Experiencing Tuberculosis: Women's Perspectives from a Rural Angolan Clinic

by

Rebecca Plett

A Thesis submitted to the Faculty of Graduate Studies of

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Abstract

This research focuses on the illness experiences of Mumuila women with tuberculosis (TB). The Mumuila are an ethnic group of south-western Angola, and the women included in this study have chosen to receive Direct Observation Therapy, Short-course (DOTS) treatment at a rural Angolan clinic. This encounter with biomedicine subsequently influences their understanding of TB, and how this illness experience shapes, and is shaped by, cultural constructions of identity. Though it is not necessarily "tuberculosis" that these women perceive themselves to be experiencing, there is a problem that creates a sense of affliction, felt bodily, that precipitates the decision to seek treatment and impacts a woman's social identity. Semi-structured interviews with patients and staff (together the clinical population) and informal/participant observation were utilized to generate data, which was then analyzed using the grounded theory approach as outlined by Corbin and Strauss (2008).

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Chapter 1 – Introduction

The meaning accorded to tuberculosis as an illness has differed across time and space, is continually in flux, dynamic, and re-interpreted daily. Tuberculosis (TB) therefore is, and perhaps always has been, more than the sum of its bacterial parts, and is currently becoming an increasingly problematic infectious disease worldwide. As Inhorn and Brown (1997:32) point out, "infectious disease problems are both biological and cultural, historical and contemporary, theoretical and practical." Anthropological perspectives on TB seek to situate it within these spheres, and this research represents a further perspective on the multi-disciplinary knowledge base of TB, embarked upon precisely because of the quintessential dynamism that characterizes this particular interaction between microbe and human. In particular, it focuses on the illness experiences of Mumuila women with tuberculosis who have chosen to receive treatment at a rural Angolan clinic, how their encounter with biomedicine at this clinic has influenced their understanding of TB, and how this illness experience shapes, and is shaped by, the cultural construction of identity.

The Mumuila are a sub-group of the Nyaneka-Humbe ethnolinguistic group comprising only 3% of the total population of Angola, concentrated in the Huila province in south-western Angola (Warner 1991). The women interviewed were those living with tuberculosis who chose to seek out health care services from a rural clinic near the city of Lubango. Initial observations at the clinic (Rio da Huila) were made after volunteering at the clinic in the spring and summer of 2007 as a guest of the medical director and physician, Dr. Karen Henriksen.

Physiologically, tuberculosis is caused by a bacterium of the genus *Mycobacterium*, of which there are several species infectious to humans (Roberts and Buikstra 2003). The initial infection is often contained by the human immune system, leading to the development of lesions of bacteria-filled scar tissues known as tubercles, and hence the name "tuberculosis." Re-activation, known as secondary infection, can occur from five to ten years after the initial infection. Transmission occurs through the respiratory route, via infected droplets. Once infected, the most common symptoms include prolonged cough and wasting, the latter being the classic sign of TB and historically leading to the development of the dominant metaphor of tuberculosis as consumption, due to the progressive wasting away of the infected body. This metaphorical construction, the mysterious etiology of the disease, and lack of available treatment defined TB as socially significant within European culture and biomedical history, as it both produced and reproduced cultural values and identities within the social system (see chapter 4 for further discussion).

With the discovery of the tuberculosis bacillus in 1882, however, the discourse shifted (Gandy 2003), and TB became known as a disease of poverty due to its association with crowding. Then, with the discovery of pharmacological agents effective against the bacilli, the newly optimistic arena of public health declared the end of infectious disease, and TB as the scourge of Western countries. In the 1980s, however, TB incidence rates were beginning to climb in non-Western countries, despite effective treatment. So much so, in fact, that TB is now responsible for the highest mortality rates found in sub-Saharan Africa, representing some

29% of tuberculosis cases worldwide in 20051.

This modern disease crisis is known as the "new tuberculosis" or "re-emerging TB," primarily characterized by increasing rates of multi-drug resistant disease (MDR-TB), and global scale, World Health Organization-implemented, control programming (Gandy 2003). Literature on the "new TB" is situated in the larger academic context of public health research, of which there is a tremendous body of work on TB control programming in Africa. Direct Observation Therapy Short-course (DOTS) programming is, at this time, the only treatment regimen for curing tuberculosis. It is premised on the notion of direct observation of patients by health care staff (simply put, watching patients swallow pills) and is dependent on passive early case detection, meaning those who have TB-related symptoms must voluntarily present themselves for treatment (Gandy 2003). Though pharmacologically effective, the DOTS program has not met with the success that was initially anticipated, and the plethora of literature on the subject focuses mainly on the identification of barriers to effective treatment.

The barriers identified by public health/epidemiologically oriented literature are wide-ranging, citing everything from macro-level access issues like poverty (Chauhan et al. 2005), treatment delay and the "problem" of traditional healers (Barker et al. 2006, Banerjee et al. 2006), health sector reform (Wilkinson 1999), economic barriers such as fees for health services, transportation, accommodation, and subsistence costs, and the

¹ World Health Organization

²⁰⁰⁸ The Stop TB Strategy. Electronic document, www.who.int/tb/strategy/en/index.html, accessed September 23, 2008.

loss of income, productivity, and time (Chauhan et al. 2005), to patient non-compliance and issues of adherence to treatment regimens (Grange and Festenstein 1993).

Gender as a barrier to accessing care is also frequently identified in the literature. Stigmatization of patients with tuberculosis due to "structural violence" can be seen to occur – these structures of culture or society working to prevent access to health care and adhering to therapy (Pratt et al. 2005). This structural violence often acts most profoundly against those in positions of vulnerability, particularly women.

