionally sought to benefit from the nurses’ passing by – an old man flagged us down to ask the nurse behind the wheel to explain what the prescription medications that he was carrying with him were for, and if it was safe to combine them.

Interactions with patients and their families could be incredibly frustrating – when SM (another nurse), my research assistant, and I approached one patient’s home we realized that we had entered in the middle of a domestic fight. The patient’s mother was screaming, accusing the patient of being an abusive alcoholic and was asking us for help. The nurse suggested that she needed to go speak to the hospital social worker, or, if her son was dangerous, to call the police. We listened to the dramatic exchanges for several minutes, but the nurse sitting behind the wheel eventually decided to drive on. The entire household was still yelling; this family’s problems were left completely unresolved.

When injection nurses attempted to help their patients beyond the injections themselves, it was often unclear what the next step would be. While the nurses had a clear mandate to provide injections, some other resources were not always satisfactory. Nurses could report medical events to a physician who might prescribe medication or recommend
that the patient come in to the hospital, and they could refer their patient to the hospital social worker. Yet nurses were rarely in a position to fully address patient problems that were not strictly related to tuberculosis medication.

In fact, nurses’ interventions were not always fully welcomed by their patients. Most of the TB team’s vehicles were painted a particular shade of yellow and bore a department of health logo and thus were easily recognizable as department of health vehicles, even from a distance. This was a large problem for some patients who complained that they did not want regular visits from these conspicuous cars, since all the neighbors would see them and know something was wrong. Some were specifically concerned that the neighbors would assume they were being treated for HIV/AIDS, since the department of health vehicles had become most closely associated with HIV-related activities in recent years. Many (though not all) of the tuberculosis patients in question were in fact HIV positive, but did not necessarily want this to be announced to everyone living off the country roads used by injection nurses and TB tracers to get to their houses. Many people I spoke to said that attitudes towards HIV had changed so that it was no longer considered as shameful or stigmatizing as a decade earlier. Tuberculosis was still a better disease to admit to, however. As FS, a TB tracer, put it: “With a yellow vehicle everyone sees it’s a government vehicle, and it’s from health. And if the vehicle comes to your house, they’ve got this thing in their mind that [...] someone’s got HIV. And HIV, I don’t know, they don’t treat HIV as a disease. [...] If you [have] HIV and TB, they treat those things as different. [...] It’s embarrassing to have HIV, in people’s mind. If you have TB it’s better.”

Some people tried to hide their disease from their own spouses and children, as well as their neighbors. One nurse told me that a patient hid her medications among other multicolored pills and told her husband she was taking vitamins. Some made arrangements with their nurses to see them far from their own homes and preferred waiting in the sun for
the nurse and the truck to arrive at a semi-public roadside over a home visit. When a tracer came to find a new or lost patient, however, there was no way to hide – once the tracer arrived in the general area of the person he was looking for, he would ask as many neighbors as necessary where this person lived, until the patient was found.

**Enrolling the global patient, locally**

Nurses and tracers often talked about the difficulties of finding patients who did not want to be found and the strategies they used to find them. The effort started with the more-than-complete documentation of potential tuberculosis patients even before they were fully diagnosed. The routine medical charts recorded patient addresses, but TB nurses found that the standard registration process often did not document sufficient accurate information to successfully find a patient in the mostly unmapped Msinga landscape.

In fact, Msinga residents were notorious in some circles for choosing to live in a remote backwater and actively trying not to be found by government-sponsored surveillance. In news articles and novels, Msinga was often portrayed as a place where people who had gotten in trouble in the big city returned to hide or – in the case of HIV and TB – to die. Others had willingly made themselves known to the TB office by seeking medical care in Tugela Ferry but found the TB program onerous and wanted to escape. According to TB nurses and tracers, patients often offered vague, incomplete, temporary, or obsolete contact information. For this reason, TB staff did not rely on addresses, but instead meticulously documented the name of each patient’s home area, the name of the closest school, and the name and grade of a child-relative who attended that school and would be able to direct TB tracers to the patient’s house (and squeezed it into boxes on forms that

---

were not designed to accommodate so much information). When patients changed
addresses or left home, tracers sought information from relatives and neighbors about the
patients’ new whereabouts. One patient, for example, 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
questioned her relatives, found her, and convinced her to finish her treatment, letting her
know that “if I run away, it’s my life.”

The tracing team and its active approach represented an important surveillance arm
of this state-sponsored public health program. Without it even thorough documentation in
the TB registers only performed a weak function. Tracers occasionally remarked on their
role as arms of the government. As a tracer and I were negotiating a narrow road hugging a
mountain one day, he pointed to huts in the distance, 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.” While it was hyperbole to say that the road had been built specifically so
that he could find his patients, I often heard that road development that had taken place
over the previous several years in this remote area in transition had made it significantly
harder to hide. TB tracers also enrolled government-funded school teachers dispersed in
schools across the region in their task of finding patients. On several occasions I witnessed
teachers identifying young school children to the TB tracers and releasing them from class
so they could direct the tracers to the relatives they were looking for.

Tracers also participated in a flow of paper between the hospital TB office in Tugela
Ferry and outlying clinics, where the care of standard drug-susceptible tuberculosis
patients was managed. Though most TB patients in the region passed through the hospital

---

516 Anonymous Patient, interview by author, October 2010, Tugela Ferry, South Africa.
517 Many Msinga schools were in poor condition, and many children had to walk substantial distances
to get to schools, but from the perspective of TB tracers with vehicles, they provided relatively good
coverage of the area.
TB office to be registered, they were generally “transferred out” of the hospital register to their most convenient local clinic as soon as their paperwork was processed. Patients were sent away with a few days worth of tuberculosis treatment and instructions to see their local clinic nurse. Tracers would often drive these patients to their local clinics and then home, both to ensure that the patient remained in care, and so that they would know first-hand where the patient lived – another tool with which to stave off patients efforts to elude the reach of the TB program. To ensure that patients actually made contact with their local clinics, their information was not only entered into the tuberculosis register, the blue patient chart and the green carrier card, but also into a book of transfer forms. A slip from this form was given to the patient, who in turn was to give it to the clinic nurse, who in turn returned it back to the TB office in Tugela Ferry via a TB tracer. Back at the office, the TB office clerk regularly sifted through returned stubs, found the original entries in the transfer book, and stapled the stubs back onto the form. Using this tool, the clerk could determine if patients had successfully made the transition from the hospital to the local clinic. The patients found in this way were then available to feed into research efforts around tuberculosis as well. Thus researchers both directly and indirectly relied on extensive government involvement even in this remote populations’ lives.

**Memory: Clinically useful, ineffective for research**

As we have seen, the office-based TB DOTS staff spent an extensive amount of time and energy writing and re-writing patient information onto various types of stationery, and great emphasis was placed on the completion and submission of these forms. The most valued TB nurses, however, did not rely on tuberculosis registers, medical charts, and transfer forms to keep track of their patients. Instead, the nurses and tracers in Tugela Ferry emphasized their memory as the most important tool required for their work. Paper was used primarily to fulfill bureaucratic reporting requirements, which were many.
Clinical effectiveness required much more than well-kept paper records, however. It required a personal memory archive of patient histories and local geography.

Tracers, in particular, took pride in their unaided mastery of the Msinga landscape. One tracer explained to me that after working on MDR-TB for six years, he knew his way around every part of Msinga on one side of the river, and that everyone knew him: “They call me by name as I drive out there – anywhere.” Rather than relying on documented information, this tracer preferred locating people without formal assistance, based on his knowledge of area designations and common family names. He boasted that the physician who worked most closely with the MDR-TB research project had recognized his intimate knowledge of the landscape: “Dr. Bamber calls me the map.” Dr. Bamber herself had introduced another tracer to me stating that this was the man who knew all of the XDR-TB patients in Msinga and could find them all, no matter how remote.

