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TUBERCULOSIS AND THE PHENOMENOLOGY OF EXISTENCE IN SOUTH
AFRICA'S RURAL WESTERN CAPE

Maria Francisca O. de Souza Santos

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Thesis Advisors: Dr. Sally Frankental and Dr. Susan Levine

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Maria de Souza Santos
University of Cape Town, Department of Social Anthropology
Sally Frankental, Ph.D., Department Chair

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ABSTRACT

According to the World Health Organization's (WHO) 2008 report on tuberculosis (TB), South Africa has the highest rate of TB in the world after Swaziland. It is estimated that there are nearly half a million South Africans living with TB. This paper explores how people interact with embodied manifestations of TB within a specific macrocosm of existence, namely a South African grape-farming region. I argue that in addition to classic factors of biosocial significance the lives of those living with TB are by and large marked by the associated symptoms of insecurity, instability, and precariousness. This continued experience of precariousness shapes how individuals react to and deal with the specific embodiment of their illness. I further argue that the current public health care system is poorly conceptualized for the specific lives of its patients in that it primarily aims to address a limited set of biomedical manifestations through clinical encounters, thus failing to recognize the larger contexts of individual situations. I conclude that the phenomenological experience of precariousness leads people to react to the manifestation of TB in ways that can be interpreted as resistance to the macro factors that create a constant baseline experience of volatility. A clear understanding of these contexts needs to be actively incorporated into public health policy.

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CHAPTER ONE

Introduction

This master's minor thesis research has been undertaken with the intention of developing a further understanding of the subjective embodied experience of tuberculosis (TB) in a particular macrocosm of existence as shaped not only by geographic location but also by social, political, and economic factors in space and time. I embarked upon the research in order to examine how structural inequalities shape daily life and, in turn, how people maneuver within individual spheres of existence. Adding another layer of significance to Marx's classic statement about history's heavy burden on individuals making their own present,¹ Kockelman states in his paper *Agency: The Relational between Meaning, Power, and Knowledge* that "we make ourselves, but not under conditions of our own choosing" (2007: 376). Building upon this premise, I set out to examine how it is that TB patients "make" themselves and define the constructions that lead to their individual situations. I pay special attention to the ways in which the dominant government sponsored biomedical

¹ "Men make their own history, but they do not make it just as they please; they do not make it under circumstances chosen by themselves, but under circumstances directly found, transmitted from the past. Tradition of all the dead generations weighs like a nightmare on the brain of the living" (Marx 1957: 13).

system of care is inadequately conceptualized and structured for treating persons as TB sufferers and also to how, why, and to what extent certain individuals resist such treatments.

In accord with many social scientists who have examined local and global etiologies² of TB (Dubos and Dubos 1953; Farmer 1997; Farmer 2004b), I take the position that TB, at this present juncture and within the geographic context examined, is more than simply a medical disease, but rather a social disease with an aspect of biological etiology. I therefore contend that TB is a “biosocial disease” (Baer, Singer and Susser 2003; Farmer 1999; Grange et al. 2001a; 2001b; Singer and Clair 2003). TB should be considered a biosocial disease because it is the result of certain historical, political, and economic factors, many of which are directly connected to the structure of an increasingly neoliberal world. TB thrives as an indicator of social injustices and follows, as medical anthropologist Farmer has noted, “social fault lines” (1999: 5), disproportionately affecting those who inhabit economically, politically, and socially marginalized geographic and social spaces. I thus use the biosocial view of TB as a baseline for considering singular episodes of its existence.

I have chosen to focus on TB and to look at how and by what means individuals confront this form of structural oppression when it is manifest in themselves or in friends and family members. What I aim to probe in this paper is how specific elements of the social, political, and economic climate play out in the everyday experience of health and how people shape the ways in which they interact with the symbolic manifestations of their oppressed positions. Precariousness, uncertainty, instability, insecurity, and volatility define the “mesoscopic worlds”³ of many of the TB patients I met, yet people still managed to find

² I use the term *etiology* as it is generally defined (as the cause or reason of a disease), as opposed to its strict biomedical definition (wherein one makes reference to a biological cause of disease).

³ I take this term from Rawnsley who defines *mesoscopic world* as being “the common world in which we live our lives, the world of our environment as we experience it, the character of our localities, some things which we encounter in our everyday intercourse and involvement” (2007: 626).

ways to shape their experiences of life and health. People refuse to render themselves powerless objects of circumstance; they resist and define their own lives and realities. This paper examines how TB is inscribed in people's lives and bodies, and explores how individuals put into action the practice of confronting the systemic form of violence manifest as TB.

Following Abu-Lughod, I am attempting to focus on an "anthropology of the particular" (1991: 157) with the goal of illuminating specifics of lived existence. This type of anthropology seeks not to look for general "cultural" rules but rather to convey a recognition of human commonality:

the particulars suggest that others live as we perceive ourselves living, not as robots programmed with 'cultural' rules, but as people going through life agonizing over decisions, making mistakes, trying to make themselves look good, enduring tragedies and personal losses, enjoying others, and finding moments of happiness. (Abu-Lughod 1991:158)

Although there is a commonality to all humanity, an individual's multidimensional location of existence creates a unique mesoscopic world in which he or she maneuvers; it is this space that I will examine. Furthermore, the very status of an individual as a TB sufferer indicates a probability of constraint that deserves specific examination.

-The Setting-

Fieldwork was conducted over the course of two and a half months beginning in January, 2008. During this time I lived on a farm a few kilometers away from a small town that anchors an agricultural valley. My daily research was primarily concentrated within this single location in the Western Cape Province of South Africa. The valley is by no means isolated from the surrounding areas, yet its geographical features, combined with a certain

sense of “community” unity, provided spatial boundaries within which I focused the research.⁴ The valley is the largest table grape producing area in South Africa and the wealth that the industry produces is evident in the grand, well-maintained traditional Cape Dutch style farm owners’ houses and farm buildings. In contrast to these visible signs of prosperity, the valley is dotted with dense informal settlements. Valley residents who reside in informal settlements overwhelmingly lack basic infrastructure such as convenient access to water, electricity, and proper sanitation. Ironically, one of the smaller informal settlements envelops an electricity sub-station, yet the residents themselves do not have access to electricity. The tragedy of such a situation is accentuated by the evidence of past fires that have charred several homes.⁵ In addition to the informal settlements and the Cape Dutch farm compounds, there are the “blok”⁶ houses on the farms which serve mostly farm workers and their families. These houses vary in terms of amenities; some are well equipped with basic facilities while others are unsanitary, lacking the basic necessities for a healthful life.⁷ Finally, there are a variety of government-constructed houses in the town, some of which were built under a Reconstruction and Development Programme (RDP)⁸ initiative soon after the end of apartheid.

⁴ Although I note a kind of natural cohesion to the valley, I by no means wish to imply that the valley represents a “bounded community”; the valley and its residents are inextricably and fluidly linked economically, socially, and politically to surrounding areas and well beyond.

⁵ Fires in the informal settlements are linked to a lack of electricity as alternate sources of energy are often the cause of fires. Over the course of my stay in the valley several people mentioned their desire for electricity, stating that they would feel more at ease knowing that their children were not around candles and oil lamps. For the residents, obtaining electricity is associated primarily with safety as opposed to convenience. Furthermore, the municipality has been identified as a “high risk community” with regard to fire protection because of a lack of facilities to deal with possible fire emergencies (Joseph 2007).

⁶ *Blok* style houses refer to the usual compound style houses built on the farms for workers and their families.

⁷ The appalling condition of many local dwellings has been a recurring topic in regional newspapers (e.g. Raymond 2005; Williams 2006).

⁸ RDP stands for Reconstruction and Development Programme. The RDP was established after the fall of apartheid as means of redressing some of devastating social and economic realities brought about by over 40 years of apartheid rule (Cameron 1996). The program focused on six areas: general public works, healthcare, land distribution reform, housing, expanding electricity access, and the provision of clean water (ibid).

The town itself is unofficially segregated. The west (“white”) side contains several well built and carefully maintained structures including houses, churches, several banks, a private school, shops, a petrol station, a pharmacy, a movie rental store, a tourism office, a police station, a private clinic, et cetera. This western side has all the amenities of a prosperous small town. The eastern, “non-white,” side is home to the RDP houses, several smaller houses of similar style, a few “shebeens” (informal drinking establishments), a dance club, some small shops, and the government clinic. I never saw a “white” person walking on the east side of town during my stay. The two main public schools lie on the eastern side of the town. No streets directly connect the two sides of town. A rail line cuts across the valley and a pedestrian overpass connects east to west, but the two sides remain clearly separate. Race and class appear to be inextricably linked, as the division of the two sides of town is not simply economic (visible by the type of houses and distribution of cars) but follows apartheid era racial divisions. Those identified as “white” tend to inhabit in both physical and metaphorical senses the west side of town; those identified as “colored” tend to live on the east side of town and its periphery; while those identified as “black” or “African” inhabit the peripheral settlements.⁹ Those who live in the large farm manor houses are invariably white, while those who live in the “blok” houses on the farms tend to be colored. The lines of physical demarcation and racial separation largely define housing types, access to basic physical infrastructure, employment opportunities, language, and health status.

⁹ Like most current anthropologists (Hale 2006; Rolph-Trouillot 2002), I take the view that race is a social construction in that it does not exist in a scientific or genetic sense but rather exists as a part of the daily lived reality of individuals and is internalized as a part of one’s sense of identity. I thus follow those who term themselves critical race theorists. In the South African context the existence of race and racial categories is complex. Historically imposed racial categories have been used to construct and maintain oppressive economic, social, and political systems. I shall use racial categories with these thoughts in mind and hereafter refrain from using quotations. Furthermore because this paper is concerned with issues of power as opposed to those of identity, I shall follow the example of several academics (Fanon 1963; Gilroy 2001; Ramphela 2008) and rely primarily on the somewhat abstract dialectic categories of black and white. I will use black to refer to all racial groups who were systematically oppressed under South Africa’s colonial and later apartheid state, and white to refer to those who belong to the “racial” group of the oppressors.

According to the 2001 census, the population of the larger municipality is 65.6% colored, 20.1% African, and 13.9% white (Western Cape Municipal Information 2007: 959). The lingua franca is Afrikaans with almost 80% of locals citing it as being the language spoken in their homes (ibid). Other languages spoken include English (2%) and isiXhosa (14%) (ibid). The patient files from the valley's main clinic show that of the 151 active tuberculosis patients 55 (36.6%) are classified black or African and the remaining 96 (63.4%) are classified colored; none are classified white. Although simple figures may mask a great deal of complexity, it is nevertheless interesting to note that the TB burden among those classified colored correlates roughly with their percentage of the population, whereas those classified African carry a much higher disease burden for their proportion of the population. There is no doubt that this disease distribution is a reverberation of apartheid era policy and the deep impact that it has to this day.

Farm work is the primary source of employment in the valley. This work is usually temporary and I was repeatedly told that one was lucky to get a year-round job. Due to the seasonal nature of the table grape industry one is more likely to secure employment around harvesting time from November to May. Basic employment on one of the farms pays around 800 rand a month.¹⁰ Because of the seasonal nature of employment (and the accompanying low wages) many people form informal cooperatives with friends and neighbors. During the summer working months they invest together in basic bulk items such as oil and flour in order to make it through the winter. Individuals lucky enough to have more secure employment typically are those working as full time general farm laborers or in various

¹⁰ This is well below the estimate for the Household Subsistence Level (HSL) of 19 200 rand per annum or 1 600 rand per month (Nodal Economic Profiling Project 2007). The HSL is estimated to be the absolute minimum amount that a household could subsist on. This figure has been strongly criticized for being too conservative in its calculations.

managerial positions on the farms. Other sources of employment include public sector jobs (with the police force, local government, schools, or the public clinic), or in one of the private non-agricultural sectors (mostly local merchant businesses in town).