Problematically, however, by "gender" many of these studies are referring to "women" as a homogeneous group. The women in these studies are seen to be particularly affected by poverty, which in turn creates problems for women to access health services that are too expensive or distant, and, for TB especially, leads women to default on treatment.

Additionally, some studies focus on the "psychological" effects of tuberculosis, whereby women are subject to increased stigmatization and potential ostracism from their communities (Long et al. 1999).

The impetus for such women-centred studies is to assess the degree to which DOTS is hindered by "gender" through epidemiologically oriented sex-segregated studies used to assess relative incidence of infectious disease between men and women (Caldwell and Caldwell 1994). Anthropological studies of infectious disease and TB in particular also often focus on women and issues of access to health services, or perceived "barriers." Indeed, there is a significant body of ethnographic literature on women's health specifically, and most anthropological research on health and medical systems in non-Western settings include a gendered discussion of health (Inhorn 2006). Taking heed of the comments by Lock and Kaufert (1998) and Inhorn (2006) that "women's health" in

anthropological literature often equals a focus on reproductive issues, in focusing on TB, this research represents a perspective on women's experiences with disease and illness in relation to non-reproductive phenomena.

In addition, Angola's incidence rates for TB are equal for males and females². In other studies where disparity in incidence rates occur, the differential may be examined based on economic or political issues, where, for instance men have greater TB burdens because their work places them at higher risk (Nichter 1997), or that women suffer disproportionately from TB because they are subject to structural violence and patriarchy rendering them more susceptible to infection (Long et al. 1999). Because of the equal incidence rates, the focus on women in this study is subsequently based on the interest in understanding the unique perspective and knowledge that Mumuila women possess in negotiating TB as an illness.

The methodology employed in this study is ethnographic in nature, utilizing participant observation and semi-structured interviews with Mumuila patients and staff members at the clinic. As this research is anthropological in nature, ethnography was employed in order to allow women's own narratives about their experiences to emerge. These narratives were then situated within the larger contexts of the clinic setting, the biomedical encounter, politics, ecology, and economy – all of which contribute to how women understand TB in relation to their bodies and themselves as sick individuals within their contexts (Lock and Kaufert 1998). Specifically, themes emerged out of the analysis of data and will be discussed in depth: the embodiment of tuberculosis, how it

² World Health Organization

²⁰⁰⁷ Global Tuberculosis Report. Electronic Document,

www.who.int/tb/publications/global report/2007/pdf/afr.pdf Accessed January 16, 2009.

"feels" and its physiological effects; how the encounter with biomedicine further shapes the construction of TB as illness; TB as gendered illness, and how it affects and is affected by the political, economic, and environmental spheres of a woman's life and identity.

The biomedical encounter in which the construction of TB occurs takes place within a clinical context, and the inclusion of both women and staff members in elucidating such an encounter better represents the clinical population (Pelto and Pelto 1996). In selecting this particular population, it allows for the investigation of the relationships, interactions, and networks that are negotiated and produced in such a setting. The specificity of the information produced, however, means it cannot be used to generate general information about a population. Because of its focus on this clinical population, this research therefore draws on several helpful anthropological frameworks to place the narratives produced in such a setting within the larger contexts which create them. Foremost among these perspectives is Kleinman's (1980) notion of explanatory models of illness which examine the signs and symptoms by which an illness is recognized, the presumed causes, recommended therapies, pathophysiology of the illness, and prognosis. Because this research focuses specifically on TB, it is helpful to utilize this model in examining how Mumuila women create their explanatory model of TB. At the same time, "explanatory models" of illness do not fully account for the issue of social context in the creation of such models (Lazarus 1988), one of particular pertinence in the narratives of Mumuila women.

The social world within which explanatory models are created are, in part, delineated by the notion of therapy management groups. As outlined by Janzen (1985),

such groups are involved in the process of making decisions about the choice of health care provider, the performance of therapeutic rituals, or the preparation of medications, all of which allow individuals to interpret their roles within this society, and manage their social relationships. Embedded in the idea of therapy management is that of a social network, that the creation of medical knowledge (including etiology of illness, therapy, and one's explanatory model) is produced and reproduced in relationships and interactions with one's family, neighbours, friends, and community, and within the biomedical/clinic setting (Pearce 1993). This notion is particularly helpful in elucidating the relationships between staff and patients at the clinic in the treatment process, and how they negotiate their interactions within the scope of their explanatory models of TB.

Anthropological studies in health and medical fields also necessitate some comment on the particularities of language, and this research is no exception. Most prominently, a clarification as to the use of the words "disease" and "illness" in relation to tuberculosis must be made. For this study, "disease" will be used to connote the formally taught definition of mental or physical pathology from the biomedical perspective, one in which the body is "perceived as a specific entity independent of the patient's social circumstances and personal characteristics" (Hepburn 1986:61). The term "illness" will be used based on the following: "illness constitutes the culturally-defined feelings and perceptions of physical and mental ailments and disability in the minds of people in specific communities" (Pelto and Pelto 1996:302). In this sense, illness represents a culturally embedded construction, and one that truly encompasses TB as a social phenomenon.

Part of the impetus to define common terms lies in the tension within medical anthropology regarding its association with biomedicine and biomedical discourse (Lindenbaum and Lock 1993). Though attempts are made within the analysis of this information to reject the naturalization of the concepts of the "body" or "health" as reflective of biomedical categories, a public health or epidemiological orientation is necessary to illuminate the nature of the interaction between Mumuila women and the health services they utilize at Rio da Huila. As Pelto and Pelto (1996:293) point out, "health problems throughout the world constitute a sector of applied research that is by nature interdisciplinary." Further, a biomedical perspective on tuberculosis is historically situated within a Western context in which TB played a distinguished role in the collective cultural consciousness. Such historical consideration still informs contemporary TB programming, therefore interacting directly with Mumuila women with tuberculosis.