Even as TB tracers prided themselves in knowing where their (past and future) patients were located, the expansive and partially “uncharted” nature of Msinga’s landscape constituted a particular challenge to outside researchers. Tracers’ memories were a good clinical tool with which to ensure that patients had the opportunity to access tuberculosis treatment. Memory was not a great research tool, however, unless it was somehow translated into data that outside researchers could use. Researchers found it difficult, for example, to determine whether or not there was family or regional clustering of MDR-TB and XDR-TB cases in the community. There was a technological fix: in the wake of the discovery of XDR-TB in Tugela Ferry, Umzinyathi district’s funding partner, the Italian Cooperation, provided tracers with GPS devices. The Italian Cooperation, in coordination with the local department of health and the American researchers studying XDR-TB,
requested that the tracers note down patients’ GPS coordinates.\textsuperscript{518} Tracers were initially paid by the Italian Cooperation, and maps showing the distribution of the MDR-TB and XDR-TB in Msinga have been made based on such GPS data. Early maps were displayed on the TB office walls and were presented at scientific conferences. Yet over time, the TB tracers found the GPS technology unnecessary and tended to “forget” it in the office. By the time I spent time with tracers in 2010 they only rarely used GPS, though they continued to carry forms with them that called for the entry of GPS data. GPS technology did not help tracers locate their patients or bring them into treatment. For this, they relied on their memory and the maps in their own heads, along with local information provided by people they met along the way.

Like the memories of tracers, the strength of specific nurses’ memories was noted and praised by physicians, as well. Dr. Moll recommended a particular TB nurse to me by praising the fact that she knew all of her patients off the top of her head, without the help of the tuberculosis register, and could always answer questions he had about the patients. I myself saw Sister Madi in action when a question arose about a patient who had been seen at the TB office some time ago, and she was immediately able to answer it. She confirmed the information by quickly leafing through dozens of pages in the tuberculosis register and almost immediately pointing to just the right entry. The organizational weakness of the tuberculosis register (which is organized by treatment start date rather than, say, patient name) was overcome by the nurse’s ability to recollect the details of the many patients who came through the office.

In practice, the extensive use of memory by nurses and tracers to effectively manage their clinical program was perhaps not surprising. Clinical memory strategies were insufficient, however, to produce good data for research and bureaucratic reporting. Clinical practice needed to be translated into standardized, transportable forms of knowledge that could be rendered independent of individual nurses and TB staff, and which were legible to public health bureaucrats and academic researchers. At the level of the TB office in Tugela Ferry, the requirements of public health reporting were dealt with by making the production of official documents such as the TB registers, transfer forms and patient charts part of the routine of being a TB nurse. These routine practices of document-completion were regularly reinforced through trainings, site visits from supervisors, monthly reporting requirements, and the demands of the nursing hierarchy. As we have seen, researchers’ data needs were dealt with by adding yet another layer of data documenters who duplicated and reformatted clinical and public health data.

**Nursing work in a global community context**

Unlike physicians and administrators, TB nurses and tracers in Tugela Ferry did not frequently express a sense of being important players in a broader international research endeavor, even as I sought them out to spend time with them on their drives to patients’ houses and asked them to agree to be interviewed for my own research. Tracers were unable to name the researchers who were likely to use the GPS-derived information in their work, even though their jobs as tracers required them to actively collect household data on MDR-TB and XDR-TB patients; nurses, similarly, were unable to identify the roles of most of the numerous American principal investigators who occasionally came through town to monitor the progress of their research projects.

Tugela Ferry’s government TB workers did not speak of themselves as working for the “community-based management of MDR-TB,” let alone as being part of a global debate
about the merits of different strategies of drug-resistant tuberculosis management. While the work they did was presented in national and international venues, their own relationship to the representation of their work was quite removed. Sister Msomi, the nurse-manager for Tugela Ferry's TB office did attend the South African TB conference, among others, and she sometimes presented her office's work on MDR-TB and XDR-TB to colleagues from other provinces and countries who came Tugela Ferry to learn more about how they could improve their own programs. My conversations with several injection nurses made clear, however, that most of them only partially understood that their activities were an object of great interest both nationally and internationally. Though they had received training on the South African TB program and the management of MDR-TB, they had not been explicitly trained on the fact that they were now conducting “community-based management of MDR-TB” as it was called by researchers and higher-level department of health managers. This became apparent when Mr Mndebele, the Umzinyathi district manager who oversaw department of health operations in Tugela Ferry, conducted a small research project in which he interviewed his own subordinate tuberculosis staff at the Church of Scotland Hospital and asked them what training they had received on the community-based management of MDR-TB (something they were actively doing every day). They all replied that they had not received any.

**Fundamental building block or donkey work?**

In Tugela Ferry injection nurses were the primary professional witnesses to MDR-TB and XDR-TB patients’ process of going through community-based tuberculosis treatment. They were not usually the ones, however, who were given the task of providing input on the program’s successes and failures. As Steven Feierman has pointed out in his piece *When physicians meet*, a major challenge in global health programs is that those people on the ground carrying out the work rarely have the opportunity to provide fine-
tuned feedback to those administering and funding the programs. In Tugela Ferry the local physicians easily spoke to international partners and funders and were very empowered toward them, yet it seemed like communication and feedback broke down at the level of the tuberculosis nurses, even as nurses officially bore the responsibility for the tuberculosis program. This became blatantly clear when Mr. Mndebele, the above-mentioned department of health district manager, in an exception to this rule, interviewed several injection nurses in 2011 as part of a small evaluation of the community-based management of MDR-TB that he was conducting as part of an academic Masters program. When he asked the nurses what their biggest challenges were, most of them mentioned logistics and material 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. Several nurses were elated about being able to communicate with the district manager about their work (for the first time in three years), and hoped there would soon be improvements. Mr. Mndebele, meanwhile, admitted that he was aware of some of the problems with vehicles which had accumulated since the vehicles were originally allocated when the TB office was expanded in 2007, but that it was difficult to keep up with the ongoing budgeting that the program required now that the acute crisis related to XDR-TB was no longer felt.519

Mr Human, the CEO of the hospital in Tugela Ferry, discredited the importance of the hospital’s TB office nurses’ input almost entirely. He argued that despite the fact that the management of tuberculosis treatment is almost entirely nurse-driven, it was not the nurses who uncovered the MDR-TB/XDR-TB outbreak, and it was never the nurses who provided significant intellectual input into how to manage the MDR-TB/XDR-TB outbreak. In his view, TB nurses did the routine “donkey work” of discharging, transporting and transferring patients, while it was researchers from outside who had truly made an impact.

519 Jabulani Mndebele, interview by author, 10 March 2011, Tugela Ferry, South Africa.
on programs for MDR-TB in Msinga.\textsuperscript{520} He – perhaps correctly – attributed the bulk of the success that the hospital in Tugela Ferry had seen in improving its tuberculosis program to the hard work of Dr. Moll and the input provided by people in his international networks. Yet I would argue that without the so-called donkey-work very little would have gotten done, in the end.

\textbf{In the field}

TB nurses were frequently reminded of the broader world’s interest in their work, however, when Dr. Moll arranged for outside visitors such as myself to ride along with one of them as they traveled to see their patients. Many visitors to Tugela Ferry showed a great interest in learning more about what had happened in the aftermath of the discovery of XDR-TB and wanted to spend time traveling through Msinga. In this sense, TB nurses were very involved with promoting the community-based management of MDR-TB.\textsuperscript{521}

Ride-alongs with TB nurses served numerous purposes. For tuberculosis program coordinators from other provinces and countries who were starting or improving MDR-TB treatment programs they served a pragmatic educational purpose.\textsuperscript{522} Other common riders belonged to rotating groups of visiting medical residents (junior physicians) who spent six weeks in Tugela Ferry helping with patients at the HIV clinic. For them, the ‘purpose’ of the trip was perhaps less obvious. I thought of these ride-alongs primarily as a type of global health tourism – a form of entertainment that gave foreign visitors to Tugela Ferry a glimpse of the “Africa” they had expected to find. The young American doctors spent busy

\textsuperscript{520} Hans Human, interview by author, 14 January 2011, Tugela Ferry, South Africa.
\textsuperscript{521} The nurses in Tugela Ferry seemed unaware of the global uniqueness of the epidemiological situation they worked in every day, however. Months after my first ride-along, after I had spent many days with the TB nurses in Tugela Ferry, one of the nurses 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 drug-resistant TB in America?” My answer was truly devastating: “No, we don’t. Not to this extent.”
\textsuperscript{522} Around the time I left Tugela Ferry in 2011, Philanjalo was setting up a training program (funded by URC) which would use Tugela Ferry and Greytown as a “center of excellence” to train others on MDR-TB care.
weeks working in a new, modern-looking HIV clinic, dispensing standard drug-therapies with the help of trained, uniformed, bilingual nurses and the support of experienced South African doctors. They enjoyed spending a day off “out in the community” visiting the region, seeing people’s houses and poor living conditions up-close. Some international visitors (including medical students) achieved the same aim by accompanying a community worker as she visited orphans and vulnerable children. I was frequently present when at the end of a ride-along day Americans would assemble in hospital guest-houses over dinner and share their photographs of cute African children and colorful round houses overlooking rolling hills, in some cases talking about the T-shirts they had donated, or the game of peek-a-boo they had played with a toddler.