European colonists first settled the valley in the 1700s. A railway station was built in 1875 in the valley's main town and it was then that the town burgeoned as the valley's economic and political center. Like the rest of the nation, the region's present has been formed by a history first of colonialism and later of apartheid; this history has had a formative impact on the demographic realities of health and ill-health. Examining individual bodies and their relationship to history in *When Bodies Remember: Experiences and Politics of AIDS in South Africa*, medical anthropologist Fassin theorizes that "the body is not only the immediate physical presence of an individual in the world: it is also where the past has made its mark" (2007: 175). Fassin reminds us of the importance of a body's four-dimensional location (where the fourth dimension is that of time) and the impact that this has on one's physical well being.

In a recent health and mortality assessment of the region, tuberculosis is cited as the main cause of premature mortality, with HIV/AIDS and homicide following in second and third place (Groenewald et al. 2007: 7). There is one public clinic on the east side of town, two smaller clinics in more rural areas, and one private doctor in the west side of town. For health matters deemed more serious, clinic patients are referred to one of the hospitals in a town a half an hour or 20 rand taxi ride away (at the time equivalent to the cost of about three loaves of bread). There is a hospice near one of the hospitals to which valley residents can be referred. The clinics are all government run and provide free basic primary healthcare including treatment for TB (consisting of clinical visits, medications, laboratory tests, and hospitalization if deemed necessary).

-The Research-

As a student of anthropology, my research was primarily based on participant observation. For two and a half months, I lived on one of the farms and spent my days and nights “hanging out” with TB patients, home based care (HBC) providers, direct observational therapy (DOT) workers, clinic staff, as well as other valley residents. In addition to participant observation, I conducted 20 life history interviews with individuals who had either tested micro-bacterially positive for TB, were undergoing treatment for TB, or who had completed a course of TB treatment within the past year. In the interviews I focused on people’s experience of TB, but covered a wide range of questions about family, personal relationships, work, et cetera. In terms of selecting interviewees, I approached all eligible candidates (based on the above criteria) I encountered, and interviewed all those willing to grant me the privilege. The selection of interviewees does not constitute a representative cross section of TB sufferers in the valley; it represents those people I encountered during my daily activities who were willing to be interviewed. In addition to the more formal interviews, I conducted informal interviews with clinic staff, HBC providers, TB patients, DOT workers, and general residents whenever possible and appropriate. Finally, I reviewed all of the active TB patients’ files from the valley’s main clinic. In this review I charted all the adult active patient data. The categories used were age, type of TB (pulmonary, extra-pulmonary, etc.), drug resistances, HIV status, type of living environment (farm housing, formal housing, or informal housing), gender, racial categorization, employment information, weight, previous medical conditions, previous episodes of TB/history, treatment start date, and type of regime (see Appendix A for results’ highlights). Although this more epidemiologically oriented mini-study did not prove to be directly helpful

for the overall purpose of my research, it did provide insights into who was receiving TB care at the clinic.

In a modest attempt to give something back to those who so generously helped me with this project, I offered to find clinic patients who had either “defaulted”¹¹ on their TB treatment or who had tested micro-bacterially positive but who had not been to the clinic to receive their results and start treatment. I also drove patients to the clinic, took friends and family to visit hospital patients, helped people navigate the public health system, and aided in the process of obtaining social service grants. Although I could not even begin to repay people for generously sharing their lives with me, these small gestures helped, I hope, to balance the one sided nature of anthropological research.

In ethical terms, there were two areas of overriding concern which shaped how I technically approached the research: first, assuring that proper and full consent was obtained from all participants; and second, assuring that all associated individuals referred to retained their anonymity. For the in-depth interviews, I obtained written consent (see Appendix B). Participants signed a form granting me permission to use the information shared. The form stressed that participants were in control of the degree of participation; they could withdraw at any time. I also signed the form as a way of sealing my commitment to uphold its conditions. For others I encountered, I explained the purpose of the research and consent was obtained verbally. I explained to all participants that I would not use real names or identify

¹¹ I have used the term “defaulted” because that is what is used in “medical speak,” yet it should not be used without considering the implications of such a term. The Oxford Dictionary of Current English defines the word *default* as “failure to fulfill an obligation” (2001: 230); this implies that the patient is the one at fault for not completing his or her treatment when there are in fact many other factors to consider, such as the social and economic obstacles that the patient must overcome in order to successfully complete treatment. What this term does is shift the onus of blame completely onto the patient when in actuality there are innumerable reasons why an individual may or may not complete his or her treatment, many of which could have to do with the nature of the care provided. Furthermore, use of the term “defaulted” implies that completion of treatment regime in the bio-medical is the baseline of normality and assigns the status of deviance to those who do not “comply.” In this paradigm, the patient is disallowed the opportunity to choose whether he or she starts, continues, opts for an alternate regime, or takes no action, and is thus denied full control over his or her body.

individuals according to where they worked or lived. Furthermore, I agreed not to reveal the actual name of the valley. Throughout this paper I have upheld both of these ethical pledges.

-The Context

In the South African context, tuberculosis poses an enormous threat to the general health of the nation. The World Health Organization's (WHO) most recent report on TB ranks South Africa as seventh in the world in terms of the severity of the epidemic (2007: 137). In 2005, there were an estimated 270,187 new or relapsed cases reported from clinics and hospitals in South Africa (WHO 2007: 24).¹² South Africa is therefore home to 5.27% of the 5,126,159 people (WHO 2007: 24) formally diagnosed with TB. This figure is especially surprising when one considers that according to the UN's most recent report on the world population, South Africa is home to an estimated 48,577,000 of the world's 6,671,226,000 people (World Population Prospects 2006 2007: 39: 43), or approximately 0.72% of the world's estimated population. South Africa therefore has a TB burden that is 7.32 times that of the global average. Although it is problematic to generalize about conditions that create an atmosphere conducive for TB, when one examines the 20 other countries along with South Africa that are judged to be most severely affected by TB, one notes that they are all plagued by inequality as measured by the UN's Gini index classification set forth in the 2008 Human Development Report.¹³ This connection between inequality and TB is something that Farmer

¹² It should be noted that this figure does not take into consideration those who have not been diagnosed; thus the actual figure could be significantly higher.

¹³ The top twenty ranked countries in terms of the estimated severity of the TB epidemic (it should be noted that this is not just based on the estimated percentage of people who have TB but takes into consideration other factors such as the estimated total number of people who have TB) as assessed by the WHO in descending order are as follows (Gini index ranking is in brackets): India (36.8); China (46.9); Indonesia (34.3); Nigeria (43.7); Bangladesh (33.4); Pakistan (30.6); South Africa (57.8); Ethiopia (30); The Philippines (44.5); Kenya (42.5); The Democratic Republic of Congo (n/a); Russia (39.9); Vietnam (34.4); Tanzania (34.6); Brazil (57); Uganda

has discussed in both *Pathologies of Power* (2005) and *Infections and Inequalities* (1999). Farmer posits that it is “inequality itself [which] constitutes our modern plague” (1999: 15). Furthermore, in the context of South Africa, the systems of labor acquisition and management under colonialism and apartheid often increased the burden of TB among the non-white labor force through a variety of both medical and other policies (Packard 1989a; 1989b).

Although it is difficult to prove the argument that there is a connection between TB and gross systemic socio-economic inequality, there is little contestation that there is a strong connection between poverty and TB. The classic risk factors which place one at a higher risk for contracting TB are malnutrition and crowded living conditions; both are undeniably associated with poverty the world over. For centuries, tuberculosis has been associated with poverty in Western consciousness.¹⁴ In South Africa the connection is doubly evident as TB primarily affects those suffering from conditions marked by poverty and also because it makes the experience of the illness more severe than for the rare cases amongst economically advantaged bearers. In South Africa TB flourishes in many informal urban settlements and rural communities in which inadequate living conditions and poverty dominate the struggle for survival.

A second compounding factor that has affected the severity of the TB epidemic in South Africa is the high rate of HIV infection; among adults, the HIV prevalence rate is estimated to be 18.8% (2006 UN/WHO report on the Global AIDS epidemic 2006: 506). HIV weakens the immune system, thereby creating the opportunity for the bacterial disease of TB to take hold. In South Africa the connection between HIV and TB is strong; among TB

(45.7); Thailand (42); Mozambique (47.3); Myanmar (n/a); and Zimbabwe (50.1). On average, these countries have a rating of 41.75, which indicates a high degree of economic inequality.

¹⁴ See Sontag's *Illness as Metaphor* (1978) for a discussion on this.

patients tested for HIV, 52% were positive in 2005 (WHO TB report 2007: 137). As with TB, there is a strong connection between HIV and poverty, further compounding the connection between TB and poverty.¹⁵

In view of the connection between poverty and TB it seems logical to take the perspective of many critical medical anthropologists who maintain that “health issues” are contextually determined by “encompassing political and economic forces that pattern human relationships” and that these “shape social behaviors; conditional experiences; reorder local ecologies; and situate cultural meanings, including forces of institutional, national, and global scale.”(Baer et al. 2003: 4) While on an individual level there are numerous convergent factors that create a space for disease to take hold, on the macro level the economic reality of poverty is a primary determinant of an individual’s poor health status (Grange et al. 2001a; Haan et al. 1987; Link and Phelan 1995). As the basic unit of human existence, the body carries the physical manifestations of social injustice, such as poverty, in the form of disease and ill-health. It follows therefore that diseases (and indeed other manifestations of ill-health) are not suffered equally once contracted, nor are they contracted equally across economic, social, class, cultural or other socially constructed lines (Cohen and Martin 2003; Farmer 1992; 1997; 1999; 2004a; 2004b; 2005; Hahn et al. 1995). Accordingly, we must accept that TB displays, to use Mc Neil's term, a form of "macroparasitism" (1977) wherein it is the "social relations of exploitation that are the ultimate cause of much disease" (Hans et al. 1997: 36). With such factors of political economy in mind, I set out to understand how on the individual level people deal with, react to, and resist succumbing to this manifestation of injustice and exploitation.

¹⁵ It should be noted here that anthropologists such as Paul Farmer have detailed the linkage between poverty and HIV (2006; 2005). Such a connection has also been revealed in many other studies (Chan and Reidpath 2003; Kaufman et al 2004); thus the connection between HIV, poverty, and TB becomes doubly important.

Recent and current anthropologically oriented research projects in South Africa that focus on TB tend to ignore the ways in which the acquisition and experience of TB are contextually derived from a host of political, economic, social and historical conditions; they also fail to examine the multiple ways in which individuals act, react, confront, and deal with their illness. Ongoing anthropological projects range from examining the knowledge of “traditional healers” concerning TB diagnosis and treatment with “herbal medicines” to examining the efficacy of using “lay healthcare workers” on farms (SA Health Info 2007). Additional examples of recent work from South Africa include “Contribution of Traditional Healers to a Rural Tuberculosis Control Programme in Hlabisa, South Africa” (Colvin et al. 2003). There have also been a series of projects that focus on modes and paths of transmission in urban areas; they include “Transmission of Tuberculosis in a High Incidence Urban Community in South Africa” (Verver et al. 2004) and “Impact of Social Interactions in the Community on the Transmission of Tuberculosis in a High Incidence Area” (Classen et al. 1999). There has also been research on barriers to non-governmental involvement in treatment, aptly titled “Combating tuberculosis: barriers to widespread non-governmental organization involvement in community-based tuberculosis treatment in South Africa” (Kironde and Nasolo 2002). What these works collectively demonstrate is a lack of research focused on TB sufferers’ experiences and subjective actions associated with their illness while concurrently considering political and economic factors that affect these people’s realities of existence.