Chapter 2 – Research Setting

Colonial History

Tony Hodges (2004:1) asserts that Angola is a paradox: "one of the best resource endowments in Africa has been associated not with development and relative prosperity, but with years of conflict, economic decline and human misery on a massive scale." Hodges' linguistic choices certainly reflect an image of Angola as viewed through the lens of the resource-hungry Western economic gaze. At the same time, Angola's apparently paradoxical nature highlights the potential danger of capitalist development: for nearly 30 years, Angola was in a state of war that began upon its independence from Portuguese colonialism and was propagated through the exploitation of two of the West's most precious resources — oil and diamonds. As Michael Renner describes, "the ideological differences that first sparked the war came to reside in the dustbin of history, but resource-driven greed and corruption proved to be powerful fuel for its continuation." (2002:6)

Angola's modern resource-driven conflict and political and economic context cannot be understood in isolation from its 500 year colonial relationship with Portugal. Portuguese sailors began exploring the northern Angolan coast in 1482, during the time when Portugal was enjoying world pre-eminence in navigation, exploration, conquest, and overseas trade (Wheeler 1971). Initial encounters between Africans and the Portuguese were with the Kongo people, whose king controlled a sizeable kingdom

straddling the border between what is now the Congo and Angola. With the establishment of a Portuguese trading post on the coast, the two nations forged a mutually beneficial and positive trade relationship, with the Kongo king soon after converting to Christianity and adopting a Portuguese name (Newitt 2008; Wheeler 1971). For the Kongo elite, a strong relationship with the Portuguese meant opening up new trading opportunities which built upon the extensive trade routes amongst African kingdoms. This was especially true for those trade routes that had existed before the arrival of the Portuguese within what would become Angola (Newitt 2008).

This positive and mutually beneficially relationship lasted until 1575 when due to a changing political and economic situation in Europe, Portugal became interested in developing the slave trade in southern Angola (Wheeler 1971), one that was already well established (though on a smaller scale) within African kingdoms (Newitt 2008). As opposed to previous peaceful relationships with African kingdoms, this meant military conquest of the kingdom of Ngola to the south of the Kongo. Portugal, being a small and relatively poor European nation, had insufficient numbers of troops to launch an attack of sufficient scale to conquer and control the areas they wished, so they enlisted the aid of Africans to boost numbers (Wheeler 1971). In exchange for assisting the Portuguese slave trade, those African kingdoms which participated benefitted from the opening and expansion of trade routes and goods from Brazil (Newitt 2008).

The Portuguese built fortresses at strategic coastal locations to facilitate the trade of Angolan slaves to Brazil – Portugal's major colony in South America – to work on sugar cane plantations, resulting in the dependence of Angolan colony on Brazilian imports and supplies (Newitt 2008; Wheeler 1971). When Brazil achieved independence

from Portugal in 1822 and the slave trade declined, the Portuguese were forced to develop other economic interests to maintain control of their African colony (Wheeler 1971). Wheeler (1971) suggests that up to 4 million Angolans were taken in the Portuguese slave trade, and the military efforts to maintain control of such economic interests meant that between 1579 and the 1920s, scarcely 5 years went by without an incursion; the history of violence in Angola has therefore been nearly constant since the arrival of Europeans in the 16th century (Wheeler 1971).

Between 1920 and 1960, Angola went through an uncomfortable transition from subsistence agriculture to a market economy. Major exports became coffee, cotton, sisal, and corn due to an "opening up" of the interior following a railroad-building rush (Newitt 2008). This also meant significant changes to the influence of the Portuguese on Angolans living in the interior. Where the Portuguese had maintained a strong coastal economy through trade with Europe and the Americas, now cities in the interior like Huambo were being built and settled by white immigrants (Newitt 2008). Further, entering the market economy in this way meant an increase in contract and migrant labour and changes in land-use patterns, where the majority of agricultural land was suddenly being used for growing crops for export and serving to deepen the oligarchy of rich whites in Angola (Henderson 1979). Young adult Angolan men would find employment on plantations or in the cities, leading to a re-arrangement of social networks and population distribution (Henderson 1979).

This period was also a time of major political upheaval in Portugal. Antonio de Oliveira Salazar came to power in 1932, during which the nature of the "colonial mission" of the Portuguese nation was contested (Bender 1978). In the mid 20th century,

Portuguese nationalism was based on "self-adulation" regarding the successes of their colonial mandate, but after Portugal's internal political situation became less than exemplary with the rise of dictator Salazar, national pride became centred upon their record of exploits "overseas": "the glorification of the colonizing mission principally served the psychological rather than the political needs of successive Portuguese regimes" (Bender 1978:xx).

Further, following increasingly anti-colonial criticism from the United Nations in 1951, Portugal began the aggrandizement of the emerging racially mixed societies in Angola and Mozambique (its other major African colony) and the re-naming of these colonies as "overseas provinces" to counter the perception of their "colonial" enterprise in Angola (Bender 1978). Therefore, while Britain and France were preparing for the independence of their African colonies spurred on by the emerging policies of the UN, Portugal maintained control, justified and asserted by the historically unique absence of racism among the Portuguese (according to the Portuguese). The colonization of tropical, non-European territories was seen to be characterized by racially egalitarian legislation and human interaction (Bender 1978). This "lusotropicalism" became national and international rhetoric serving to highlight Portugal's "unique contribution to the progress of Humanity and Civilization" (Bender 1978:xxi) and was exemplified by harmonious multiracial societies like Brazil. This "racial tolerance" policy was both lauded and supported by Western governments – especially the US – foreshadowing their unfortunate contributions to the Angolan war in the last half of the century (Bender 1978).