Beyond tourism or voyeurism, these ride-alongs also provided an opportunity for visitors to witness the conditions of life and work in Msinga and Tugela Ferry in order to solidify the argument for the moral necessity of biomedical (and social) intervention. Though encounters were fleeting, these trips provided opportunities for visitors to “see how Zulu people lived,” and affirm the belief (widely held among these visitors) that health care should be provided even in dire circumstances. Global health practitioners in some humanitarian traditions have had an explicitly stated function of not only providing medical care to people in need, but of vocally bearing witness to the conditions in which they operate. The organization Doctors without Borders, for example, calls its members to “witness” suffering and human rights abuses and stand in solidarity with those who are suffering. The founders of Partners in Health, similarly, draw on catholic liberation

523 I take this phrase from the aunt of a Zulu nurse I lived with for several months in Durban. When she briefly met me at a family function she named me Thandeka (loved), because I loved the Zulu people and wanted to “see how we Zulus live.” This was all very tongue in cheek and was part of a conversation that included a discussion of how generous her white employer had been when she was a domestic worker, and ended with a request for money from me.
theology to demand that health professionals make a preferential option for the poor, since “those who are in any way and for any reason deprived, marginalized, or vulnerable have a special moral claim on the community.” Successful global health organizations employ first-hand accounts of the lives of the poor and disenfranchised to make a moral argument for intervention and are able to attract funds this way, as well. Especially in international work around HIV/AIDS first-hand knowledge and compelling narratives provide valuable currency that can be traded for monetary support when deployed effectively. Much of Paul Farmer’s argument for a right to health and international health intervention consists of telling the stories of people and places he has met and seen, and explaining the world from the perspective of having been there. In a similar vein, much of the lower-profile global-health work conducted by undergraduates, medical students, and resident physicians comes at least in part from a desire to “be there;” to experience first hand what the conditions of the world are, and from the wish to be able to tell their own morally compelling stories of suffering, and including themselves in part of the solution.

I do not exclude myself from this analysis. Towards the end of my first day-trip with an injection nurse I could not help thinking that that I had now “seen” MDR-TB in Msinga. I took note of this thought in my fieldnotes and immediately questioned it. What had I seen? In brief visits to people’s houses I had perhaps come to understand a little more about the material conditions in which tuberculosis patients in Msinga lived; as we drove along I eyed a harsh-looking landscape through the window. I saw dry riverbeds and occasional

---

boreholes or water pumps; a few vegetable gardens and a tractor, but mostly dusty hillsides with few clues as to how people sustained themselves. I wondered: Why were water pumps so far from houses? We passed several schools and clinics in various conditions. One school had a big solar panel in front – I wondered whether the others had any electricity. We passed four clinics – markers of the department of health’s presence even in more remote parts of the district. But how effectively were they staffed and how well did they function?

I found the geology intriguing. How did all the stones get here in this formation? Why are there so many dry riverbeds that make it look like instead of water, rocks flow through these valleys? It was dry season, but I was told that even in the wet summers, most of these river beds would still be dry, though others would flood, cutting off roads. We passed strange aloes, including enormous leafy grassy structures that dry up into gnarled papery branches in different shades of brown and black; we also passed acacias whose small leaves were surrounded by thorns, though these did not seem to prevent goats from eating them. Much of the landscape was nearly free of vegetation.

The harsh landscape was also stunningly beautiful. I took note of the intricate afternoon play of shadow and light on the mountains. The hillsides offered so many hues of greens and browns. The clouds were striking, reflecting a combination of fluffy white and dark grey against a bright blue background with clearings of brilliant radiance emerging from behind them. The buildings added to the color. A small one-room tuck-shop had been painted neon blue. Other houses along the hillside were painted in bright pinks and bright greens. On the way back to town we sighted several birds of prey cruising in the sky, majestically surveying the landscape. Our trip was briefly delayed by a rather more pedestrian pack of donkeys being led down to the river.

---

529 I later came across newspaper articles featuring Msinga school children who need to wade or swim through neck-high water in order to get to school every day.
One day, when NF and I had been driving for about four hours, we parked to eat our lunch under a tree on the top of a hill from which we could see rolling hills and a river winding away in the distance. I pointed out how beautiful the scenery was. She looked at me skeptically and shrugged, saying, “The people here live like animals.” Perhaps she wondered how I had missed this, considering we had just left the house of a dying XDR-TB patient who was lying alone on a mat in a dark hut that was in disarray – a picture-perfect scene of another kind. It dawned on me that I had succumbed to the rural romanticism of the “real African” landscape. With that simple sentence she simultaneously made clear to me that the view was not the point, but she also socially distinguished herself, an employed, educated nurse, from the poor, rural, often uneducated clients she was visiting.

As I tried to “read” the landscape and gain an “understanding” of Msinga, it became blatantly clear how far removed a ride-along was from really providing such understanding. In my notes I asked myself a series of both obvious and naïve questions that a ride-along was not equipped to answer. For me, these ride-alongs were one part of a much longer and broader project that would help answer some of these questions, while others remained unanswered. There was a clear risk, however, that a ride-along like this one could become a once-off event which left a dramatic impression without really providing the insight it seemed to offer. Photographs taken on such ride-alongs, meanwhile, found their ways into private photo-albums, public blogs, and research presentations that hit home the importance of providing tuberculosis treatment to patients in such a simultaneously beautiful and desperate setting.

---

530 This was not the only time a Zulu in Tugela Ferry was bemused by my admiration for the landscape. A Zulu mission worker who spent a lot of time organizing activities and outreach for mostly white visitors (some of them international, though many South African) once took me to a spot on the top of a hill that has a beautiful vista. She had brought me there because “I know that you white people like to look at our mountains.” In a similar incident, I took a walk with a Tugela Ferry municipal worker along the Thukela river. He pointed to a picturesque small island in the middle of the river and postulated that it would probably appeal to white people.
The “first” ride-along

In chapter 3 I described how Dr. Moll decided to impress Dr. Friedland the first time he came to Tugela Ferry by leaving the modest hospital in the tiny town, and instead taking the American Professor to outlying areas of the district. Friedland had been getting frustrated with the slow pace of setting up research on combined HIV and TB treatment in Durban and had decided to look elsewhere: “It seemed like it was going to take a long time if ever for this larger project in Durban to actually materialize, and I had an idea, and the funding source for the work that I was doing was very encouraging about it, to actually test this strategy in a rural area. Because that’s where most people still live in Africa, that’s where probably the worst HIV and TB epidemics are, though they are bad everywhere.”  

When explaining how their collaboration came about, Dr. Moll and Dr. Friedland both credited Tugela Ferry’s rural, “African” location with a crucial role in bringing them together. Moll took him on dirt tracks to the “real old Africa” in the hills and together they visited destitute people in their traditional Zulu huts. When Dr. Friedland later discussed the HIV/TB research in Tugela Ferry, he described the inhabitants there as a “very traditional Zulu community” and emphasized the town’s remote location far from the infrastructure of Durban. “There’s one tarred road that leads into what was the former Zulu homeland. Everything else is dirt roads or tracks. About 70% of people don’t have piped water or electricity. It’s really quite impoverished.”  