In this paper, I explore the ways in which individuals affected by tuberculosis (taken as a physical manifestation of the social injustice and oppression) react to and deal with their illness and its encompassing complications. I explore the ways in which people use their status as TB harborers as a means to assert subjectivity. In the next chapter, I examine how a

home based caregiver acts intersubjectively with TB patients to help them navigate their lives in the hope of working through the uncertainty that defines both their health situation and their everyday struggle for existence. I also critically examine the clinical focus on biomedical manifestations of ill health in terms of how different health “professionals” are positioned to interact with patients. In the third chapter, I explore how the experience of gender and race affects peoples’ sometimes shifting positionality in private and public realms and the effect that this has on the experience of TB. I specifically consider how individual black, male TB sufferers demonstrate resistance to “care” in relation to the perceived precariousness of their dominant position in domestic realms. In the fourth chapter, I examine the cases of individuals who demonstrate resistance to clinical care and try to identify factors that contribute to individual choices to refuse clinical care.

CHAPTER TWO

Intersubjectivity and the Role of Home Based Care Providers

“Divided between anger and hope”

-Alain Touraine, *A New Paradigm for Understanding Today's World* (2007: 101)

While conducting field research in the valley, much of my time was spent with Elize, a HBC (home based care) provider and DOT (directly observed therapy) worker. I was fortunate that she not only allowed me to observe her working with friends and neighbors, but that she also became a good friend. At the end of the day, Elize and I developed a habit of stopping at Lea's house on one of the farms. Lea, also a DOT worker and HBC provider, grew up with Elize on one of the farms. Conversations about their experiences as they selflessly served those around them with resilient determination gave me an invaluable insight into their understanding of life, health, and illness. Their understanding, borne out of both concrete and metaphysical experience of life with those around them, is not fully in line with the biomedical model. Elize and Lea view the misfortune of illness as the result of specific contextual situations. Questions about how people had caught TB were met with explanatory narratives involving “hard work on the farms,” or “lack of money in the house

for everyone to eat,” to entrenched “dependency on alcohol.” Although they are both extremely knowledgeable about TB in the biomedical sense, when asked how people caught the disease they did not answer that it was, for example, because they were living in close quarters with others who had TB, or because they were more susceptible to infection as a result of their HIV status; instead, they consistently invoked structurally significant etiological factors. These women understand that the lives and experiences of illness of those around them are marked by insecurity. Their subtly asserted positionalized understanding of TB has been developed from experience with people as subjective beings, and the focus of their work defines them as progressive actors in the valley. Elize and Lea recognize the uncertainty and precariousness of the disadvantaged positions of those who have TB and strive to reclaim some sense of justice and hope; they daily conduct “unequal struggles against a power, against an order... [they are] divided between anger and hope” (Touraine 2007: 101). French sociologist Touraine has focused much of his work on examining the importance of the role the subject in society and social movements. Touraine posits that it is the subjective actor (defined as one who is the victim of forces of domination) who is at the forefront of social movements (1988; 2007). Touraine’s actor-centered theory of social action and transformation offers hope that the kinds of actions performed by Elize and Lea could be the beginning of a movement or a revolution in the way that healthcare is structured, carried out, and experienced. Ironically, it is their marginalized positions within the biomedical healthcare system that allow them to develop an experiential understanding of illness and to act intersubjectively.¹⁶

¹⁶ I use the terms *intersubjectively* and *intersubjectivity* to indicate the shared or co-developed “inward reworkings of the world” (Biehl, Good, and Kleinman 2007: 15). Additionally, I build upon Touraine’s assertion that “Subjectivity,... is the expression of the dominated” (2007: 95), I take intersubjectivity therefore to be the shared expression of reworkings in the face of acts of domination.

Driving around the valley with Elize, it is practically impossible to find someone she does not know or who does not know her. Elize was born almost fifty years ago on a farm a few kilometers from town. She left school in 6th grade at the age of 14 because she became pregnant. She claims that although she did not realize it at the time, this pregnancy was the result of what she would now consider to be rape. She now heads a household on the east side of town that includes her daughter, son, grandson and nephew. Elize formally worked as a HBC provider until about a year ago when she says the state funded organization (a local NGO) that oversaw HBC began to crumble “because of politics.”¹⁷ According to an official who works for the department of health in the neighboring town (which acts as the municipal seat for the valley), the organization that managed the HBC is still receiving funds to manage the services, yet on the ground there was no evidence that services were being provided through this organization. Although Elize is no longer paid for her HBC services, because of her long and deep relationship with individuals and families in her former capacity, she has been unable to extricate herself from the responsibilities of her former official position and now provides her services voluntarily, without pay.¹⁸

Elize would regularly tell me of this or that person who had called on her in the night with a specific ailment, a pressing health concern, or simply for advice, help and the support of a friend. What Elize has developed is an empathetic understanding of the uncertainty and precariousness of life and health that characterize the lives not just of TB patients, but also of most of her relatives, friends, neighbors and fellow valley residents. In her daily work, Elize was unswerving in her dedication and determination to care for patients not only in a physical

¹⁷ The man who heads the organization is apparently “friends” with local politicians, but not well liked or trusted by many valley citizens.

¹⁸ Since the end of my active fieldwork, Elize has been awarded some local funding in order to establish a small network of HBC services, but the insecurity of the funds (and her associated position) is indicative of the low value placed on non-institutionalized care.

sense but to understand their personal lives so that together they could try to find ways in which to re-cast their subjective experiences positively.

Elize's position in the valley allows her to provide services to individuals on a biomedical level (she is a DOT worker and the clinic uses her as liaison with patients), but her understanding of people's lives in the non-clinical sense allows her to help them manage not simply their illness but, more broadly, their everyday lives. On one of my first days in the valley, I accompanied her on a visit to Dorothea's house. Dorothea's mother had approached Elize the night before, worried about the health of her daughter. When we arrived at Dorothea's house on the east side of town (about three blocks away from the clinic), she was sitting against the side of the front door and looked as if she could barely hold herself up. She seemed tired beyond her 42 years. Her nails were tightly curved around the tips of her fingers, indicating chronic health problems.¹⁹ She was tall, but extremely thin and had a scarf loosely wrapped around her head, barely covering her bald scalp. She was unable to suppress a deep, heavy cough. Although we were outside, a distinct "sick" smell permeated the area. Elize later said, "Did you smell that? That is what TB smells like."²⁰

Next to Dorothea were her two young sons who had distended bellies and discolored hair and skin, classic signs of kwashiorkor (malnutrition from protein deficiency). They were

¹⁹ According to biomedical knowledge, nail curvature of this type is often an indicator of oxygen deprivation to one or more of the vital organs.

²⁰ Elize's comment on the smell of TB later proved to be of significance. When I asked the nurse in charge of TB at the clinic if TB had a specific smell she said that it did not (this fact is supported by the body of medical data on TB). However there has been a recent series of research based in Tanzania that suggests that TB does have a distinct and even isolatable smell (Science 2004). In Tanzania there has even been a movement in which rats are taught to smell TB so that people do not have to wait for laboratory test (which can take a long time, especially in isolated areas). Apparently these trained rats have a higher rate of success in identifying TB than standard laboratory sputum tests. This point illustrates that Elize developed a more experientially and phenomenologically based understanding of TB that goes beyond what is taught within the strictly biomedical clinical system in the valley.

both subdued and one clutched a piece of discarded plastic. Dorothea's husband, who has a history of being physically abusive, had apparently left a few days before (Elize told me that this happened often), but had come back the night before. Dorothea's mother said that they had been drinking and fighting (both verbally and physically). Looking at Dorothea, I found it difficult to imagine that she could have "fought" in her weakened state. As Dorothea and her mother updated Elize about her situation, she listened and asked questions not only about Dorothea's health but tried to get an understanding of all those factors which defined Dorothea's life from her own perspective. Elize took in the details of Dorothea's physical health situation and encouraged her to discuss her relationships with neighbors and family, as well as her concerns about the future. Dorothea explained that she was hesitant to return to the clinic as she feared the uncertainty about what the future held for her and her sons. Through such discussion and interactions Elize developed an understanding of Dorothea's subjective view of her own life. In a later interview, when I asked how Dorothea's life had changed since she was younger, she said, "When I was younger I could go on without drinking, now I cannot go on." Dorothea said repeatedly that she felt at a loss about what to do, and that she thought of her current ill-health as just another event in a long series of struggles she had been forced to face. She believed she no longer had the will to act in the face of yet another hardship, and was unwilling to persevere in her lifelong fight in an adverse world. She seemed resigned to become a victim of circumstance.

Dorothea lives with her two young children; sometimes her mother, husband, a cousin and uncle also stay at her small, deteriorated house. Both she and her husband regularly use alcohol. Although she was sick for my entire stay in the valley, I often saw her and her husband passed out on the street near the "club" in the evening. As a young girl, Dorothea said she felt special in school because she was clever and excelled at athletics. She hoped to

become a schoolteacher. Both Dorothea and her mother told me she was the pride of her family. Along with her three brothers, she was raised by her grandmother and sometimes by her mother. After Dorothea's younger brother was born, her father left; he was a heavy drinker who worked on the farms.²¹ Her mother also worked intermittently on the farms, as well as a housekeeper and cook, but had (and still has) a drinking habit. While in standard nine at the age of 18, Dorothea became ill and lost her hair; she is unsure to this day of the specific cause. Her family had no money to buy a wig so, embarrassed about her appearance, she stopped going to school. This was the turning point in Dorothea's life. Soon after leaving school, she began working as a cashier at the till of a small shop; that is when she started drinking. Her often heavy drinking continues to this day and much of the money that passes through her hands is spent repaying debts accumulated from procuring alcohol. Dorothea's two young boys are unmistakably malnourished. Neighbors told me that they give the boys pieces of bread so that they have some food. The older of the two boys has confirmed TB and the youngest has not been tested. Dorothea has never officially registered her second son and so she has only one childcare stipend (about 200 rand per month); besides her mother's old age stipend, the single childcare stipend is the only steady income coming into the household. Dorothea's mother also has TB. Dorothea has had TB twice before. When I first met her,

²¹ The use of alcohol as an agent of oppression of farm laborers has a long and complex history, the acute effects of which are glaringly evident to this day. The Western Cape (including the valley where I did my research) has a long history of imposed alcohol abuse on laborers (the "dop" or "tot" system or "wine for work" (Crush and Ambler 1992: 10)). The tot system created both subdued laborers who became easier to control as well as entrenched employees whose dependence on alcohol assured that they would remain employed. As Crush and Ambler explain in *Liquor and Labor in Southern Africa*, "those in power saw alcohol as a source of revenue and profit and as an effective tool of social engineering and control" over their laborers (1992: 2). Pamela Scully emphasizes the importance of this form of abusive control by making the connection between an increase in the need for laborers with that of the intensity of the tot system (1992). Scully argues that for "capitalizing farmers it [the tot system] provided a base from which to intensify production" (1992:72). Scully contends that the tot system "reached into the social experience and practice of the farm workers' world, helping to make alcohol consumption a feature of rural underclass culture" (1992: 62). Although I did not hear of any instance of the tot system still being implemented in the valley today (it is now illegal), the effects of over one hundred years of such an abusive system are evident as both statistics and my own observation attest to the extreme alcoholism that still prevails in the valley. Alcoholism is therefore evidence of historical labor abuse.

although for some time she had been presenting symptoms that she and those around her connected with TB, she had not been to the clinic for a sputum test.