As Patrick Chabal (2008:3) describes, "into Angola was introduced the poor and poorly qualified Portuguese." Portugal, being the poorest country in Western Europe,

possessed specific character underlying their colonial mandate and, according to Chabal (2008) created a situation of skewed economic development resulting from the legacy of economic failure in Portugal. Further, those Portuguese settlers within Angola developed a classist and racist attitude (despite the nationalist rhetoric to the contrary) – according to Wheeler (1971), sentiments such as 'white is still better than black,' and 'I can have power and prestige in Angola at the expense of Angolans that I cannot have in Europe' prevailed. In part, the racism of the Portuguese at this time also stemmed from insecurities over the threat of impoverishment due to natural disasters and social calamities (Clarence-Smith 1979).

Beginning in the 1920s, the changing economic landscape lead to increasing urbanization. Employment in the cities subsequently became highly competitive, and with that came further racial discrimination. As Clarence-Smith (1979:57) suggests, such discrimination "was just one of the ways in which a section of the petty bourgeoisie (fishermen, small farmers, petty traders) attempted to maximize their own security at the expense of others." To solidify this security, the Portuguese government in Angola developed an assimilation policy which followed the French example of categorization of Africans within their colonies. This categorization was based on the concept of "assimilation...that was meant to deal with the competition for urban employment between Africans educated in mission schools, the Afro-Portuguese (those Angolans with both Portuguese and African ancestry), and poor white immigrants." As Newitt (2008:53) suggests,

To become an *assimilado* [someone who is "assimilated"] a person had to display stipulated levels of education, Portuguese culture and economic

independence, criteria that could be raised or lowered to regulate admission into the colonial elite.

Almost all Afro-Portuguese and nearly 50,000 Africans were given assimilated status. This new identification formed a new educated elite, separated from the majority of the population, and from this group came the leadership of the nationalist movements that would challenge both the Portuguese for independence, and the Portuguese nationalist rhetoric supported by Western countries (Newitt 2008). If the Portuguese colonial mandate was as "racially tolerant" as postulated, why did no Angolans hold positions in either the public or private sectors and in the educational system, and why forced labour, expropriation of African lands, and arbitrary arrests and torture continue to exist (Bender 1978)? Somewhat ironically, as Newitt (2008) points out, the formation of an educated, elite, urban nationalist movement striving for independence nevertheless was a continuation of the Portuguese colonial social distinction of "assimilated" that they were striving to overcome.

Recent Conflict

Political discontentment within the country finally led to an attack on a government prison by Angolans, aiming to release political prisoners (Henderson 1979). In the following years, other uprisings led to the formation of nationalist political movements in Angola with three major rival factions vying for control: UNITA, MPLA, and FNLA. The FNLA (*Frente Nacional de Libertação de Angola*, or National Liberation Front of Angola) was initially backed by the United States and Mobutu of Zaire (who was courting Western favour), but was defeated by Cuba in 1976

(Birmingham 2006; Pearce 2005; Hodges 2004). The left-wing socialist faction MPLA (Movimento Popular de Libertação de Angola, or Popular Movement for the Liberation of Angola) led by Aghostino Neto and supported primarily by mixed-race (mestico) intelligencia in Luanda maintained strong ties to the Portuguese political faction that opposed dictator Salazar's right-wing regime, and refused the independence of its colonies in the 1960s (Pearce 2005; Davidson 1972; Wheeler and Pelissier 1971). Seen as pro-communist, the MPLA were backed and supplied with weapons and troops from both Cuba and Russia. Jonas Savimbi, leader of UNITA (União Nacional para a Independência Total de Angola, or the National Union for Total Independence of Angola), rallied the majority Ovimbundu people in a fight against the primarily European/mixed race MPLA and were backed by the United States and South Africa. who entered the fray intent on maintaining their tenuous political control of neighbouring Namibia and so sought out UNITA as an ally sympathetic to their cause (Pearce 2005). Independence from Portugal was achieved in 1975 with nothing more ceremonious than a lowering and raising of a flag symbolizing the transfer of power (Henderson 1979).

From its beginning, the fighting in Angola was fuelled by the Soviet Union and the United States as an extension of the Cold War conflict raging elsewhere around the globe (Pearce 2005). Given the very extensive international involvement in Angola's war, the main impetus for attempts to settle the conflict originated in changes in the external environment (Hodges 2004). With the end of both the Cold War between the US and the Soviet Union and apartheid in South Africa in 1991, the involvement of those countries in Angola's conflict became meaningless (Hodges 2004).

Negotiations for a peace treaty between the MPLA and UNITA were underway in 1991, and a treaty was signed in anticipation of hopefully holding democratic elections in 1992; UNITA felt confident about finally capturing power from the MPLA, and so agreed to a cease-fire and UN-supervised elections (Birmingham 2006). The confidence with which Savimbi agreed to hold elections was founded primarily on the perceived political and ethnic rural-urban split: urban Angolans saw themselves as better educated and more sophisticated than rural Angolans, and maintained their ideological ties to the MPLA and their socialist leanings, despite the fact that the ideological basis of Angolan politics had long since become ambiguous (Birmingham 2006). Since Savimbi's support base was primarily rural and the majority of Angolans lived in rural areas, the United States urged Savimbi to agree to a cease-fire and election feeling assured of his victory (Birmingham 2006).