Friedland emphasized the poverty of the area’s inhabitants, and called the location a “very resource-limited setting,” whereby the point of his research was to test the feasibility of integrating TB and HIV in such a setting. Neither Dr. Moll nor Dr. Friedland described Tugela Ferry’s poverty or rural location as a disadvantage or limitation for the research project itself. Instead, these features meant that

---

531 Gerald Friedland, interview by author, 27 March 2007, New Haven, CT.
532 Anthony Moll, interview by author, 23 July 2007, Tugela Ferry, South Africa.
533 Ibid.
researchers had a good reason for being there, and they provided some compelling detail about the condition of the people being provided for. Friedland emphasized the collaborative nature of the relationship between Yale, UKZN, Philanjalo, and his US-based donor. Philanjalo, as an organization, had well-established ties with poor people in their own remote, and visibly traditional community settings. I suspect this was an appealing feature of doing research in Tugela Ferry that mitigated potential ethical concerns Friedland might have had about conducting research among poor, disempowered people.\footnote{I credit Friedland with being a thoughtful researcher who had extensive experience working in conditions of unequal power relations, as well as a respect for history and justice. His past experiences included working for the peace-corps in Nigeria in the 1960s, working as an inner-city physician who saw AIDS patients early in the epidemic as an infectious disease specialist who took a special interest in injection drug users in New York, and as a global health AIDS physician who set up programs in South Africa. Even people who were very critical of the international research endeavors happening in South Africa appreciated Dr. Friedland’s work and respected him.}

The distinctly "African" landscape provided the appropriate backdrop with which to highlight the human suffering which AIDS and tuberculosis were causing in the context of poverty and cultural difference. Peripherally involved South African clinicians who knew about Tugela Ferry were inclined to believe in the intrinsic wholesome nature and justification of research there. Dr. Moll and some of his colleagues in Tugela Ferry were famous in clinical circles for their inspirational dedication to working in difficult conditions to help their destitute, rural patients. It was tempting to think of Tugela Ferry and its Church of Scotland Hospital (COSH) as home to a close-knit community where poor patients work hand-in-hand with physicians and researchers. Durban-based researcher Nesri Padayatchi, in a conversation about community advisory boards (a formal mechanism through which community members are consulted about research), stated: “I think the way COSH operates, you know, and it’s a small community, COSH is actually a whole CAB [community advisory board] in itself, because they work quite closely with the
community.” This was a rather bold claim, considering that the Church of Scotland Hospital is a 350-bed hospital with hundreds of nurses and sometimes over a dozen doctors, serving a potential population of just under 200,000 people.

Implicit in the ways both Friedland and Moll spoke about Tugela Ferry is the notion that there is an “Africa” or “real Africa” out there that desperately requires intervention. In modern, urbanized, industrialized South Africa, this real Africa is not always readily apparent, but must first be found. Friedland left his research site at a clinic in bustling downtown Durban to find a more rural location where he might have a greater impact; Moll, similarly, turned away from the little rural town of Tugela Ferry on the main access road to the less accessible bush in order to make a more compelling argument that his potential collaborator should chose his area as a research site. Of course, Durban, Tugela Ferry, and outlying Msinga are all “in Africa.” What, then, does this term mean (other than a continent which can be found on a map), and what work does it do in global health research?

As James Ferguson has pointed out, Africa is often represented as a continent in constant crisis and in need of help, defined by “tradition,” “simple societies,” and “societies without history.” The concept of Africa serves as a type of pre-formed shorthand that draws on a cluster of associations and pre-conceived notions. These associations are at work in the fundraising campaigns which show bloated black children in ragged clothes looking with pleading eyes into the camera; the same shorthand is in operation when a Lufthansa clerk in the Berlin airport tells me I should not be surprised that the airline lost my luggage on a flight that originated in Africa, afterall. As Ferguson puts it (paraphrasing

---

535 Nesri Padayatchi, interview by author, 6 April 2010, Durban, South Africa.
536 The assumption that COSH has essentially achieved the aspirational ideal of immediate community involvement was also somewhat dangerous, since it rendered unnecessary a close consideration of research ethics in Tugela Ferry.
Achille Mbembe), Africa "serves as a metaphor of absence – a “dark continent” against which the lightness and whiteness of “Western Civilization” can be pictured.”

Dr. Moll taps into a complex set of notions about Africa, then, when he says he drove Dr. Friedland “back in time to real old Africa, where patients [...] are really in bad circumstances out there in the rural community.” Time-travel has been achieved by moving through space to find something that matches a more authentic conception of Africa, whose inhabitants “don’t have electricity, don’t have water supply, live off the ground, you can say, there's no cell communication, basically cut off from modern facilities." This depiction implicitly (even if not explicitly) coexists with the notion that poor, traditional Zulus have been scratching away at the earth for generations, barely getting by for lack of initiative, lack of environmental stewardship, and held back by their own backwards cultural practices. Of course, Friedland himself acknowledged KwaZulu-Natal and South Africa's much more complicated and exploitative history by describing Msinga as a “former Zulu homeland.”

**Finding the real Africa**

In the minds of visitors and locals, the “Africa” of poverty, lack of infrastructure, disease, backward culture and much-needed intervention coexists with a more romantic

---

538 Ferguson, *Global Shadows*, 2.
541 I regularly encountered these ideas during my stay in South Africa, including in Tugela Ferry. Doctors working in Tugela Ferry often expressed the opinion that their patients were in part to blame for their own poverty and backwardness; the main Zulu preacher at the local mission frequently blamed people's misfortunes on traditional ancestor worship; one of my Zulu hosts wondered out loud why it was that Zulus were lazy and poor, while refugees in the community managed to eke a living through resourcefulness and very hard work in difficult conditions; one physician (who worked very hard for his Zulu patients) commonly made comments that Zulus only had their own backwardness to blame for their misfortunes.
542 Friedland, interview by author, 2007. Dr. Friedland’s own sense of South African history was in part shaped by the novels of South African author Zakes Mda. He recommended the novel *Hearts of Redness* – a book which is inspired by Xhosa history and which traces the causes of contemporary conflict to unresolved historical grievances and the merciless march of capitalism – to all of his colleagues who came to work in Tugela Ferry.
“Africa” of stunning landscapes, traditional arts and crafts, exuberant song and dance and large majestic animals, as well as mystical moments of self-recognition. In the city of Durban, international visitors (including biomedical researchers) are often surprised at just how difficult it is to find either “Africa” in this town of sunny beaches, Botanical Gardens, horse-races, casinos, and several large, fancy, air-conditioned indoor malls selling familiar brands at familiar prices. McCord hospital, for example, a common site for clinical tourists in Durban, is located at the edge of a wealthy and mostly white part of town where gated villas and apartment complexes compete for views of the Indian Ocean. Nearby coffee shops offer wireless internet, scones for breakfast and pizza topped with avocado, butternut and feta for dinner. Local flavor can be found at down-town tourist traps: Indian spice markets, the muthi market (where African women in traditional attire sell herbs and roots), and beachfront stalls selling beaded jewelry, Zulu hats and carvings from all over the continent. Durban presents itself to biomedical visitors as a stuffy suburb of a sunny beach town. Those with aspirations to discover the “real” Africa often find they need to leave the confines of the city to do so.

Relatively few visitors sought out Msinga. For many South Africans Tugela Ferry and the surrounding Msinga represent a “deep, deep” rural Africa in its most intimidating and devastating form. South Africans remember Msinga as the site of intense “faction fighting” or “tribal violence,” in the 1980s and 1990s and as far back as the 1880s. Throughout the apartheid era, Msinga was emblematic for South Africa’s long-standing legacy of segregation and devastating policies of the apartheid government that actively removed black people from their homes and relocated them to some of the least desirable territories of the

country. Due to low rainfall and poor soil, only limited parts of Msinga were suitable for cultivation even before people were concentrated there. As early as 1846, the first British Magistrate assigned to the Msinga region was dismayed to arrive in an area as “barren as the sand of Arabia.”

Today, the area is still known for deadly criminal and political violence, crushing poverty and disease, as well as a strong adherence to traditional Zulu culture, including polygamy, practices of deference and respect (ruling the relationships between women and men) and the keeping of cattle and goats. The circulating notions and mental images are dramatic – one Bed and Breakfast owner in a more quaint part of KwaZulu-Natal asked a friend living in Tugela Ferry how she coped with hearing the screams of the women being raped at night; another friend of mine once asked me how often I heard gun-shots. As a 1990 book review in the New York Times put it, “Msinga is one of the most violent, most ecologically devastated places in South Africa.”