What, in Dorothea's own words, got her to the point where she "cannot go on without drinking"? It would seem to be her unfortunate position in a world that has allowed her no opportunities; her world is plagued by uncertainty and precariousness; she has learned to be certain only about disappointment. She has lost all hope for her situation, although she knows she can seek free TB care at the clinic; having twice relapsed, she believes on a certain level that clinical care does not "cure." Unfortunately, Dorothea is not unique: of the 151 active TB patients at the valley's main clinic, a staggering 69 (or 45.7%) are receiving re-treatment care. Now, when faced with a third round of similar treatment, it is logical for her to doubt that the effort is worth making. Furthermore, the last time she was treated for TB she was hospitalized for an extended period of time; she now associates treatment with leaving her home, children, and losing her independence.

In discussing Dorothea's situation, Elize refers to the complexities of TB and to the situations of those afflicted with the disease; she says Dorothea has "fallen into a hole" from which she cannot get out. She expresses frustration at her limited ability to help people deal with their contextual locations which created the opportunity for TB to take hold, and which, because they persist, make TB difficult to endure. Dorothea's case is evidence that TB cannot be "cured" by just providing medical care; it is also necessary to address the underlying macro factors as manifested in the micro realities. Although it is impossible to say for sure what in Dorothea's case led her to contract TB for the third time, a host of factors no doubt created her vulnerability. These factors are all associated with her poverty, caused and perpetuated by her subordinate position in society; as a black female, she was born into an environment defined by instability and supported by an unrelenting structure that perpetuates

systemic violence. As a girl and young woman, she^{at} excelled school and sports, but poverty blocked her way. Though her family thought she was “special,” “different,” and that she would succeed, she succumbed to the pressures of her restricted environment. Finally, the role of alcohol in Dorothea’s life points to the historic and continuing oppression of laborers by an abusive system that sought to maximize control of labor for increased productivity and profit (Scully 1992; Parry and Bennetts 1998; Kasmire and Carbonella 2008).

In the face of extreme insecurity about life in general and matters of health in particular, Elize has worked to gain an understanding of Dorothea as a subjective being in order to act intersubjectively, bringing hope to situations within their shared frame of reference. Elize addressed Dorothea’s specific fears related to dealing with her tuberculosis by finding an informal “foster care” provider who agreed to watch the children should she need to be hospitalized again. She also arranged an appointment with the department of social services on their next visit to the valley to try to obtain a birth certificate and childcare stipend for her second son. She made arrangements to take Dorothea to the clinic to start her daily treatment. When Dorothea returned to the clinic for treatment, Elize acted as her DOT supporter, even walking with her to the clinic in the mornings to make sure she got her daily injection. In these various ways, Elize is the actor providing holistic care, addressing both subjective and biological realities. Elize was able to convince Dorothea to seek care because she gained her trust through a shared subjective understanding of Dorothea’s encompassing health and precarious life situation. Paradoxically, it was by acting outside the bounds of the state provided biomedical care that Elize succeeded in providing Dorothea complementary biomedical care and personal care addressing some of the sense of insecurity that Dorothea continually experienced.

The role that Elize played in Dorothea's life was by no means unique. During my time in the valley I witnessed Elize's brand of holistic intervention in many cases. Donovan's was just another such case. Donovan, 18, first came into contact with Elize when I was working alongside her. After Donovan's father died in a work related accident when he was a young child, he lived with his mother who, according to the family, began using alcohol frequently. After the death of his father, Donovan's mother had two other sons and continued her heavy use of alcohol. People who knew Donovan growing up said he was always friendly, and good-natured; the kind of boy one instantly took a liking to. He comes across as a caring young man and often talks of the close relationships he has had with his younger brothers. Although he was 18 when we met, I initially took him to be barely a teenager; a combination of his innocent air and thinness (at one visit to the clinic he weighed only 37kg) made him seem younger.

When Donovan was 14, his middle brother (then 9) became ill due to complications of HIV/AIDS. It was Donovan who cared for him; his mother was usually out drinking or looking for something to drink. Donovan's brother's illness caused frequent nosebleeds and towards the end of his struggle he began bleeding from his mouth and ears. It was Donovan who cleaned and cared for him. That is how Donovan believes that he himself became HIV positive. Soon after the death of his brother, his mother also succumbed to complications from the HI virus. After her death, he went to live with his maternal grandmother, her partner, and an aunt (and her three year old daughter) in a small shack in the town's burgeoning informal settlement. All three adults have serious alcohol problems and the child has foetal alcohol syndrome. The grandmother, her partner, and the little girl have, or have had, TB. On Donovan's 18th birthday (almost a year before I met him), he received a portion of a settlement from his father's death totaling 11,000 rand (that is more than a farm laborer

in the area earns in an entire year). At this point Donovan started becoming weaker and his grandmother assumed control of the money. Within less than two months the money had been spent, apparently mostly on alcohol. Donovan then went to live with a paternal uncle and his wife on one of the farms in the valley, where he had been for a few months before Elize and I met him. He describes his aunt as like his mother, always drunk or looking for something to drink. His uncle apparently only drinks in the evening and on the weekend. Donovan says he is happy staying with his uncle and that it is an improvement over living with his grandmother, but also notes that there is not enough to eat. Although he is on ARVs, his CD4 count has shown little improvement; the combination of this with his TB has meant that he has continued to weaken. When I first met Donovan, we would walk in town, but after a few weeks he no longer had the energy to walk and we would drive to town and sit. After spending time with him, he confided that he was still due some money from the investment of the settlement made after his father's death; that was a source of both worry and hope. He was hopeful that he could use the money to be more comfortable at the end of his life and to be able to take care of himself, but he worried about what would happen if it fell into the wrong hands. Elize decided that it would be best to see the lawyer who had been given control of the money; it was then discovered that he would not receive the money for almost a year. It was also unclear if it would go to his younger brother upon Donovan's death. Donovan was clearly very disappointed that he would be left without any real means of caring for himself in his last months of life. It seemed that he had come to associate receiving the money with his ability to control and improve his health situation. When it became apparent that the money would not be forthcoming, Elize suggested that we take him to apply for a disability grant. In order to apply for the grant, over the next few days we obtained letters from the police station, the owner of the farm on which he lived, his doctor (who was

based outside the valley), and the school that he had once attended. The process was difficult and it would have come to naught without Elize's knowledge and skill in navigating through the bureaucratic obstacles.

As in Dorothea's case, Elize was able to gain an understanding of Donovan's confined situation as he interpreted it, and work to make things better in the ways he prioritized. Donovan felt disempowered, trapped, and longed for financial independence. Elize understood how Donovan's disappointments with his health and life had led him to understand his situation as he did, and she worked to bring him security in ways he felt most important.

In a recent conversation with Elize, she told me that I would not believe it if I saw Donovan now; he is apparently "walking around like a happy healthy angel" and he has just received his first disability grant. Elize's actions, based on understanding Donovan's need for security, sought to bring him hope and, more importantly, a sense of stability. Her multiple etiological understandings of why Donovan had become ill (in addition the biological co-infections of HIV and TB, Elize maintained that it was his family's abuse that had caused his decline in health) allowed her to help him address the nonclinical factors that exacerbated his illness.

Dorothea's and Donovan's cases are unique in their specificity, but several key factors occur repeatedly among the valley's TB sufferers. Access to relatively high standard of free bio-medical care (probably better than most TB patients in South Africa and in many other countries) does little to improve peoples' situations; and the structural factors that arguably have led people to contract TB make their experience of illness more devastating. Although Elize's intersubjective actions could not mend or rectify these conditions, they

provided the patients with something of a reprise and a definite hope about their situations; she worked to mend some of ills and misfortune the world had brought them and had been magnified by TB. In these circumstances, it is not doctors, nurses, or other “highly valued” health workers in the bio-medical clinic, but the HBC givers who are able to help people define their experience of illness.

When examining the situation in South Africa, there is overwhelming evidence that the country and its people are divided along lines which run on both visible and invisible tracks. These lines have been formed and shaped by the overlapping and intertwined experiences of colonialism, apartheid, neoliberalism, race, and class. The stratified biomedical structures of care available to valley residents are emblematic of the political, economic and social systems since the advent of colonialism.²² Using a Foucauldian model of analysis, many of these structures (such as the farm with its “blok” style housing, farm and government schools, farm warehouses, the clinics, etc.) can be classified as panoptic in that they are structured to operate as a means of surveying and exerting power over the lives of citizens.²³ The physical structure of the clinic is not only panoptical in a material sense; its hierarchical organization of personnel as well as its systemic objectification of patients compounds their disempowerment and functions as a means of disciplinary control over their bodies and lives.

At all levels of the public health care system in South Africa (and indeed in most regions of the world where the western biomedical system is used) there is a strict structure

²² I make reference to those structures that have dominated the farm labor system, private business, and government. Furthermore, paternalism based upon gendered, racial, and age categories is also dominant. What is important about this is that such familiarity with similarly structured systems could lead to a sort of internalized knowledge and memory of experience with these often oppressive systems.

²³ See “The Eye of Power” section in *Power/Knowledge* for a discussion of Bentham’s Panopticon prison and other similarly modeled structures of power that seek to solve the problem of how to exert control over “a great number of persons in the hands of very few” (Foucault 1980: 151).

of stratification and power upon which the authority of the biomedical system rests. Those who have received the most scientific and clinical training occupy the upper strata and often treat not only those below them (such as HBC givers like Elize) in a paternalistic manner, but also those whom they are supposed to serve. In the context of the valley, I observed that the organization of care replicates the larger socioeconomic structure; white men occupy positions imbued with the greatest degree of authority (although they are physically absent from the valley's clinics), followed by white women, and, below them, non-white men and women. What is notable about this medical system is that those who receive the most formal schooling, and who are therefore deemed to have the most clinical knowledge, are those who have the least in-depth personal contact with those receiving care. For those trained in the biomedical context, the process of becoming a healthcare professional usually involves training that shifts their view of patients away from them as subjective individuals towards them as objectified bodies with determinable scientific biological pathologies (Konner 1987; Jewson 1976). It is often those who have the least "medical training" and occupy subordinate positions in the clinical and social realms (such as HBC providers) who are most in touch with the lives, persons and social beings of patients. Those at the "top" of the power spectrum interact with the body in a decontextualized manner, while those further down interact with the person in context; as with Elize, they develop a metaphysical understanding of the being. As Foucault details in *The Birth of the Clinic*, the historical process that created Western medical authority and the "clinical gaze" has also created a system in which the idealized doctor has only to *look* upon the naked body to *know* what the problem and *see* how the "pathological fact appears in its singularity" (1973: 109). Furthermore, biomedicine has recently increased the objectification of the body by shifting away from clinically based medicine to "laboratory medicine," thus further isolating the biological body by sampling

isolated bits of the physical for scientific reactive tests (Armstrong 1995). Medical sociologist Armstrong has posited that we are approaching an era of biomedicine in which the decontextualization of the body will be carried into the fourth dimension; a subsuming surveillance of the body-as-object will transcend the physical space of the immediate body and operate in the temporal dimension (ibid).

The fault of this system is that it is based on knowledge of the decontextualized body and operates within a discourse that assumes that disease and ill-health are only the result of facts or causes amenable to medical or scientific classification. It negates the contextual aspects of life that contribute to disease, such as historical, economic, political, social, and societal factors. This system of care is created solely with the objective of treating the scientific medical pathologies; it fails to realize that the prevalence of disease, in this case TB, can be understood, explained, and addressed only by relying on a variety of etiological paradigms. As Lock and Scheper-Hughes argue in their seminal piece “The Mindful Body: a Prolegomenon to Future Work in Medical Anthropology”, “Medicalization inevitably entails a missed identification between the individual and the social bodies and a tendency to transform the social into the biological” (1987: 10). A related criticism of this system is that it is entrenched in a Cartesian mind body dualism. This stands in opposition to a phenomenological²⁴ understanding of the body in which there are seamless connections between a subjective mental perception of the body’s experience and the actual physical; the physicality of perception incorporates the experience of the political economy of existence.