When the UN recognized Jose Eduardo dos Santos as the democratically-elected winner by a margin of 2 to 1, Savimbi refused to acknowledge the results as legitimate and instigated renewed fighting, more intense than previous to 1992 (Birmingham 2006; Pearce 2005). This time though, the MPLA, who had long abandoned any socialist pretence, was not backed by their former Soviet allies, and UNITA lost the support of the United States who had all but guaranteed a victory for Savimbi in the elections (Birmingham 2006; Pearce 2005). In order to finance the conflict, both sides sought to control Angola's lucrative resources. UNITA financed its operations through the control of Angola's rich alluvial diamond deposits, utilizing diverse smuggling routes to get diamonds out and military equipment in (Renner 2002).

In 1998, a UN embargo focused international attention on the conflict in Sierra Leone and its "conflict" or "blood" diamonds, and severe sanctions were placed on the trade of Angolan diamonds as well (Renner 2002). Despite this embargo, however, Zaire/Congo, Burkina Faso, Rwanda, Zambia, Namibia, and South Africa all assisted the illegal diamond trade with false paperwork and customs documentation (Birmingham 2006; Renner 2002). Redundant military equipment from eastern European countries made its way into Angola in much the same way, even despite a UN arms embargo (Renner 2002).

In light of the diverse diamond smuggling networks in Angola, and since so much blood money became involved in the sale of Angola's diamonds as in the sale of those from Sierra Leone, the UN imposed penalties on nations that facilitated the diamonds-forweapons trade (Birmingham 2006). These penalties proved to be a significant setback to the financing of UNITA's armies and, in order to maintain military power, looked to other sources of revenue and particularly the offshore oil installations controlled by the MPLA. Though the diamond trade provided significant revenue to UNITA, oil was far more lucrative, bringing in at least ten times more revenue for the MPLA (Birmingham 2006). However, despite repeated attacks by UNITA armies, the easily defended petroleum installations remained in MPLA hands. Because the MPLA controlled the oil resources and were comfortably in a position of power, President Dos Santos took full political advantage of these repeated attacks, revamping his image as one of peacemaker, continually dogged by the ever-violent Savimbi and UNITA (Birmingham 2006). As a result, Dos Santos and the MPLA received nearly unlimited and unilateral support from

Western governments (Birmingham 2006) – a significant shift in foreign opinion from the early independence movement.

In 2002, however, with (covert) assistance from American, Israeli, and South African agents (and economic interests in Angola's diamond and oil deposits), the MPLA located and executed Savimbi in his jungle stronghold (Pearce 2005). Subsequently, UNITA agreed to disband its militant wing, and has since taken up position as the official opposition (Pearce 2005). Democratic and peaceful elections held in September 2008 once again secured another term for dos Santos and the MPLA.

In 2002, after nearly 30 years of conflict, the country was reeling from the collapse of administrative infrastructure and a bleak economic situation severely compromised any government support for social institutions. According to Chabal (2008), the interaction of certain factors created the modern nature of Angola: years of Portuguese rule and its impact on the relationship between ethnic and regional groups, anti-colonial and nationalist movements, and the effects of oil wealth. The result leaves post-war Angola with a chronic lack of educational materials and school books, and hospitals lacking sufficient medicines or equipment (Pearce 2005).

The UN estimates the number of displaced persons in Angola to be 4 million; after the war ended, a major demographic shift occurred throughout the country in order to accommodate the movement of these persons (Ayisi 1998). Further, approximately 6-8 million landmines were laid throughout the course of war, particularly around oil installations and water sources, on roads and bridges, and in markets and schools. While mines cost about \$3-\$10 U.S. to lay, it costs approximately \$300-\$1000 to remove them, leaving much of the landscape (particularly around Kuito in Bié province) still littered

with mines. Ten years ago, there were around 80,000 victims living with amputations from land mines in Angola, one of the highest rates in the world (Ayisi 1998). Despite its history of conflict and lack of infrastructure, however, Angola is resilient; signs of new development and foreign investment are abundant as the country readies itself for a new peaceful chapter.

Southern Angola

The clinic, Rio da Huila, is located in south-western Angola approximately 40 kilometres south of Lubango, the capital city of Huila province, along the main highway connecting Lubango and Namibia to the south. The region of "southern Angola" is distinct from the rest of Angola, and its history cannot be extricated from its particular ecology and the interaction of the various ethnic groups in the area. The northern regions of the country are resource-rich and distinguished by significant rainfall and forest, while southern Angola has few natural or human resources, and forms the northern marches of two deserts, the Namibe and the Kalahari, separated by a formidable escarpment (Clarence-Smith 1979). This escarpment is at its steepest to the west of Lubango, where the Huila plateau falls nearly 1500 metres straight down to the coastal plain 150 kilometres to the Atlantic Ocean at the port of Namibe.

The semi-desert coastal plain is sparsely populated, but the Huila highlands surrounding Lubango are more densely populated due to higher rainfall. Due to the swath of semi-desert, the escarpment, and the uneven distribution of population, transportation and communication within southern Angola has historically been limited (Clarence-Smith

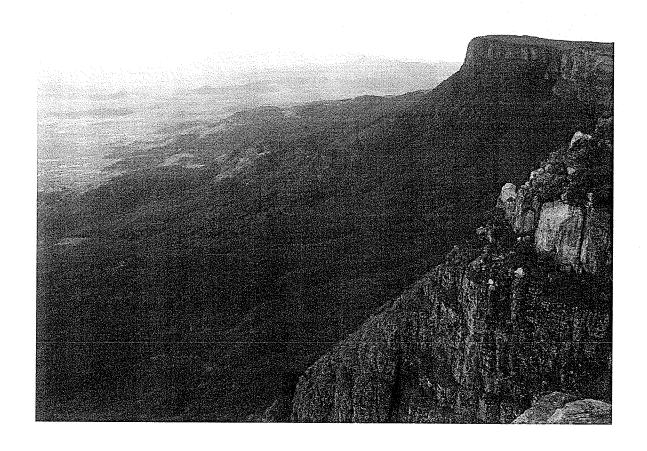


Figure 1: The escarpment geographically separating the coastal plain from the Huila highlands. This particular outlook is known as Tundavale. Photograph by Rebecca Plett, 2007.