One person who shaped both South African and international outsiders’ perceptions of the Msinga region is South African journalist and author Rian Malan. In the final chapters of his internationally circulated best-selling memoir My Traitor’s Heart, Malan engages with simultaneously beautiful and devastating images of Msinga. Throughout the book, Malan explores his social position and conscience as a white, Afrikaaner, South African who identifies as an anti-apartheid liberal expat in the US, yet finds himself both unable to

545 Thanks to Jeffrey Guy for this quote. I don’t currently have the correct citation for the source.
546 I am not claiming that these accounts are accurate in any simple way, but that these are the dominant circulating descriptions.
547 The answers to those questions: though no doubt women were raped in Msinga and throughout the world during my stay there, I never heard their cries; I also never heard gun-shots (though I heard several stories about shootings).
process his white guilt and unable to identify with black Africans in the rapidly changing South Africa of the late 1980s. In an attempt to gain meaning from these conflicted emotions, he travels to Msinga to seek out Creina Alcock, the widow of Neil Alcock, a white liberal who immersed himself in rural Msinga life and dedicated himself to helping Zulu agricultural development but ended up being murdered.\(^{550}\)

The book was read by many of the mid to long-term clinical visitors to Tugela Ferry, and also by some of the short-term medical residents. In the book, Malan grants that the Msinga landscape at sunrise has “enormous dramatic potential,”\(^ {551}\) but he also describes Msinga as a “shithole”\(^ {552}\) and “famine-stricken hellhole,”\(^ {553}\) which is incredibly resistant to change or improvement. Malan struggles to “explain” Msinga and its significance:

Msinga is ... Oh, God, how do I explain Msinga? Msinga is wild, and yet it is not leaping with buck and lions. There is probably not a single antelope left alive in the entire valley. The district is crisscrossed by tar roads and power lines, packed with tin-roofed shanties and mud huts. It is a place of head-spinning contrasts. In Msinga, you see black men driving goats, and black men driving BMWs. You see Zulu women going down on all fours at the feet of nondescript old men in ill-fitting three-piece suits; they are tribal chiefs or headmen, and must be shown respect. You see bare-breasted Zulu maidens with shaved heads and bodies draped with beads. They seem to have stepped out of National Geographic, but if you look closer you see that they’re wearing Day-Glo leg warmers and running shoes. You see men in traditional dress carrying briefcases through the bush, and school-uniformed teenagers dancing through the wastelands with ghetto blasters on their shoulders. So Msinga isn’t quaint, and it’s not storybook Africa. It is a sprawling rural slum, infested with dope smugglers, gunrunners, and bandits. It is the iron age shit squalling and sullen into the twentieth century. Its people look broken as they eat the dust of your passing car, but in their hearts they are proud and untamed, and utterly ungovernable by anyone\(^ {554}\) (emphasis added).

How Malan knows what is in Msinga residents’ hearts I cannot say, but in other words, Msinga is a confusing mess that simultaneously conforms to African stereotypes and defies them. I quote Malan at length not to argue that his impressions of have shaped

\(^{550}\) Ibid.
\(^{551}\) Ibid., 344.
\(^{552}\) Ibid., 360.
\(^{553}\) Ibid., 367.
\(^{554}\) Ibid., 354–355.
tuberculosis research in Tugela Ferry in any meaningful way, but as a tool with which to explore the complex and confusing ways in which global health research relies on the ambiguous and contradictory juxtaposition of tradition and modernity or poverty and commercial (and academic) resources.

Visitors and locals alike emphasize that Msinga is a traditional place. The logo of the research and care organization, Philanjalo, is a sketch of an iconic traditional Zulu thatched-roof rondavel (round-hut) on a hill surrounded by trees; photographs from Msinga often feature women in traditional Zulu attire. Modern Tugela Ferry residents are often fashion conscious and dress in trendy jeans and tailored blouses but they also show off their Zulu style, documenting their tradition-inspired wedding and heritage day outfits of leather loin cloths and shields, or beaded necklaces and skirts on facebook.

In narratives about Msinga and Tugela Ferry, appealing images of a traditional, rural, self-sustaining, self-contained agricultural life were easily, yet uncomfortably, linked with less appealing notions of African poverty, violence, lack of infrastructure (roads, electricity, water, sewage, education), corruption, cultural "backwardness" and disease. Hans Human, the CEO of the Church of Scotland Hospital in Tugela Ferry between 2005 and 2011, is a white Afrikaans-speaker who had worked his way through municipal bureaucracy positions in small towns of different South African provinces. When he decided to take the job in Tugela Ferry he imagined the area as a calm, restorative place: "When you drive through small little towns, you see the old people, sitting, moving after the sunshine, at the rondavel. You see the women working in the mealies, [who] carry wood, everything looks so peaceful, and so quiet, and so relaxed." His first impressions of a rural idyll were deceiving. Instead he found a stressful work-environment, where the staff was

555 Rondavel = traditional Zulu round hut.
556 Mealies = Field corn.
557 Hans Human, interview by author, 14 January 2011, Tugela Ferry, South Africa.
embroiled in institutional politics and infighting: "My perception quickly died off. From 'this peaceful little village' to 'It's just chaos.'”

Dr. Ade Apelehin, a Nigerian physician who came to Tugela Ferry as a stepping stone towards geographic upward mobility, similarly thought that a job in Tugela Ferry would be a wholesome change from his urban hospital job. Years earlier, during an assignment in rural Nigeria, he said he enjoyed relative calm and a high degree of respect. Yet he soon learned that African rural quaintness was not the same everywhere. He had known about high rates of tuberculosis and AIDS, but also struggled with xenophobia, professional jealousies, and a constantly perceived undercurrent of the risk of violence.

The *Time Magazine* article that launched Dr. Moll’s AIDS work to international prominence (and the attention of President Bush’s speech-writers) in 2001 presented Msinga as one of the many sites of a generic African nightmare, where AIDS is a fire in the “dry timber of African societies,” which is killing millions. It is a silent fire, not evoking the outrage and action it deserves due to overwhelming stigma and denial that “cannot keep the virus at bay.” The author describes how, accompanied by Dr. Tony Moll, “who has driven [her] up the dirt track from the 350-bed hospital he heads in Tugela Ferry,” she noticed the potential - yet unfulfilled – beauty and promise of Msinga’s landscape: “The spectacular view of hills and veld would gladden a well man, but the 22-year-old we will call Fundisi Khumalo, though he does not know it, has AIDS, and his eyes seem to focus inward on his simple fear.” According to McGeary, Msinga at this time was not a place to live, but a place to

---

558 Ibid.
559 Pay was also better since government physicians working in Tugela Ferry receive hardship pay for working in a former homeland area. The difficulty of recruiting physicians also meant that Dr. Apelehin, a relatively young doctor, was promoted to a higher ranking physician than he would have been in Pietermaritzburg.
560 Ade Apelehin, interview by author, 24 February 2011, Pietermaritzburg, South Africa.
die. Mr Khumalo had been working in Johannesburg, and knew many other men who were “on-and off sick.” “When they fell too ill to work anymore, like him, they straggled home to rural villages like Msinga Top.”

Msinga was not just the place of final despair, however. McGeary found hope from this despair in the fact that “every day good people are doing good things. Like Dr. Moll, who uses his after-job time and his own fund raising to run an extensive volunteer home-care program in KwaZulu-Natal.” Msinga was also a place for redemption and respite. As one Cape Town Christian blogger stated after returning from a mission trip: “Msinga is about hills and hills of dry grasslands, breathtaking sunsets, life-changing spiritual sessions, resting and finding yourself part of a new family, the family of Christ. It's about reaching out to those who really need it the most, it's about forgetting about yourself for at least two weeks, letting God work through you and it's about meeting and learning from new and interesting people.”

At this point you, the reader, may wonder what all these meandering and contradictory impressions of Msinga really mean for drug-resistant tuberculosis or global health research. In my view, the simultaneous conception of Tugela Ferry as rural African idyll and African disaster was not just incidental to the HIV and tuberculosis research and care that took place there. In the 1980s Dr. Moll, who had recently completed his medical training in Cape Town, South Africa, found himself seeking out Tugela Ferry as a place to practice bread and butter medicine as a Christian and to fulfill his sense of mission among people who needed him. He has been described as a country doctor who actively eschewed high-powered academic medicine and research at the beginning of his career in

---

562 Ibid.
564 Anthony Moll, interview by author, 13 May 2011, Tugela Ferry, South Africa.
order to live in a remote area. At the same time, international biomedical professionals like Prof. Friedland found themselves drawn to Tugela Ferry by the opportunity to conduct such research at the peak of a devastating and internationally important epidemic while having a maximum impact on an identifiable community. In the wake of Dr. Friedland’s involvement in Tugela Ferry, dozens of US-trained physicians, medical students and nursing students (among others) sought out opportunities to work in Tugela Ferry, as well. For his part, Dr. Moll turned out not to be a “simple” country doctor and became comfortable conducting research and representing XDR-TB to the international community at HIV/AIDS and tuberculosis meetings around the world. Yet the rural and remote nature of Tugela Ferry as a research location, and the intense needs of the poor, rural, black and South African study population remained central to Friedland and Moll’s presentations on XDR-TB. The local details get somewhat lost in front of an international audience, however, as Tugela Ferry morphs into a generic sub-Saharan African site of biomedical and social intervention. The rural African location of Tugela Ferry remained crucial in the recruitment of clinicians and researchers to the area. Researchers almost seemed to work off a generic, though compelling, script when describing the place to biomedical audiences.