As previously stated, the valley’s clinical structure of organization follows the biomedical or clinical model. In the main clinic there is a general doctor who comes once a

²⁴ I am relying on the term *phenomenological* as used by Merleau Ponty in *The Phenomenology of Perception* (1962) and later refined in *The Visible and Invisible* (1969).

week to see patients whom the “sisters” (trained nurses) have determined need more specialized care. In addition, there are more specialized doctors who make visits every few weeks or months to follow cases identified as more severe, such as those involving complications from HIV, juvenile TB, and resistant strains of TB. The “sisters,” are distinguished by uniforms with epaulettes and see the patients only after they have been screened by the administration and the nurses’ assistants. All the positions in the clinic are distinguishable by various uniforms with distinctive features such as pins. Below the health care workers who have titled positions in the clinic are personnel who are not in uniform and who perform various menial jobs. Finally, occupying no official position in the setting of the clinic, but belonging to the general structure of care, are the HBC givers like Elize and Lea, who are marginalized in the schema of the health care structure. They often have little formal training²⁵ and work on a “voluntary” basis for stipends roughly comparable to those of farm laborers, about R800 per month (at least in theory; as in Elize’s case, it is not uncommon to receive no financial compensation for their services). HBC givers act as intermediaries for those who are physically unable to reach the clinic on a regular basis; they check up on patients between visits and do such things as massage patients with circulation problems, bathe patients, and use wheelchairs to push patients to the clinic who would otherwise not be able to make the visit. An important aspect of their role is that HBC givers provide a service to the ill in a setting relatively free of indicators of relative positionality, institutionalized power structures, and panoptically structured spaces, outside the realm of the clinical. They provide physical “hands on” care, aiding patients in a direct manner with a greater degree of physicality than other health workers, thus connecting with their patients phenomenologically

²⁵ For example they have received certificates after attending a weeklong training workshops sponsored by an NGO.

and metaphysically. They relate as equals and act as supporters, friends, and advocates. This positional placement of HBC providers allows them to act intersubjectively with patients in that they develop a common subjective understanding about patients' state of being and illness. With this shared understanding, a path can be found to better identify and address precarious individual situations.

Although they are not able to address the historical and structural realities of existence that have created TB sufferers, HBC givers are positioned to act intersubjectively to appropriately address the needs of individual patients which are the effects of a disparate abusive structure.

What allowed Elize's interventions to constructively affect lived experiences of illness was that they were not embedded in the panoptic health care system that produces an oppressed objectified patient. By acting intersubjectively, illness (an indicator of oppressed situations) was confronted. I argue that Elize was the most important actor in the process of allowing TB-laden people to assume some control over their lives. Although reclamation of the physical state of being may not extend beyond the ontological realm, she at least enabled the creation of a subject (as opposed to object) existence. In the cases of Dorothea and Donovan, Elize brought a certain sense of security and hope amidst their history of repeated misfortune. Through her direct connection to individuals and co-inhabitation of the same social world, Elize has been able to develop a metaphysical consciousness of their total experience of being; it is through this intersubjective connection that she is able to act with precision and meaning among those who are harmed by the unjustly structured mesoscopic worlds they live in.

As I have demonstrated in the representative examples of Donovan and Dorothea, the lives of most TB sufferers are not fully theirs; they are plagued by a lack of security resulting

from decades of systemic violence. I suggest that tuberculosis and living in a state of insecurity and precariousness are co-infections in that one perpetuates and magnifies the other. It follows that to fully treat TB we must concurrently, or, better still, preemptively address the precariousness that most TB patients experience throughout their lives. To do this, HBC providers like Elize are uniquely positioned, as they are intensely aware of the individual ways in which patients experience instability of existence. Their own experience has given them the kind of understanding that enables them to creatively address realities of existence. In light of this, I argue that the position of HBC provider needs and deserves greater recognition within the public healthcare system; and that more resources should be allocated to programs to directly support HBC providers. Touraine argues that subjectivity is the beginning of change and of social movements, and that it is the only way to address oppressive power. Let us hope that the intersubjective actions of HBC providers like Elize are the beginning of the desperately needed change and revolution in the health care of so many devastatingly sick valley residents-and South Africans.

CHAPTER THREE

Gendered Responses to Clinical Tuberculosis Treatment

“Black man, you are on your own”

-Slogan commonly attributed to Steve Biko (1946-1977)

When examining the ways that individual men and women react to, deal with, and confront TB, one develops an awareness of the gendered ways in which the greater macro environment (through its many tentacles of oppression) creates the space for TB to differently affect individuals on the micro level. By examining and comparing gendered experiences of TB, one can better understand how gendered bodies are subjugated by power in different ways. It is important to distinguish between the complex ways in which gender is theoretically experienced in society versus how it is actually experienced by individuals of a certain race and socioeconomic status. Idealized notions about what gendered existence should be and what society allows in practice differ. Building on Foucault’s notion that

resistance accompanies power,²⁶ this chapter comparatively assesses the ways in which resistance and assertion of subjecthood are differently expressed by males and females in dealing with TB. My purpose is to better understand the ways in which oppressive systems of power (racial, social, and economic) are exerted and experienced along gender lines in this still patriarchal, post-apartheid, neo-liberal state. I try to answer the question of how embedded gender roles affect individual experiences of tuberculosis in the particular context of the valley.

In the broad context of South Africa, the gendered experience of power during the colonial and apartheid eras was complex but it was largely structured around the primacy of male authority. This gendered paternalism cannot be understood without taking into account the cofactor with which it is inextricably linked: race. Considering the racialized male, South African anthropologist and activist Ramphela argues that black “men are denied the rewards to which the status of manhood entitles them in a male dominated society” and that “the end of apartheid has not necessarily changed the reality of many poor black men” (2000: 114). In this context, at least since the beginning of the colonial era,²⁷ black men have lived in an environment which, in both its overt and sub-textual ways, is structured on relative male dominance; yet as racial individuals they have been unable to assert positions of dominance in the public sphere. As sociologist Hearn has argued, gendered power orders “intertwine with capitalist, imperialist, racist and other oppressive social relations” (2007: 17).

Historically, the fear of the physically powerful “native man,” often “categorized within the sexual as opposed to the intellectual mode” (Saint-Aubin 2005: 25), led to a gendered

²⁶ “Where there is power, there is resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to power” (Foucault 1978: 95-96).

²⁷ Guy even argues in “Gender Oppression in Southern Africa’s Precapitalist Societies” (1990) that such was the case before the colonial era.

difference in the treatment of men and women in the labor force (Salo 2007: 167). It is ironic that the political and economic systems were based upon the commoditized physical power of black men as laborers in the mines, on farms, or in industry. As social historian Packard put it, there was a kind of “racial capitalism” (1989b: 687), or what Foucault would call “an era of bio-power” (2004: 81); yet there was an underlying fear that the very physical strength upon which the empire was based threatened the position of the dominant oppressors.

In order to protect again these “other” men there were complex systems in place to assure that these men stood little chance of asserting their “manhood”; they were both symbolically and in their named status forced into remaining eternal “boys” at least in the public sphere²⁸ (Van Onselen 1992: 136). Paternalistic systems of labor organization on the farms resulted in a situation wherein “farm workers [were] treated like children-they [were] looked after and protected, and [had] the status of minors who [were] subject to the authority of the household head”(Orton et al. 2001: 470). Women, although oppressed, were paradoxically allowed some opportunity to assert their independence, at least in the public sphere, by being given a relative degree of economic freedom. In the Western Cape “women were favorably located as preferential labor... [and thus] wielded enormous economic power within their communities” (Salo 2007:161).²⁹ Additionally, it has been suggested that female adolescents (as opposed to their male counterparts) have been afforded more opportunity to escape the paternalistic structure of organization on the farms (Waldman 1996: 67). The system did not overtly challenge black women’s gendered role as subordinate to the male publicly (they were still subject to the power of their white bosses), but did challenge that of

²⁸ I would furthermore argue that the traditional “blik” style worker housing on farms is panoptic in that it is structured to enable white farmers to maintain optimal surveillance over workers so as to exert maximum of control over their personal lives and labor.

²⁹ It should be noted that this was not necessarily the case on farms where men were historically granted the legal right to control their wives’ labor (Orton et al. 2001: 471).

black men's (they were subject to the power of their white bosses on racial lines and thus deprived of their manhood by the racial trumping of gender by the organizational structure of power). Furthermore, beginning in the 1980s, there was a shift towards feminization of the Western Cape's fruit and wine farm workforce, followed by several initiatives on regional farms aimed at empowering female workers (Kritzinger and Vorster 1998). The private sphere, however, remained the only one in which men were allowed to assert their "manhood" and many have suggested that this is why violence in the home became an issue (Hearn 2007: 27; Morrell 2005; Posel 2005; Ramphele 2000: 275). Although the apartheid era is over, and official national policy no longer reflects a desire to further such abuses, many individuals still live with the conscious memories of oppression and the reverberations of the active policy are slow to disappear. Some even argue that "decolonization" in South Africa has not yet occurred; to quote Fanon, we have not yet seen a movement wherein the "social structure [is] being changed from the bottom up" (1963: 35) and the "The last shall be first and the first last" (1963: 37). In South Africa today, although apartheid has ended in the legal sense, by and large white individuals, although they are a minority of the population, remain in control of the economy. Mbeki makes a strong point when he argues that South Africa's neo-liberal state has been, and continues to be, worse for the "black masses" than the state of apartheid and colonial rule. Mbeki argues that Black Economic Empowerment (BEE) is somewhat illusory as the associated enterprises are funded by white capital (BBC News 2004; Mbeki 2005). I would even argue that this assessment could be extended to the political arena as we no longer seem to be living in a world in which politics control the economy, but, as the world becomes increasingly neo-liberal, we find ourselves more and ever more in a world where economics rules politics.

In farming areas of the Cape, the end of apartheid resulted in the ejection of unskilled

laborers from farms and in a decrease in opportunities available in the mines; thus there was a decrease in the ability of relatively “unskilled” male laborers to find work, leading to an intensification of entrenched economic poverty (Seekings and Natrass 2005: 338). The combination of these factors has led to a situation in which black male dominance in the private realm is being encroached upon as the opportunities to assert masculine authority (which rest upon men’s position as primary breadwinner), become less available. The changing power structure has created resistance and, as Abu-Lughod argues in her article entitled “The Romance of Resistance: Tracing transformations of Power Through Bedouin Women,” examining resistance teaches us about the “complexities” of “shifting structures of power” (1990). In her paper, she builds on Foucault’s notion that power is necessarily accompanied by resistance and posits that by examining the “rich and sometimes contradictory details of resistance the complex workings of social power can be traced” (1990: 42). By examining how racial, gendered individuals react to biomedical tuberculosis treatment we can gain an understanding of the ways that individuals experience shifting manifestations of power.