1979). The Portuguese initially built another sea-port at Namibe to develop transportation networks for the aforementioned reasons, and the economic development of southern Angola by the Portuguese was based primarily on local trade networks and small-scale fisheries (Clarence-Smith 1979). Therefore, because of the geography of the region, the "colonial nuclei" of Portuguese settlements were restricted and discontinuous, and the influence of the Portuguese on the people of southern Angola was less pronounced than in the north (Clarence-Smith 1979).

Following the abolition of the slave trade, the Portuguese became increasingly interested in the area to develop further nationalist interests and to secure a Portuguese foothold on the continent, as other European colonial powers were intent on doing. In particular, there emerged a vision of filling southern Angola with white Portuguese settlers and African slaves in order to secure the colony for Portugal (Clarence-Smith 1979). Around 1910, Portugal became further interested in the development of a plantation sector based on immigrant labour; this would involve the imposition of taxation and forced labour of Africans (Clarence-Smith 1979). Based on both the process which the Portuguese undertook to achieve these ends and the resource-poor landscape, the effects were not as grand as was initially hoped for, however.

In the 1880s, white settlers began moving into the Huila highlands, since the Portuguese colonial government had a policy of giving white settlers "vacant" land (Clarence-Smith 1979). The shifting cultivation practices of the African groups in the area meant that land was not settled permanently, resulting in the government letting white settlers take whatever land they desired, at its most extreme suggesting that all Africans would be "exterminated" from the land anyway (Clarence-Smith 1979:80).

Though this did not happen in actuality, all the most arable and preferable agricultural land was taken by white settlers. Further, the Portuguese engaged in cattle and slave raids of the neighbouring African clans and tribes. The incoming settlers, officials, and missionaries also increasingly took over succession disputes, and arbitration and judicial functions in African communities – functions previously presided over by chiefs of clans (Clarence-Smith 1979).

After a time, a group of "social bandits" (Clarence-Smith 1979:80) from within various Nyaneka tribes and clans developed to form an organized resistance to what they perceived as European interference. These bandits initially came from the hierarchy of chiefs of surrounding clans and tribes, and were eventually joined by escaped slaves and ex-soldiers who assisted in building fortresses to attack the Portuguese. Eventually, however, when the social banditry aspect devolved into petty robbery, the groups ceased to receive support from their communities and were defeated by the Portuguese (Clarence-Smith 1979). This form of violent resistance to Portuguese invasion was unique to southern Angola, and particularly the Huila highlands, in which the Nyaneka felt it necessary to defend certain aspects of cultural way of life that became increasingly under attack by the European settlers.

Ethnicity

Within Angola, there are three main ethno-linguistic groups or clusters, which make up nearly 75% of the population – Ovimbundu, Mbundu, and Bakongo (Hodges 2004). The largest single ethnic identification in Angola is Ovimbundu, representing about 37% of the population (Warner 1991). Rio da Huila is situated in an area

populated by the Nyaneka-Humbe, an ethnolinguistic grouping comprising only 3% of Angola's total population and concentrated in Huila province (Warner 1991). Due to the geography of the region and the shorter period of colonial involvement previously discussed, the Nyaneka-Humbe were not as influenced by Portuguese colonialism as other parts of Angola, nor did they undergo the intense urbanization process which the rest of the country underwent (Clarence-Smith 1979).

In the 1920s and 1930s, the economy of southern Angola was significantly affected by the Depression, resulting in the stagnation of the economy in the 1950s. In the 1960s, with insurrection beginning in the northern parts of Angola, the Portuguese became fearful of new peasant violence, and so concentrated on creating social and economic changes for Angola, particularly in the south (Clarence-Smith 1979). This meant an increase in health and education spending, increased communication and transportation including airstrips and paved roads, and a new hydroelectric dam. Lubango doubled its population between 1960 and 1970 and became the main commercial and administrative centre over Namibe (Clarence-Smith 1979).

Due to the intense attention paid by the Portuguese, this period was also marked by increasing urbanization, and noticeable outward signs of Western/Portuguese cultural influence on many Africans. During this time, however, the Portuguese "cultural influence" was resisted to a greater degree by the Nyaneka, who tended to maintain "traditional" cultural practices and subsistence agriculture, therefore garnering a reputation for un-sophistication (Clarence-Smith 1979). In fact, the literature which mentions the Nyaneka refer to their "cultural conservatism" in the eyes of the rest of Angola (Warner 1991; Clarence-Smith 1979), or their reputation in Angola as "hopelessly

backward and conservative people" (Clarence-Smith 1979:103). Though the phrase "culturally conservative" is perhaps an inappropriate choice of descriptors, the reputation of the Nyaneka people, and specifically the Mumuila (a sub-group of Nyaneka) on whom this research focused, maintain a reputation of being resistant to modernization, rural, and "backward."