Dr. Sheela Sheno, who was a Yale infectious disease fellow conducting operational research in Tugela Ferry under Dr. Gerald Friedland’s mentorship, who also supervised visiting medical residents working in Tugela Ferry’s HIV clinic explained to me how she described Tugela Ferry to a Yale audience. (I asked her what her “spiel” is.)

The spiel is that this is a small, very rural area, serving about 200,000 people, at a district level hospital that’s serving a very traditional Zulu population, who are very poor and disadvantaged, and in an area that’s been hugely affected by HIV and TB, and there’s a large-scale epidemic of both HIV and TB here, reflective of HIV/TB in - generally - in sub-Saharan Africa. There’s a third epidemic of MDR/XDR-TB here

---

566 Clearly there is something to be said here about the perceived moral value of helping (helpless) rural “traditional communities” versus helping disparate, mobile, urban moderns.
that complicates everything. But that there is a lot of fascinating clinical pathology to be learned, and the exposure to HIV and TB is immense, and that is something you will not get anywhere else; certainly not in the US. And [visiting doctors are] just going to have a fantastic clinical experience. You know, the other part of that is to understand a little bit about traditional Zulu culture, and to learn about the interplay between social-cultural factors and the relationship to HIV and TB. Obviously there’s a limit to what you can do with that, but it’s not solely clinical practice. So, like what are ARVs, and the side effects of TB meds and stuff like that.\textsuperscript{567}

In her description, Dr. Shenoi considers both generalizable and unique aspects of Tugela Ferry. She emphasizes that Tugela Ferry is \textit{generalizable to sub-Saharan Africa as a whole} in as much as it is rural, small, traditional, poor, and HIV/TB affected, as well as a great clinical training site superior to opportunities available in the US. Tugela Ferry is \textit{unique} in its emphasis on MDR/XDR-TB, and in its particular (limited) local color, where social context is important, though primarily interesting as it relates to clinical treatment.

Similar pitches were used in promotional materials used by Yale and Philanjalo. Shenoi stressed that Tugela Ferry is in a “Zulu” area – not simply African – and mentioned the unique status of drug-resistant tuberculosis in this region. The rest of the description, however, applies to many sites of global health research in sub-Saharan Africa. It ignores some of the darker things that preoccupy South Africans when they discuss Tugela Ferry – including the risk of violence and the risk of infection with deadly tuberculosis. Also not incorporated is the fact that visitors who come to this “small, very rural” area find themselves in the bustling trade town of Tugela Ferry, living in comfortable accommodations within a gated compound.

This last point could lead to surprise. One medical student who came to Tugela Ferry on a clinical fellowship blogged praises for the comforts that were available: “My new place, [...] is pretty plush. It is fully equipped with electricity which runs an air conditioner, ceiling fans, refrigerator, and microwave \textit{reliably}. Likewise, there is running hot and cold

\textsuperscript{567} Sheela Shenoi, interview by author, 20 August 2010, Tugela Ferry, South Africa.
water that leads to **functioning** toilets, sinks, shower and even a washing machine. Last, but certainly not least, in the amenities category is the wireless internet that is allowing me to write this post - it is sometimes a slow connection, but it gets the job done”\[568\] [emphasis in original]. Zahir Kanjee, who first went to Tugela Ferry as a Yale medical student to conduct research on infection control in 2007 also found the accommodations “much nicer than [he] expected” and “pretty comfortable.”\[569\] He came to the conclusion that “practicing medicine in resource-poor settings [...] can be very much like practicing medicine in other, non-resource-poor settings.”\[570\] Years later he expressed regret about the lack of direct community contact during his stay: “I didn’t go out in the community a whole lot, I didn’t make a lot of friends out here. I worked. A lot.”\[571\]

Dzovag Minassian, a doctor who came to Tugela Ferry for five weeks as part of the Johnson and Johnson global scholars program in 2011, and wrote a highly readable blog about her experiences, was less impressed with her accommodations.\[572\] While the students mentioned above blogged frequently about other visiting Americans at the hospital, Minassian presented herself as a lonely, heroic, white doctor roughing it in difficult circumstances as she provided medicines to masses of sick Zulus.\[573\] The importance of well-trodden tropes about Africa was made explicit in her narrative: just as Rian Malan compared the inhabitants of Msinga to ethnographic photographs in *National Geographic*,\[574\] Minassian compares herself to explorers on the cover of *National Geographic*. She finds inspiration for her weekends away from the hospital in the luxury getaways depicted in

---

\[570\] Ibid.  
\[571\] Zahir Kanjee, interview by author, 25 August, 2010, Tugela Ferry, South Africa.  
\[574\] Malan, *My Traitor’s Heart*, 354.
**Condé Nast Traveler.** She articulately conveys Tugela Ferry as a place that is and is not African and rural and describes it, among other things, as “anytownafrica,” “a bustling rurapolis,” and “where the donkey croaks.” Other expats and white helpers tend to disappear from her narrative, and the trilingual Zulu law student who babysits for her toddler-aged son becomes simply a Zulu nanny. She assumes herself, her son, and a friend who accompanied her, the center of a racially precarious spectacle: “Two white women in a shiny Chevy, a blond-haired boy with piercing blue eyes and a khaki hat in a carseat in the back [...]. He is craning his neck to soak in the unfamiliar scene of people spilling into the road balancing sacks of potatoes on their heads, toting sleeping babies bundled tightly in towels cinched around their waists, pushing wheelbarrows or pulling cattle. And they are staring back.”

Echoing Conrad’s *Heart of Darkness*, Minassian tries to “make sense of how anyone, including ourselves, can stay afloat in this wild place.” After staring death in the face at the HIV clinic, she finds comfort in the fact that in the absence of a sense of time or urgency, and away from her American city obligations, she learns to let things go and to focus on the big things, primarily her toddler-age son.

Thus Msinga is experienced in multiple, intensely loaded ways: a hostile and deceptive place of dark violence and despair; a redemptive place where meaning can be found; a place of community and wholesome values; an under-resourced, *rural* place waiting for an intervention. Malan calls the notion of rurality into question with his description of Msinga not as storybook Africa, but a “sprawling rural slum;” similarly ambivalent is Minassian’s use of the term “rurapolis.” Msinga’s being “rural” means different things to different people: For Hans Human and Ade Apelehin, rural deceptively meant peaceful. For American Peace Corps workers and student missionaries from Cape Town,

---

576 Ibid.
577 Ibid.
rural often meant dealing with extensive language difficulties. One urban Zulu research worker had thought that rural people were particularly friendly until she came to Msinga and found the population polite, but distant. Several visiting Americans described difficulties connecting with “locals” that violated their expectations for close relationships with their rural neighbors. As one American student expressed, it was rather strange to travel all the way to South Africa to spend evenings and weekends with Americans (and Europeans) from elite medical schools inside a gated compound. In many conversations rural simply implied a lack of basic infrastructure. Even as Tugela Ferry’s rural location and lack of resources seemed important to its essence as a site of global health research, Americans who spent time working there both undermined and reified the implied ideas about remoteness, hardship, and community.

Sara Anjargolian, a photographer who accompanied Dr. Dzovag Minassian to Tugela Ferry for five weeks to document life with HIV, struggled – like many others – with the difficulties of connecting to an unfamiliar place on a tight timetable. She, too, needed to find a narrative that matched both her conceptions of herself and of rural Africa. For her, coming to Msinga became an exercise in redemption as she learned patience, and discovered how to “think like a Zulu,” as she put it in a TEDx talk about her work. After initial challenges accessing her desired photographic subjects Anjargolian left town with some compelling images that emphasized the dignity of her photographic subjects.

Anjargolian was one of many photographers who had come through Tugela Ferry to document the suffering and resilience of “the Zulu people” in the face of AIDS and

579 TEDxYerevan - Sara Anjargolian - What the Zulu People Taught Me About Photography and Life.
tuberculosis in the past 10 years. In my own research in Tugela Ferry I often heard grumblings about photographers and the images they literally “took” from Tugela Ferry. People especially expressed concern about a style of photography (used by James Nachtwey, for example,) which emphasized the emaciated bodies of dying black subjects by employing the high contrast of well-lit black-and-white images. One black HIV counselor broke polite racial protocol while referring to photography from Tugela Ferry that she had seen: “I think I am not going to be appropriate now. We as blacks feel [...] ‘Why do they always have cases of black people? They don’t have maybe whites and if white, they are nice and they are good looking. Not very sick, you know? I just had that thing in my mind. That it’s not good and then we feel sad and bad for the person. Really bad for the person who is on the photos.”