A case in point is Camilla’s and her husband Johannes’s experience of TB. Camilla radiates generosity and kindness; one cannot help but develop a fondness for her. Although she is diminutive in stature, her calm gentle smile fills a huge space around her; she has a quiet strength. At the age of 55 she has what I interpret as an innocent love for all those who surround her. When I first met Camilla and her husband she was in the middle of her second treatment for TB. She had undergone the standard first-line treatment three years before and, according to her file, was cured. Her TB, however, returned, and she is now undergoing the “retreatment” regime. In the first phase of treatment, she received a daily injection and a standard pill (the pill treatment will continue into the second phase). Camilla suspects that

many people in her “blok” have TB but that they do not want to get treatment because they find it too difficult and are scared of how it will affect their lives; she says that she is afraid for the children. Camilla says she is tired not only from the treatment itself, but from also having to travel to get her daily injection in the mornings before work. Every day Camilla walks about six kilometers to and from the clinic. Sometimes when she is in town she will “get lucky” and catch a ride on the back of a lorry going her direction. The doctor has advised her that when she is receiving her injections she should not work and volunteered to write a note for her boss (who is a white man; she is a colored woman). The letter, which, at her request, did not disclose the specific nature of Camilla’s illness, was not deemed sufficient and she was denied permission to take leave. Camilla does not want to insist on taking time off because she is afraid she will lose her job. When asked whether she has considered applying for a temporary disability grant³⁰ so that she would not be financially burdened by not working (her salary is on a par with the disability grant), she said that without a job she would not be able to stay in her home on the farm where she works.³¹

As a young girl and woman in her parents’ house, Camilla reports that she proudly took on many of the tasks that kept the household of ten together (her parents, herself, four sisters and three brothers of which only two are still living): “It was me who kept the house together, I used to wake up early in the morning, it was me who made the food for everyone.” At the age of sixteen she found a job as a domestic worker, but it was always her dream to have a house of her own: “to become a housewife, and to get a very good husband.” As a domestic worker she enjoyed her work and taking care of things in her “boss’s” house. A few

³⁰ Many of the TB patients I met who had been debilitated by their illness have successfully applied for and received temporary disability grants equivalent to a farm laborer’s wages.

³¹ Many farm owners provide “free” housing on the condition that those who live in the housing provide labor. This system creates a situation wherein workers feel as though they have even less bargaining power with which to lobby their employer for fair standards of treatment.

years later she met a man who became the father of her son. At this point she gave up her job as a domestic worker and began working on the farms. Life was not as she had hoped and imagined; a few years later both she and her young son “caught an infection in the liver and became yellow.” Her son died. When Camilla recovered, she left the father of her son. Soon afterwards she met the man who would become her husband, allowing her to assume the role of housewife that she had idealized as a way of fitting into her gendered place in the world. She said she lived with him for a few years before the “happiest” time of her life, her marriage: “I did not know that we were going to get married and I came from work, and we had been living in a little shack, and I came in and he said that tomorrow is the day that we [will] become married, it was a surprise for me and I danced.” Camilla says that although life is not easy, she is “very proud of the way that I am living here in my house.”

Camilla’s self defined identity is highly bound up in what she believes to be an “ideal woman”; she is a caretaker whose domain is the care and everyday maintenance of the house. As a gendered and racial individual, she remains subordinate to her boss who treats her like a child and exerts his dominance by not allowing her to take off from work for her illness. Camilla accepts this, as she places the highest value on keeping her home, the physical place she can remain in only as long as she continues her work. Reflecting back on her life, Camilla says that it has always been her dream to take good care of her own house. Camilla’s situated existence as a “colored woman” has not impeded her quest for the feminized role of domestic caretaker.

When I first met Johannes, Camilla’s husband, although he was aware of my research, he did not disclose his status as a TB patient. Like his wife, Johannes radiates kindness, and I noted the strong bond of affection between him and his wife. When he later disclosed to me his status as a TB patient, I asked why he had opted initially not to. Johannes said that it was

fine for people to know that his wife was receiving treatment but for him it was different. When asked to explain, he claimed that people would consider him to be “less.” When asked if he thought the same would be true of his wife, he replied that it was “different” but could not offer further explanation. When asked if his view of others’ response to his illness would deter him from seeking care at the clinic, he answered that he realized that he needed care but did not want people to know that he was actually receiving it. He acknowledged that the care at the clinic was “fine” but would not elaborate on his experiences. Camilla, on the other hand, said that she liked the staff and mentioned the sister in charge of the TB patients by her first name.

Camilla’s and Johannes’s relationship follows established models for a gendered division of power within the private context of the home. Although it is Camilla who is charged with maintaining the physical aspects of the house, it is Johannes who controls the space they occupy as well as their relationship. It was Johannes who decided that they would be married; instead of asking Camilla, he simply told her one-day that they would marry. In this instance Johannes exerted his masculine dominance over Camilla. In other ways, however, Johannes is forced for the sake of economic survival to submit to the power of others. For his work on the town’s golf course (he tells me that he is a “garden boy”), he is continually obliged to accept his subordinate position to white men who are his juniors. Johannes believes that he is lucky to have the job, but likes neither the people he works for (“they are not always good”) nor the difficult physical labor he must perform.

In order to receive care at the clinic, Johannes would have to submit to a structure of authority that is reminiscent of his workplace and his status as a man would be doubly challenged by being subordinated to the nurses who are not only white but also female. By publicly acknowledging his status as a TB patient, would he once again be admitting that an

aspect of his subordination had entered his private sphere of existence? Would taking his pills at home represent a symbolic control over his body? Would submission to the authority of white female nurses further emasculate him? Forced for reasons of survival to be the “garden boy” for younger white men (enabling him to exert male dominance over Camilla in his home), would it be too much for him to publicly allow another symbolic emasculation reaching into his private existence?

My experience in the valley led me to the conclusion that instances of men resisting treatment at the clinic were not simply incidental. I met several women who were receiving care for TB but whose husbands refused to make clinical visits even when they experienced serious declines in health. One of the most striking instances of this occurred with one of Elize’s and Lea’s childhood friend Dora. Dora, 49, discovered that she had TB three years ago and immediately began treatment at the clinic. Dora’s husband refused to test for TB at the time. Two years later, when his health declined dramatically, he agreed to a sputum test but it was too late and he died in hospital soon after. The occurrence of male resistance to clinical care is supported by the fact that the majority of clinical patients in the valley are women. Although there are many possible reasons for this gendered division, such as the aggregate population makeup, the small number of TB patients at the clinic (there is a small sample of only 151 people), and other factors that might increase gendered susceptibility to TB, it is nonetheless interesting to note this statistic. It should also be noted that of the 19 patients who did not return to the clinic after initial sputum tests (who I tracked down for the clinic during my first week in the valley), 13 were men.

These numbers appear to be indicative of the gendered realities lived by many valley residents. Another example is that of Erica and Neville. I first met Erica at the clinic; she had come in for her daily injection as a part of her re-treatment for pulmonary tuberculosis. She

had undergone several kinds of treatment since 2005, and had recently been diagnosed with a resistant strain of TB.³² On the day we met, she walked into the TB section of the clinic wearing a brimmed hat from under which her big smile shone. She sipped coffee from a mug between effusive greetings to staff and other waiting patients. She exuded confidence. About two weeks later I met with Erica at the house she said belonged to her boyfriend Neville. I asked if she had moved in with him, and she said that they had moved in together from another house a few years before. His sister had since moved in with them. The house was located in one of the informal settlements in the eastern part of town and, like the many of its neighbors', had been built of various scrap materials including cardboard, sheet metal, wood, hammered out metal drums, old nails, and bottle caps. It had one room with a bed and a table on which there were a few food items. When I arrived Erica found two chairs for us to sit on. Loud music played at a nearby shebeen for a few afternoon customers. In this setting, I almost did not recognize Erica; she was quiet and seemed ill at ease. I thought perhaps her apparent discomfort could have something to do with the fact that I was little more than a stranger in her house. The contrasting demeanors that Erica displayed in the two settings made me reflect about what it was about them that created such a disjunction between the two selves that were revealed.

Erica was born thirty-one years ago on one of the farms in the valley to parents who worked as agricultural laborers. Her father left at an early age, and when she was nine years old she was sent to live with an aunt. Erica remained with her aunt until she had to start

³² Erica's strain of TB is termed "multi-drug resistant tuberculosis" as it is resistant to the two most common first line drugs, isoniazid and rifampicin. Erica's TB is also resistant to ofloxacin. When I asked the nurse if she thought that Erica acquired her TB in its resistant form or if she thought that it had developed into this form within Erica, she said that she thought that it was the latter (after her initial diagnosis in 2005) as she was the only patient with this kind of TB. Her "contacts" who had TB demonstrated less resistance than Erica to these TB drugs.

working alongside her mother because the extra money was needed. She said of this time “There was no joy for me; I was there to support my mother.” When asked about her father, she said that when she was a child he would carry her on his shoulders. She remarked that when she needed something, it was her father would get it for her, not her mother. Although her father abandoned her except for an occasional visit, she expressed the belief that he was strong and in control. Similarly, when talking about Neville, she said “although he gives me money, I am scared of him. He yells at me, he is mean, he is shouting,” adding that although he gives her some money, now that she is sick “sometimes I become very hungry.” Erica claims that Neville is mean to her because she is sick and cannot work. Ironically, however, when she first started seeing him he was the one who was sick and she believes that is how she first contracted TB. In the relationships with both her father and boyfriend, Erica expresses dependence and inherent subordination to the men in question. Furthermore, although Erica did not say so outright, she hinted that Neville was abusive towards her both physically and mentally (her neighbors corroborated this). It is possible that this abusive display of power on Neville’s part is the reason she is ill at ease in her domestic setting? It would seem that Neville’s powerful aura remains in control of the space even when he is physically absent.

Although hierarchically stratified along other cross cutting lines, the clinic is relatively free of gender distinctions as the higher ranked staff members are female (at least those present daily; the male doctor only makes weekly visits). Although Erica is positioned within the structure as economically and sometimes racially subordinate to the staff (not to mention the unequal relationship between biomedical care giver and patient), she appears relatively at ease in the environment of the clinic where she is free from all too familiar gender based oppression she has experienced and struggled with all her life, first with her

father and now with Neville. In the public realm of the clinic, where she receives daily treatment and is free from Neville's abuse, she is being cured of the illness he gave her. For Erica, the clinic represents a space where she can assert herself and resist male authority while fighting to rid her body of the tuberculosis that was inflicted on her.

Erica says Neville will not get tested for TB, even at the urging of the sisters at the clinic. Because of Erica's resistant strain of TB, a more active approach has been taken in treating her case. I learned from the sisters that Neville had undergone treatment for TB some years ago, but when he came to the clinic recently at their request he was "difficult" and refused to have a sputum test. I interpret Neville's "difficult" behavior not only as resistance to the female dominated care offered at the clinic but also as resistance to being submissive in an environment in which his girlfriend Erica asserts herself. This behavior may indicate that he is struggling to find ways to exert power in the face of his powerlessness in so many areas of his life. Posel notes that the display of power in the private realm is not uncommon among South African men and suggests that extreme acts are not merely isolated incidents (2005). Unfortunately, when I asked Neville for an in-depth interview, he declined.

In the cases of Erica and Camilla, the care that they receive, although associated with power, does not challenge their gendered situation. On the other hand, their partners Johannes and Neville are faced with an environment that challenges their masculinity by positioning them as subordinate to women as patients economically and racially less empowered than those providing the "care." This emasculation is especially hard hitting as they live in a context where masculine dominance is a prominent structuring factor of organization. For Neville and Johannes, the role of the dominant man is something they must maintain, as demonstrated in their private behavior towards their partners Erica and Camilla. But, like most black men in the valley, they are denied the assertion of dominance in many public

realms; the clinical context reminds them that they are not allowed to assert their full masculine dominance due to other crosscutting positions in society. The feeling of subordination is magnified by the fact that the care that is provided is experienced in parallel with their female partners, who in the domestic realm serve as objects of their male power and dominance but who can be comparatively assertive in the clinic.