Though the ethnographic material on the ethnic groups of Angola is quite dated (see, for example, Estermann 1960 and Clarence-Smith 1979), the fact that the Nyaneka have been less subject to colonial influence (or "modernization" today) means that this material remains pertinent to a discussion of Nyaneka ethnography, particularly as it relates to the initial encounters between the Portuguese and Nyaneka and their historical relationship. When the Portuguese encountered the Nyaneka, their political organization was based on small chieftaincies. The origins of the Nyaneka and their dynasties and institutions lie in, as Clarence-Smith (1979:9) describes, "the complex movements of population and institutional changes which affected northern and central Angola in the 16th and 17th centuries." These "population and institutional changes" had to do with the slave trade, and the inclusion of Africa soldiers in procuring men to ship to Brazil which led to population movements and shifting of kinship patterns (Clarence-Smith 1979).

Cattle and maize were central to the culture of the Nyaneka as described by

Clarence-Smith (1979) and Estermann (1960) and continue to be today. As Estermann

(1960) describes, two fundamental kinship groupings exist – tribes and clans, with each

tribe regulating the inheritance of cattle. The clans are matrilineal, but women move to

their husbands' homesteads upon marriage, and the sister's sons inherit a man's cattle.

Because a man cannot marry a woman in the same clan, her sons would inherit the cattle

of her brother and therefore cattle would not remain in the homestead of a man after his death. Though a father could give his sons cattle during his lifetime, the customs of inheritance mean that effectively, cattle are owned by the clan and entrusted to a man during his lifetime (Estermann 1960; Clarence-Smith 1979).

Further, cattle constituted the main kind of capital investment, were important as currency, and were a major object of internal and external trade (Clarence-Smith 1979). Though maize cultivation was important for subsistence, the highland plateau geography of the region meant that crops were susceptible to drought or frost; cattle were, practically speaking, much heartier. In addition to cattle holding a place of importance within systems of trade, in the 19th century hunting was very important to the Nyaneka, providing commodities for trade around Africa (Clarence-Smith 1979). Extensive and long-range trade routes were monopolized by powerful chiefs, and utilized by the Portuguese for the slave trade. This system existed until trucks and lorries came to the area around 1910, and traders were replaced with fixed stores (Clarence-Smith 1979).

According to Estermann (1960), women generally performed agricultural tasks, fishing (if there was a river nearby) and food collection. Men cleared the land for maize production, hunted, herded, and raided. The few "specialized functions" requiring ritual sanction within Nyaneka culture were chiefs, smiths, and witch doctors. Slave trading was common, but because slaves were generally women and children, they tended to be "absorbed" into the lineages of the clans (Clarence-Smith 1979). Regarding the relationships between clans or homesteads, Clarence-Smith (1979) suggests that they were regulated by the distribution of resources: women by marriage, cattle by inheritance, and land by the decision of the chiefs.

Chiefs also exerted power and control as the enforcers of social control.

Specifically, accusations of witchcraft between members of a community served to keep perceived inequalities within acceptable social limits. The duty of the chief was to maintain this social code (often violently), therefore fulfilling functions of organization and coordination within the clan or tribe (Clarence-Smith 1979). When the Portuguese exerted their own influence in such matters by usurping judicial duties, for instance, the Nyaneka resisted with banditry (Clarence-Smith 1979).

The ethnic landscape of Angola changed dramatically after 1975 and the nearly 30 years of war which followed. During these years, the population underwent an intensive urbanization process, which meant an unprecedented interaction of people of differing cultural backgrounds living in proximity, vying for employment, and competing for the same, limited amount of resources (Hodges 2004). Hodges (2004), in fact, has suggested the degree to which such interaction has occurred can be termed "cultural fusion." Interestingly, this is most evident with the prominence of the Portuguese language at the expense of African languages. According to Hodges (2004), nowhere else in Africa with the exception of some island states, has a European language taken up a place of such prominence among the population, particularly due to urbanization, the expansion of education after independence and the impact of television. The post-independence government adopted the Portuguese language as an instrument of national unity, and therefore it has been (and continues to be) the exclusive medium of educational instruction and the language of the military, subsequently providing a common language for generations of Angolan soldiers (Hodges 2004).

Hodges (2004) suggests that the preferential utilization of Portuguese over African languages has led to the development of a national Angolan identity over ethnic particularism. With the migration to the cities since the 1960s, there has been a reduction of the influence of political systems recognizing the leadership of chiefs, and a shift in how kinship systems are understood. As Hodges (2004) points out, Angola's war of independence was not ethnic in nature like Rwanda's, for instance. Therefore, after nearly thirty years of intense conflict, Hodges (2004) suggests that most Angolans are interested in peace rather than ethnic identity that may incite or promote more violence.

The Clinic

The clinic (Rio da Huila) itself is located about 60 kilometres south-east of Lubango, along the highway connecting the city with Windhoek, the capital of Namibia. The clinic and surrounding community is known as Rio da Huila/Tchambangala; and by no means is "community" to be likened to its North American counterpart. The clinic is surrounded by several groupings of huts/houses comprised of family units and their agricultural land, and supplies other than what can be grown or harvested on site must be accessed by foot or taxi at small markets along the highway or at the bigger centres of Lubango to the north or Chibia to the south, both of which also have government run hospitals and clinics.

Rio da Huila is a private clinic run by an evangelical mission organization, meaning patients were charged for services. A handful of staff members there have received specialized training and education on tuberculosis, therefore making the clinic a more specialized (though not exclusive) TB treatment centre. There are about 250

patients registered in the clinic's tuberculosis program each year, and because many patients travel great distances, and often on foot, to receive treatment at the clinic and the treatment period is quite lengthy (up to 10 months), there is temporary housing available in proximity to the clinic, therefore artificially increasing the population of the community.



Figure 2: Clinic (Rio da Huila) complex. Photograph by Rebecca Plett, 2008.