These photographs (of Nachtwey’s emaciated patients in hospital beds as well as Anjargolian’s nicely dressed TB patients in front of their houses) help represent the under-resourced yet worthy place that is stressed the most in research presentations and papers, in photo-essays and brochures, and which provides the justification for the expenditure of considerable resources and effort in conducting scientific research and initiating treatment interventions in countless global health locations around the world. It is the successful accumulation and analysis of data generated by this research which builds the foundations for conference presentations, journal publications and academic careers. Yet it is a sense of adventure, moral obligation, and complex set of assumptions about the relationships of power and obligation between “us” and “them” that drives individuals to engage in the global health enterprise.

POSTLUDE: An Ongoing Crisis and the Tyranny of Koch

In chapter 1 I argued that the story of public interest in tuberculosis can be told as a story of repeated cycles of escalation followed by retreat and decline, or, inversely, as “recurrent cycles of neglect followed by resurgence.” This dissertation has followed XDR-TB from its early stages as the predicted but as yet undocumented (and unnamed) consequence of imperfect and underfunded MDR-TB treatment programs to its mature existence as a well-documented, well-studied infectious disease that threatened the health and lives of people across the globe, but especially in Tugela Ferry, South Africa. As we have seen, global emergency meetings were called, treatment pilot programs in Southern Africa were initiated, new HIV/TB research programs in South Africa obtained funding, and scores of people were drawn to Tugela Ferry to participate in the response to XDR-TB.

Tuberculosis care in Tugela Ferry was transformed as the local public health structure worked with international experts, local nurses, and motivated researchers to put in place a simultaneously innovative and pragmatic program for the community-based management of drug-resistant tuberculosis.

The global narrative of XDR-TB, with its media-ready name that conjured up notions of danger and mystery, was a crucial part of the success in generating interest and action in South Africa and abroad. Scientists, public health policy experts and clinicians worked to give XDR-TB a name and definition that was scary and inclusive; in South Africa, XDR-TB took on the emotive power of the African AIDS epidemic. Bodies ravished by tuberculosis and the backdrop of the stark Msinga landscape provided compelling visual evidence for the human toll drug-resistant tuberculosis was taking. International health agencies, private

donors, academic institutions, as well as government agencies at every level responded with expertise and resources.

By the time I arrived in Tugela Ferry in 2010 much of the excitement and trepidation of dealing with a new and life-threatening illness had given way to the every day work of treating patients and collecting data according to now-established protocols and practices. Many clinicians and researchers felt they had determined some of the key epidemiologic facts about XDR-TB and MDR-TB in Tugela Ferry and were ready to focus on operational details of TB treatment and to share their experiences in treating and managing drug-resistant tuberculosis with programs in other parts of the country. General public interest in XDR-TB in Tugela Ferry had significantly died off, though numerous presentations on XDR-TB in South Africa kept the conversation going at scientific conferences and in public health forums. XDR-TB rates in Tugela Ferry had significantly declined within three years after its discovery and in June 2014 Dr. Friedland could proudly give a keynote address to the South African TB Conference titled “The rise and fall of XDR-TB in Tugela Ferry – how we did it.”

Even as XDR-TB risked falling into a phase of neglect (or triumph), however, South Africa continued to be an essential reference point in discussions about drug-resistant tuberculosis. In 2011 the death of a health care worker in the UK whose MDR-TB was linked back to his previous employment in Tugela Ferry via molecular epidemiology (thus proving one instance of the global spread of MDR-TB from South Africa) was of sufficient interest to warrant publication in a reputable medical journal. More recently, in October 2012, an online report about the use of a new medication for drug-resistant tuberculosis in South

Korea was introduced with a vignette about Tugela Ferry and included an image of the Msinga landscape.585 It seemed like the author decided that cases in South Korea alone could not sufficiently convince the reader of the importance of MDR-TB and XDR-TB treatment.586 In July 2014 a South African XDR-TB patient, who was successfully cured with a new, expensive drug that is not yet widely available, brought the work of MSF (Doctors Without Borders) in Khayelitsha, South Africa, to public attention when she and her doctor delivered a Drug-Resistant TB Manifesto to the World Health Assembly in Geneva, Switzerland.587

**Escalation is inevitable**

Of course, XDR-TB in South Africa is not the final chapter of the history of escalating TB-drug resistance. In January 2012 I came across the following headline: “India Reports Completely Drug-Resistant TB.”588 After a epidemiological paper documenting four cases of “Totally Drug-Resistant Tuberculosis” (or TDR-TB) at a hospital in Mumbai, India, generated low levels of interest, Indian physicians reported their apparently untreatable cases (then twelve) to the Indian press.589 This was soon taken up by international science and news publications, including *Wired* and *Nature*.590 As had been the case with South African XDR-TB, reports pointed out that TDR-TB in India was the result of long-standing systemic problems with the implementation and management of TB treatment as well as difficulties

---

of diagnosis.\textsuperscript{591} The revelations of TDR-TB in India also led to a reaction from the WHO: a series of meetings was called to discuss the problem. However, unlike with XDR-TB, the WHO chose not to endorse yet another name for an increased degree of TB drug-resistance, and decided that the cases seen in Mumbai should be categorized as a sub-type of XDR-TB. This, meanwhile, allowed the Indian government (in a response not so different from early official South African responses to XDR-TB) to argue that the doctors in question were being misleading by claiming their patients had a disease that did not officially exist.\textsuperscript{592}

The cases in India were not the first ones for which the term TDR-TB had been used in the published literature: a 2009 publication from Iran had announced the “Emergence of New Forms of Totally Drug-Resistant Tuberculosis Bacilli.”\textsuperscript{593} Interestingly, the same research group had published a series of Iranian XDR-TB cases in 2006 before the now-famous South African cases were published.\textsuperscript{594} The Iranian cases alone did not generate much traction in the international conversation about drug-resistant tuberculosis, however. As we have seen throughout this dissertation, documented, published epidemiological data is only one part of a compelling infectious-disease narrative.

Several technological advances in TB treatment and diagnosis have taken place since the naming of XDR-TB in 2005. At that time, TB diagnosis in most places still relied on techniques developed in the late 19\textsuperscript{th} century, and no new anti-TB drugs had been approved by regulatory authorities since the 1970s. When early policy responses to XDR-TB focused

\textsuperscript{591} In South Africa analysis focused mostly on failing government systems and the difficulties of accessing care; in India government physicians often blamed the rampant, uncontrolled access to tuberculosis drugs from private doctors and other medical practitioners who did not prescribe the correct treatment course and did not monitor the drugs appropriately.


\textsuperscript{594} Mohammad Reza Masjedi et al., “Extensively drug-resistant tuberculosis: 2 years of surveillance in Iran” \textit{Clinical Infectious Diseases} 43, no. 7 (2006): 841-847.
on technological, pharmaceutical and laboratory interventions I was intensely skeptical. It seemed self-evident to me that the solution for a fundamentally social disease tied to poverty and poor living conditions had to be social, rather than technological. Improved socioeconomic conditions and old technologies had been sufficient in many “developed” countries to keep tuberculosis at bay most of the time.

There clearly was room for technological improvement, however, and new funding mechanisms and partnership models motivated by the XDR-TB scare have been credited with supporting the successful design and implementation of new or improved TB diagnostics tests that are faster and more effective than previous methods. Specifically, a technology called GeneXpert has shown promise as a low-skill technique for detecting drug-resistant tuberculosis and has been implemented in many TB treatment sites. In addition, there has been active development of new anti-tuberculosis drugs, three of which have shown the potential for improving the chances of survival for people with XDR-TB and MDR-TB.596

Unfortunately, even as the diagnosis and treatment of drug-resistant tuberculosis improves the diagnosis of MDR-TB or XDR-TB remains a bleak event. MDR-TB, when managed according to WHO guidelines, continues to have an overall treatment success rate

of less than 50%. On the occasion of World TB Day 2014 health journalists in South Africa took the opportunity to review the state of MDR-TB and XDR-TB treatment in the country and came to the conclusion that despite increasing efforts to combat tuberculosis of all forms the situation looked grim. The ability to diagnose MDR-TB had improved (and recorded cases between 2007 and 2012 doubled), but only 42% of those diagnosed with MDR-TB initiated treatment. Of those, only 40% successfully completed treatment, according to government figures. The decentralized management of MDR-TB whose success was heralded in KwaZulu-Natal in 2011 has not yet been successfully implemented in all provinces. According to WHO statistics, South Africa also continues to have the world’s third-largest MDR-TB burden and the biggest case-load of XDR-TB world-wide. In neighboring Swaziland, the potentially devastating personal journey of MDR-TB patients was highlighted in a recent PBS Frontline documentary. The protagonists of the film struggle greatly to follow their treatment course, and only one of them reaches the conclusion of her multi-year treatment for drug-resistant tuberculosis during the filming period – through death. There are no simple success stories here.