In conclusion, the examination of gendered experiences of TB reveals ways in which individuals resist certain manifestations of power; how existing power structures are experienced; and how men increasingly feel the pressures of a context in which their ability to assert their dominance is diminishing. In the case of tuberculosis care, female partners embrace care within the clinical structure because their idealized gendered positions are not threatened; however, male partners resist submitting to such care as an expression of gendered resistance to the decline of the power wielded by men in the private domain and of the precariousness they experience as gendered individuals.

CHAPTER FOUR

Phenomenologically Shaped Response to Tuberculosis

“In fact nothing is more material, physical, corporeal than the exercise of power.”

-Michel Foucault, *Knowledge Power* (1980: 57-8)

“The inside and the outside are inseparable.”

Maurice Merleau Ponty, *Phenomenology of Perception* (1962: 407)

As I searched for patients who had “defaulted,” I had to ask: why do so many people who have access to what appears to be good quality government-provided free clinical healthcare and treatment for tuberculosis opt out of such “treatment”? As someone who had worked in a rural clinic (albeit in a very different context) where the limited facilities could not provide for all those seeking treatment, I was surprised by the choice to reject free, readily available care by individuals who clearly realized that they were probably ill with TB.

to create an “adjustment of the accumulation of men to capital” (2004: 81). Thus, when a subject has been drained of what can be transformed into capital, he is no longer worth keeping in the system. Foucault associates the rise of global capitalism (which helped create the neoliberal South African state that appears to support the valley’s farms) with the start of an “era of ‘bio-power’”(2004: 81) in which there is an “explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations.” He explains that this era relies upon “power capable of optimizing forces, aptitudes, and life in general without at the same time making them more difficult to govern” (81) and that it is “centered around the body as a machine; its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls, all this was ensured by the procedures of power that characterized the *disciplines: an anatomo-politics of the human body*”(ibid, emphasis added).

In the valley, bodies are indeed the units of the exercise of power; historically and in the present. Individuals are subjected to an oppressive system in which incorporation is exchanged for survival. In other words, others’ power over one’s your body is the price of a basic existence. The body seems to have become just another commodity integrated into the neoliberal world economy. Using this Foucauldian concept of politics, power, and life as a platform for understanding the nature and the structure of power which controls the lives of people with TB that I encountered, it is possible to begin exploring the particular ways in which it is abusively inscribed on the body. As the body is the raw unit onto which power is inscribed, it is also the medium through which it is experienced. For TB sufferers in the valley, TB has become inscribed within their physical beings through a variety of historical, political, and social circumstances; the body politic thus molds the individual body. Valley

residents have been physically marked as an unfortunate underclass. Historically, most TB carriers have found themselves the unfortunate losers in a highly unequal environment. They are almost invariably black laborers who provide the dominant system with a practically unlimited source of exploitable labor. Under colonialism and apartheid, “race” and ethnicity was used as a basis for enacting policies that ultimately led to abuse and exploitation. Today South Africa is undergoing a process of “transformation” but, as Ramphela argues, many of the “ghosts” have not yet been put to rest (2008).

In Bradbury’s classic novel *The Illustrated Man* (1951), we are presented with a tattooed man whose body is inscribed with illustrated stories of the past. Like Bradbury’s illustrated man, peoples’ bodies (concurrently both physically and ontologically, therefore phenomenologically) are the canvases that carry the marks of often oppressed trajectories. Take for example the rather extreme case of Johnny, who is now in a wheelchair because he is partially paralyzed from the TB meningitis³³ he contracted several years ago. At the time, Johnny was working on one of the farms and, though he suspected that he was ill, he felt that he could not interrupt his work to seek treatment. Johnny supported not only himself but also his wife and young son. It was only when he had a seizure that he sought care. By then, Johnny’s body was so weakened that he was confined to a wheelchair, his drastically reduced bodily experience of the world a constant reminder of the fragility of his subordinate position in society. It can be said that his body has been inscribed (“illustrated”) with the oppression and abuse of power he has suffered; that this is his phenomenological experience of life.

Johnny’s case can help us understand some of the ways in which physical experience

³³ According to the medical literature, increased risk factors for contracting tuberculosis meningitis (i.e. a case of tuberculosis that has gone to the brain) include race and level of alcohol use. Non-white individuals and also those who abuse alcohol are at a higher risk (Merson et al 2006). In the context of the valley, both these factors cross-cut with the people most exploited.

becomes inseparable from the ontological. Johnny's physical experience has taught him that his life has been subject to abuse and power. Through living in his physical body, Johnny's subjective and phenomenological understanding of the world and life has been shaped and formed by his unfortunate experience in a restricted body.

Merleau-Ponty's work on phenomenological experience has served as a foundation for many anthropologists who address issues of corporality (Charlesworth 2000; Csordas 1990; Jackson 1998; 2005; Lock 1993: 137; Schepper-Hughes and Lock 1987). Rejecting a Cartesian mind body duality,³⁴ Merleau Ponty offers a scheme that interweaves the physical positionality of individuals as experienced in the material world with subjective ontological existence. He argues that:

The ontological world and body which we find at the core of the subject are not the world or body as idea, but on the one hand the world itself contracted into a comprehensive grasp, and on the other the body itself as a knowing-body. (Merleau Ponty 2002: 474)

Furthermore, Merleau-Ponty stresses understanding of the complete individual being as it is situated in the world, arguing that experience and perception in context are what create

³⁴ My use of Merleau Ponty's understanding of the body to build upon Foucauldian notions of society and power as exercised and inscribed on the individual, requires me to address what has been perceived as a disjunction between the two theorists' positions. I argue, upon careful examination, that no such disjunction exists. Judith Butler's piece entitled "Foucault and the Paradox of Bodily Inscriptions" (1989) argues that Foucault displays the belief that there is "materiality" to the body, which is separable and external to that of the soul, thus accepting Cartesian notions of mind body dualism. Butler contends that Foucault's work at times suggests that "the very mechanism of "inscription" implies a power that is necessarily external to the body itself" and, therefore, that "the body does not exist outside the terms of its cultural inscription": and that "the 'constructed' or 'inscribed' [bodies] have an ontological status apart from that inscription"(1989: 603). Butler maintains that this creates a paradox because Foucault is equally wedded to the idea that both "materiality" and "ontological independence of the body" do not exist outside the realm of cultural constructions (1989: 602). It is my assessment that the perceived "paradox" is illusory, as Butler has relied on a reading of Foucault's work that interprets "cultural inscription" as being necessarily separate from experience. As I interpret Foucault's work, bodily inscription serves to further define the subjective positionality of the individual and speaks to the historical trajectories of location that the individual has passed through; and that this experience forms the holistic being. There can be outside exertions of power which mark the material, but these marks on the material carry through to the holistic being.

consciousness. Merleau-Ponty takes experience as the basis for individual knowledge, thus arguing for a subjectivity of the individual. An important focus of his work is the examination of the role of the context in which the individual finds him or herself:

I understand the world because there are for me things near and far, foreground and horizons, and because in this way it forms a picture and acquires significance before me, and this finally is because *I am situated in it and it in me*. We do not say that the notion of the world is inseparable from that of the subject, or that the subject thinks himself inseparable from the idea of his body and the idea of the world; for, if it were a matter of no more than a conceived relationship, it would ipso facto leave the absolute independence of the subject as thinker intact, and the subject would not be in a situation. (2002: 474-5, emphasis added)

and:

Both universality and the world lie at the core of individuality and the subject, and this will never be understood as long as the world is made into an object. It is understood immediately if the world is the field of our experience, and if we are nothing but a view of the world, for in that case it is seen that the most intimate vibrations of our psycho-physical being already announces the world, the quality being the outline of a thing and the thing the outline of the world (2002: 472)

Given that experience of the material world is inseparably interwoven with the ontological, we must consider how the physical experience of TB sufferers whose lives have been plagued by symptoms of structural abuse and misfortune perceive their situation and physical experience of illness. What are the ways in which individuals' bodies, inscribed with illness, have contributed to the formulation of their subjective understanding of clinical care through their placement of the world? And how does this lead them to form their own histories? Although it is impossible to draw conclusions about trends as each situation is formed by micro subjective positional placement as unique as individual fingerprints, I believe that it is worth examining the specific details of such situations to begin to see how macro mechanisms of abusive power can be experienced in the specific.

At the age of 27, Frank is dealing with a recurrence of tuberculosis. Frank's TB has already left him with a severe case of asthma which, combined with the reappearance of his

illness, has left him in a condition such that he cannot walk more than a short distance. I met Frank because he was on one of the clinic's lists of patients who had not started their treatment after testing micro-bacterially positive for TB. When I went to his house in one of the informal settlements on the eastern periphery of town, I was greeted by a spirited, jovial woman and a chubby, contented toddler. The lady, I learned, was Frank's maternal aunt, and the child was Frank's. The child did not live with Frank and his aunt, but stayed at the house while his mother (Frank's girlfriend) went to work. After I went in, Elize, Frank's aunt, and a middle-aged female neighbor who had helped us find the house, went outside to wait in the small front-yard. Frank was sitting in a big chair in the dark, completely still. Although he remained nearly physically motionless, as soon as I sat down he began talking to me quite forcefully. I asked him if he knew that he had TB and he said that he knew. I asked why he had not returned the clinic, to which he replied there was no point and essentially explained that his life and body were not worth fighting for. Frank told me that he had been out with his girlfriend a few weeks before and when some men his age had made rude, antagonistic remarks, it was not he but rather his girlfriend who had said something to defend them. The telling of this episode brought forth the intense sense of powerlessness that Frank experienced; he felt his body was no longer powerful enough to defend himself or his "girl." Frank went on to enumerate the reasons why he did not see the point of undergoing treatment. He explained that even if he were to get better, his life would not improve substantially as he would be relegated to living the life he had before he became ill; that even before he got sick it was difficult to find and keep a job and the work was not what he had wanted or hoped for from his life. He spoke about his friends and contemporaries in the valley, explaining that nowadays it was becoming increasingly difficult to secure even marginal work on the farms. He felt that there was no hope for him to find something better.

Furthermore, he said, he would never be “well” again, and would always be scarred from his struggles with tuberculosis. Frank said that aside from regretting leaving his child and girlfriend behind, he wanted to die; he believed they would be better off without him. In my interpretation, Frank chose to commit suicide. Although the choice is not an active one, by opting to not receive treatment he is passively choosing to take his own life. Using Durkheim’s definition of suicide, Frank’s passive choice is indeed an act of suicide: Durkheim defines suicide as “any death which is the direct or indirect result of a positive or negative act accomplished by the victim himself”(1952: 42).

Durkheim’s still controversial, classic sociological study on suicide makes the point that suicide is frowned upon because it is perceived that the individual owes society a debt and that he “evades his obligation towards society”(1952: 333). Whether one agrees with Durkheim or not, the question of who wields ultimate control over the body is one that should be pursued. For the likes of Johnny and Frank, their experience of the world has taught them that although they might be in control of many of their immediate actions, they are nevertheless ultimately regulated by the economy of oppression that has taken away true control of their destiny. Both men are continuously and inescapably reminded of their subordinate positions in society by experiencing the world through their TB-damaged bodies. In Frank’s case, he seems to be searching for a way to regain control by choosing not to continue to struggle for life; in a sense he is resisting the manifestations of power within his physical being at the ultimate level Frank is fighting back with his complete being using his ontological to fight with his intertwined physical.