A recent Lancet publication from three provinces in South Africa (not including KwaZulu-Natal) found that long-term outcomes of patients treated for XDR-TB were very poor, independent of HIV status, with only 16% of the patients followed having a favorable

---

599 Ibid.
outcome (cure or completion of treatment) after 24 months of follow-up.\textsuperscript{601} In addition, researchers documented transmission of MDR-TB and XDR-TB from patients to community members once patients were discharged home. Thus the debate regarding the dangers of discharging infectious MDR-TB and XDR-TB patients home rather than keeping them in hospitals is ongoing.\textsuperscript{602} Reviewing the study, Neil Schluger and Max O’Donnell (who has worked on XDR-TB in Durban) concluded that “drug resistant tuberculosis is an acute global health crisis” and that “the situation regarding MDR and XDR tuberculosis is bleak.”\textsuperscript{603}

As we have seen, the drug resistant tuberculosis crisis has been “acute” for almost three decades now. Harvard epidemiologist Carole Mitnick has been co-authoring papers highlighting the global dilemma of MDR-TB at least since 1998,\textsuperscript{604} and in 2012 stated that neither XDR-TB or TDR-TB were new, but simply described a phenomenon that “in general doesn’t receive a lot of attention.”\textsuperscript{605} Long-time CDC-based TB specialist Peter Cegielski was alluding to the repeated escalation of TB drug-resistance and the recurring waves of interest in it when he quoted Bob Dylan in the title of a paper: ”There Must Be Some Kind of Way Out of Here.”\textsuperscript{606} Even as TB experts are well aware of the cycling and escalating history of the TB crisis narrative, however, successful advocates for TB care and research seem to have also recognized that repeated volleys of powerful language, compelling narratives, and

impressive imagery are crucial to directing funding and attention towards their cause. Many TB experts are well trained in the social conditions that underlie tuberculosis and know that poverty, inequality, and local politics can undermine well-intentioned efforts to provide tuberculosis care.\footnote{Several of them have combined training in medicine and anthropology, for example, and have conducted extensive fieldwork studying the connections of poverty and disease. Examples of MD/PhD’s in anthropology who have played a role in TB policy include Paul Farmer, Jim Kim, Salmaan Keshavjee and Jennifer Furin. Others, such as Ernesto Jaramillo, identify themselves as having been trained in social medicine.} Often, however, calls for TB funding focus on alarming statistics, potential risk of personal harm, and the pursuit of technical fixes. It is easier to operate politically in terms of epidemiology, laboratory standards, and technical definitions than to directly advocate for specific types of poverty alleviation strategies, let alone fundamental economic and political reform.\footnote{For discussions of the politics of WHO technical reports see, for example, Joanna Radin, "Life on Ice: Frozen Blood and Biological Variation in a Genomic Age, 1950-2010" (Doctoral Dissertation, University of Pennsylvania, 2012) and Hodžić, Saida, "Ascertaining Deadly Harms: Aesthetics and Politics of Global Evidence," \textit{Cultural Anthropology} 28, no. 1 (2013): 86-109.} This is especially true for action within the WHO, which specializes in expert meetings and technical reports based on a negotiated global consensus.

In the introduction to this dissertation the German physicians Rudolf Virchow and Robert Koch represented two schools of late 19\textsuperscript{th} century thought regarding the causation of tuberculosis, whereby Virchow emphasized the social causes of disease, and Koch wholeheartedly supported the search for bacteria as the cause of illness. Intriguingly, the Berlin conference venue of the 2012 World Union Meeting of the International Union against Tuberculosis and Lung Disease sported both a "Virchow" room and a "Koch" room. During an interview in the lobby of a nearby hotel, Ernesto Jaramillo, of the STOP TB department of the WHO, lamented the lack of Virchowian spirit in the Union and wished for an increased focus on poverty alleviation. "We live under the tyranny of [Robert] Koch, [...] fixated on new diagnosis, new drugs, and new vaccines."\footnote{Ernesto Jaramillo, interview by author, 12 November 2010, Berlin, Germany.} Meanwhile, physician and anthropologist Salmaan Keshavjee, who worked for Partners in Health’s MDR-TB programs in Russia and...
Lesotho and helped develop the Green Light Committee (which provided concession priced MDR-TB drugs to pilot projects), was less interested in dwelling on the socio-economic causes of tuberculosis. “TB is linked with poverty. [...] You know, we've known that for millennia.” Instead he compared tuberculosis with a broken leg: “We don’t know why you broke your leg. You could live in this unsafe environment, you could have been abused [...] you could live in a bad neighborhood where they don’t fix the potholes and then you tripped. [...] But the leg is broken, so when you see the doctor do you want the doctor say [...] ‘let’s sit on this for a bit and figure it out?’ Or do you want him to put a cast on you? [...] Certain things require reductionism because they're urgent. Or emergent in the case of XDR-TB.”

The multi-layered, complex process of translating the smoldering crisis mode surrounding drug-resistant tuberculosis into urgent (or emergent), technocratic, global and local public action has been at the center of this dissertation. I have attempted to link the the global and the local by tracing the movement of XDR-TB related data, expertise and processes of meaning-making between placeless halls of power (be they in Geneva, Atlanta, New Haven, Seattle, Boston, Toronto, Paris, Berlin, Durban or Johannesburg) and the clearly “placed,” or locatable, district hospital in rural Tugela Ferry, South Africa. XDR-TB did not really gain the ability to mobilize attention and resources until it became associated with Tugela Ferry, a place upon which public health experts as well as the interested lay public could project their fears. These included the fear of a global epidemic of a deadly, untreatable, airborne illness in the context of a devastating AIDS epidemic and

---

610 Salmaan Keshavjee, interview by author, 11 November 2010, Berlin, Germany.
611 Salmaan Keshavjee, interview by author, 11 November 2010, Berlin, Germany.
612 Of course these halls of power themselves are shaped by their location. I use the term “placeless” here primarily to indicate that the powerful experts I discuss in this dissertation can meet and make decisions in any number of places. It does not really matter, as long as there is an airport nearby and a venue to meet.

Here I have tied together into one document the creative craftsmanship that goes into naming and defining a new, scientific disease entity, the political messiness of acknowledging an expensive and life-threatening disease affecting a region, and the challenges of riding a vehicle with poor suspension across packed-dirt roads in order to then tenderly probe a painful buttock to find a good injection location. These seemingly disparate activities, however, all are linked together through a particular disease entity – XDR-TB – and each one of them (along with many more) helps constitute our understanding of XDR-TB, its significance, and how we interpret the response to it. The story of XDR-TB in Tugela Ferry is a complex story of presences and absences: combined TB/HIV treatment in Tugela Ferry began as an international research project due to the South African government’s reluctance to provide anti-HIV medication in the public sector; but it was also the presence of organized community members who were already providing compassionate HIV care that drew the project there. The name XDR-TB emerged from concerns over the absence of continued global MDR-TB funding, yet it was the presence of MDR-TB treatment that put the world at risk for the development of XDR-TB. Global meetings planning the response to XDR-TB would have had very little to discuss if it hadn’t been for clinical activity and data collection practices in places like Tugela Ferry, and global health researchers would not have had much to work to do if government health systems – however rocky – had not allowed them to insinuate themselves into the workings of hospitals, clinics, and laboratories. Even as government TB nurses went about their limited routines of seeking
out patients and providing medications, they were an essential executive arm of a global health endeavor that reached well beyond their own practice. Of course the true centerpieces of the entire XDR-TB story, nearly absent in this dissertation, yet right in the eye of the storm, are patients suffering and dying from XDR-TB and other forms of tuberculosis. As Dr. Friedland pointed out to the South African TB Conference in his presentation on the rise and fall of XDR-TB in South Africa, “the statistics of epidemiology are human beings with the tears removed.” 614

614 Gerald Friedland, “The Rise and Fall of XDR-TB in Tugela Ferry – How We Did It,” Plenary Talk given at South African TB Conference, June 14, 2014, http://www.tbconference.co.za/Session%20Presentations%20Folder/Thursday%2012%20June%202014/Hall%201/Plenary%20Session%202%209h00_10h30/03%20SA%20TB%202014%20plenary%20talk%206-10%20final%20Friedland%203.pdf