A few days after the meeting with Frank, Elize was asked to visit David, 38. David had been living with his aunt, two cousins and a two-year-old nephew for a few months. David’s family had noticed that he had stopped taking his medications. In addition to the

medication for TB, David had been prescribed antiretrovirals for HIV. David's everyday existence for the past 24 years has been shaped by his work as a physical laborer on the valley's grape farms. When I met him, he was in a visibly deteriorated physical state but continued to perform regular work on the farm. Those around him said that he had been communicating less and less and though he talked with me, he refused to grant me an in-depth, recorded interview. David explained that he had to continue working in order to maintain his livelihood but that he also knew that his own death was imminent. David said he felt trapped in his present state. He was unable to give a verbal explanation as to why he had stopped taking his pills, but assured me that it was not because they made him feel worse or because of any adverse side-effects. When Elize warned him that the ARV's would be taken away if it was "found out" that he was not taking them, he offered to give them back saying there was no point to keeping them.

On a subsequent visit to David's house, we brought along Xolani, a friend of Elize's. Like David, Xolani had been close to death over a year before with TB and complications from AIDS. He explained to us that his CD4 count had been well below 200, that he was completely bed ridden, but that since dedicating himself to following an ARV and TB treatment he had made a miraculous recovery. Xolani told David that it had been a difficult path to recovery, but that his life and family made it all worthwhile. Xolani emphasized the hardships and candidly discussed the hurdles he had faced such as a persistent fungal skin infection and friends and family leaving him without support at some of the hardest moments ("they left me on an island"). Xolani said that he has since rebuilt his life, that he now dedicates himself to his three young sons, wife, and mother-in-law. He described how he now runs a small informal shop from his house and says that although difficult, along with his wife's and mother-in-law's earnings from work on the farms, they manage to live their lives. He

made the point that one can recover from TB and live with HIV. David remained unmoved by Xolani's attempt to reach out and resisted any discussion of his own situation. A few weeks after the Xolani's visit, David's health deteriorated further and he became bedridden. When I talked with Elize a few months after leaving the valley, she told me that David had died.

Why have Frank, David and so many others given up fighting for their physical life? They have all learned through their experience of life and labor that their bodies and lives are not theirs to control. It seems significant that these are not just cases of refusing biomedical clinical care. When I asked whether individuals sought alternative care provided by local non-biomedical practitioners, I was answered without exception that they did not. Why such surrender and hopelessness? I propose that it is because the outside world and their position in it ("situated" within them) is felt and experienced as too great a burden to bear.

Besides those, like Frank and David, who had stopped treatment after an initial period I also encountered people who refused TB treatment from the onset of symptoms. After searching for the "block" of a man whose sputum test was micro-bacterially positive for TB, we finally found his dilapidated house at the far end of the farm. Inside, in the dark, were the elderly man and his blind wife; both were drunk. Extreme thinness and coughing were indications of their bodies' persistent struggles with TB. The husband said that he had seen blood in their saliva after coughing. Elize urged the couple to come to the clinic to begin treatment, or to simply just talk with the sister in charge of TB. We arranged to return the next morning to drive them to the clinic. When we arrived the next morning, they refused to go and told us to come back another day. After several attempts to take them to the clinic, it became clear that they were both aware of the severity of their TB, but that they had made the choice not to seek clinical care. Although they refused to discuss their rejection of clinical

care, the wife asked over and over again “why?” She would not accept Elize’s answer that she would feel better as a good enough reason to receive medical treatment, but indicated that she sought a different kind of motivation in order to persuade her of the benefits of engaging in the clinical treatment.

These examples of deliberate choice not to seek or accept clinical care for visible manifestations of TB are by no means exceptional. Of the nineteen persons who the clinic had asked me to inform of their positive TB status, five immediately refused treatment outright. If more than a quarter of the people who had tested positive in a sputum test, had not returned for treatment and refused all treatment, how many other sick individuals could there be who had never even come to the clinic? This precise question I cannot answer but it brings me back to the issue of why people refuse care. There are many ways of approaching this complex issue, but I would like to restrict myself to the simple question of why people do not want to receive help for healing their ailing bodies. I have come to believe that it is because they have learned over their lifetimes, like Johnny in his wheelchair, that they are ultimately not in control of their bodies. The continual experience of volatility, physical instability and lack of control creates a sense of utter frustration; rather than continue to fight, they choose to abandon the struggle and to free themselves of the hold that the outside world has on them. People refuse medical care because they, themselves, want to determine in some way the path that their ailing bodies take. Although they cannot control how they are situated in the world, they want to feel they are in control of how the world is situated in them.

CHAPTER FIVE

Conclusions

In this paper I explore the ways in which individuals affected by tuberculosis (considered as a physical manifestation of social injustice and oppression) react to and deal with their illness and its encompassing complications. As a result of examining individual situations molded by experiences of TB, I have come to the conclusion that TB and the social condition of precariousness are co-infections. These states of existence entrench and perpetuate each other in the lives of individuals. That TB and precariousness are co-infections becomes notably apparent when examining how an individual's phenomenological experience of life, as well as gender and race, impact experiences of illness. In order to work at redressing some of the injustice suffered by those afflicted with TB and work towards improving their experience of life and what their placement in the world allows them, we must take action. These actions must be shaped by a reliance on multiple etiologies, inclusive of those that take into account factors of political economy that entrench instability and precariousness. In examining how HBC providers interact and work with TB patients, one can observe the benefits of providing holistic care based on a diversified range of etiologies

that include not just biologically based ones, but more also those which are the result of considering people's restricted contexts of existence.

By examining gendered experiences of TB, one sees how men progressively feel the escalating pressure of a context in which their opportunity and ability to assert and occupy a dominant role in the private, domestic realm is diminishing. Comparisons of how male versus female partners react to and manage their cases of tuberculosis and care show that female partners (such as Camilla and Erica, for example) embrace care within the clinical structure as their idealized gendered positions are not threatened, yet male partners (such as Johannes and Neville, for example) oppose submitting themselves to such care as an expression of resistance to the declining power men wield in the private domain and of the precariousness that they experience as gendered individuals. Such gender based divergent experiences of TB must be kept in mind when considering how to better help and serve those whose lives are tragically marked experiences of TB.

The trajectories of many of the valley's less fortunate laborers and others whose lives have been defined by history's oppressive legacies, continue to be marked by the persistent phenomenological experience of oppressed existences. Through living in the world they have been taught that their lives are not fully theirs to lead and their bodies not theirs to own. Many TB sufferers palpably feel the impact that the outside world has had upon and within their bodies; they feel the instability within their physical being, and this molds how they view not simply their illness, but how they continue to experience and act in the world their bodies are situated in. The continued encounters people make while inhabiting a physically volatile body can create individuals who at once fight succumbing to outside intrusions on their self, but who also demonstrate a willingness to abandon the struggle and the hold that the outside world has taken up in them. People refuse care because they want to determine

the path that their ailing bodies take; although they cannot control how they are situated in the world, they want to at least feel they are in control of how the world is experienced within them.

The effects of the acts of home based care (HBC) providers, who operate on the margins of state provided clinical care, are quite different from those entrenched in the hierarchically organized biomedical model of care. HBC providers (like Elize) *serve* to ease the state of instability experienced subjectively by those who have TB and are thus progressive actors within the schema of South African health care. It is my hope that the kind of intersubjective acts of care that I witnessed represent the beginning of a grass-roots movement in healthcare, and that we may soon see a revolution in state provided healthcare that embraces and utilized multiplicitious paradigms for understating and addressing the TB epidemic in South African and, in doing so, also responds to the needs of individuals at risk of contracting or already burdened with this devastating illness.

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Appendix A

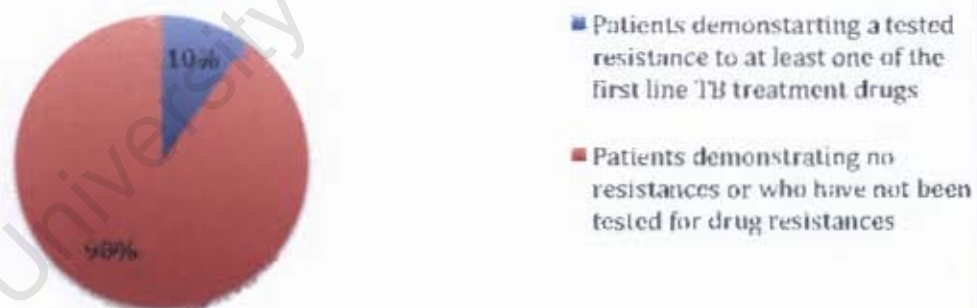
Summary of Clinical Patient Data

The following charts represent various statistical breakdowns for the 151 active clinical patients receiving treatment for tuberculosis at the valley's main clinic.

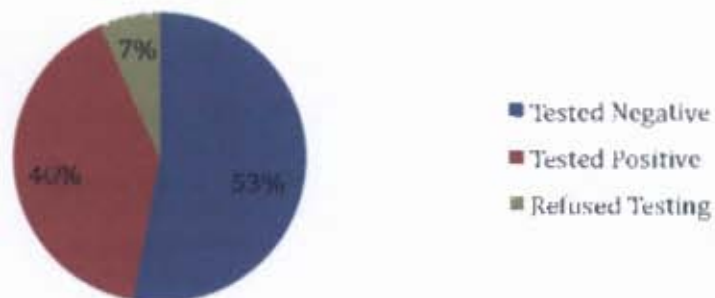
Previous History of Treated Tuberculosis



Drug Resistance



HIV status



Gender



Patient Ages as of March 1st 2008



"Racial" Classification



Appendix B

CONSENT DOCUMENT FOR PARTICIPATION IN RESEARCH

Masters Thesis Research at University of Cape Town, Department of Anthropology

Title of Research Study: TB Patient Personal Experiences

Please consider this consent form carefully. Ask any questions you have before you make a decision. The researcher will answer your questions.

1) Why is this research being done?

The purpose of this study is to understand the personal stories of illness (historical and present) of TB patients so as to deepen understanding not only the individual (your) experience as a TB sufferer but to understand how your story is situated in the greater world.

2) What will happen if you decide to be in this study?

You will participate in either or both formal or informal interviews with the researcher, over the course of the research period (January-March 2008 and possibly longer). Some of our conversations might be recorded, but I will always ask and re-ask your permission to record verbally before starting to record. You may also consent to participate in the research but not to have your participation recorded. It is of great importance to note that if you decide to participate in the study I might use observations or informal conversations for my research so if there is anything that you would like me to not include in my study please let me know so that I can accommodate your wishes. If there is something that I note to be of an especially sensitive nature I will do my best re-ask that I can use this information.

3) What are the possible risks of being in the study?

There are no known risks to participating in this research. I will attempt to be as sensitive with the information shared with me as possible. If at any time you wish that I not use any of the information shared with me please let me know and I will not use the information. In all of the produced works I will keep your (and any other persons names/identities that may be discussed) private. I will also not make know your address, the farm, and area in which you reside.

4) What information is kept private?

Your individual privacy will be maintained in all written products resulting from the study. If the interviews are audio recorded and then transcribed, all names and identifiers will be taken out; a number will be assigned to your transcript. Only the researcher will have access to the audio recordings.

5) Can your participation end early or can you withdraw participation?

Your participation in this study is completely voluntary. You have the right to refuse to answer particular questions. You may elect to withdraw from participation at any time and you may specify that any or all the information collected from you not be used and any possible recordings deleted.

6) Participant Consent

By signing below, you agree to be in this research study. Your signature below will indicate that you have decided to volunteer as a research participant; that your questions have been answered satisfactorily; and that you have read and/or understood the information provided above. Additionally, my (M de Souza Santos) signature here acts as a further way to secure my promise to you that I will adhere to the above conditions.

Audio Release: I give consent to be audio recorded during the process of research: Yes No

This form has either been read/explained to me by Maria _____ or I have read it _____ (Please initial)

Print Name: _____

Signature of Participant: _____ Date: _____

Researcher & Interviewer signature: Maria de Souza Santos _____ Date: _____