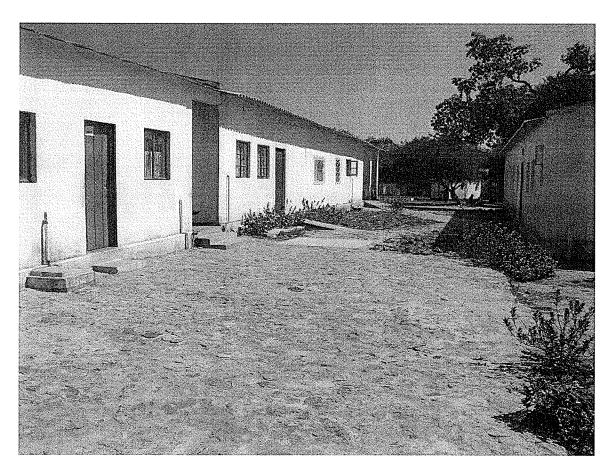


Figure 3: Clinic (Rio da Huila) complex. Photograph by Rebecca Plett, 2008.

Chapter 3 - Materials and Methods

Data was collected through semi-structured interviews and informal observation (participant observation) over five weeks in November and December of 2008 at the clinic (Rio da Huila) in south-western Angola. In total, patient interviews were conducted with twelve Mumuila women, all over the age of 25. Ten of the twelve women were residing at Sanzala at the time of the interviews, the 'housing complex' available to patients and their families, adjacent to the clinic itself; the other two women came from communities within a few kilometres of Rio da Huila, therefore preferring to remain at home and coming to the clinic at two weeks intervals to receive tuberculosis medication. At the time of the interviews, the length of stay at Sanzala for the patients (i.e., the length of time the women had been receiving tuberculosis medication) varied from a few weeks to several months. Eleven of twelve women were diagnosed with pulmonary TB, the other with extrapulmonary TB. Almost all were diagnosed as "new cases," and none of the women had long periods (over three days) of defaults in their treatment histories. Interviews were also conducted with the three staff members working most closely with the TB patients

Interviews were all conducted at the clinic site, in an outdoor setting. This was at the wish of the participants; all agreed to proceed with interviews during the time they were waiting for their medication, or during work hours at the clinic. Women who were Mumuila and who were, at the time of the interviews, receiving medication were approached to participate in the patient interviews. Initially, staff members at the clinic reviewed the medical charts of tuberculosis patients receiving treatment, and identified

those women who were Mumuila by name (and occasionally by identification of traditional dress). After spending time with the staff members at TB clinics, familiarity with the patients, the staff, and the clinic was established, leading to more interviews as the research period progressed.

The interview schedule focused on several areas. For patient interviews, questions were asked regarding the nature of the women's daily work (dependent on the agricultural calendar and seasonal change), the household structure, the "feeling" of tuberculosis and when they deemed it necessary to seek treatment, what they perceived the cause of TB to be, and the information given to them following the diagnosis of TB. Staff interview questions centred on the perception of TB patients by staff members, perceived etiologies of patients with TB and the surrounding community, and problematic aspects of treatment (specifically DOTS). These interviews were therefore intended to elicit staff member's perception of the clinical encounter, and how they interacted with women experiencing TB. Wording of the interview questions was occasionally changed to elicit further information, and, following the example of Menegoni (1996), questions on sensitive matters such as witchcraft were asked in a more indirect manner (for example, "some people think tuberculosis is caused by witchcraft, and others think it is caused by germs. What do you think about that?")

The interviews were translated from Portuguese into English, and in some instances from Lumuila (the language of the Mumuila) to Portuguese to English. All of the interviews with tuberculosis patients were assisted by translators from the community and from Lubango; the interviews with staff members were one-on-one in Portuguese. Further, all interviews were recorded and transcribed. To maintain the confidentiality of

the participants, coding was employed to secure the anonymity of the women, and no particular information will be used in this document which may identify the individual women who participated in this research.

Informal observation/participant observation took place within clinic hours, perhaps best described as "loitering in public places" (Pelto and Pelto 1996). This loitering often involved discussions with staff members and patients, whose conversations were entered in field notes. Presuming I was "loitering" because I wanted to be put to work and not merely "observe," staff included me in the public health clinics offered on various days at Rio da Huila. In these instances I was able to participate in maternal health clinics, vaccination clinics (both maternal and infant), and in DOTS clinics. All of these experiences proved to be fruitful learning opportunities, particularly as they relate to women's health in a wider context.

The Clinical Population

Though many "people groups" utilize services at Rio da Huila, the Mumuila represent the majority of the population in Huila province, and were selected as the focus or starting point of the current study to reduce the potential for complexities associated with sociocultural/ethnic variation. The colonial history of Angola, discussed in depth in the previous chapter, has created a scenario in which the Mumuila are viewed as "backward" by other ethnic groups in Angola as they have not been as subject to "modernization" (i.e., Western influence and urbanization) as others. This situation, coupled with the view that the Mumuila are more pragmatic about illness than others and

less inhibited by shame (Dr. Karen Henriksen, personal communication), creates a unique perspective on the subject of tuberculosis in the anthropological literature.

Further considerations included the decision to conduct interviews at the clinic as a conscious attempt to limit the "artificiality" of the interview setting (Hammersley and Atkinson 2007), considering the "interview" phenomenon within the clinic setting is typically reserved for interactions between patients and medical professionals. Since the purpose of this anthropological research was not clinical, attempts were made to place the interviews within a "neutral" setting, often chosen by the participants themselves. A review of the literature on ethnographic studies in settings similar to Rio da Huila suggests that comfort level and the setting of interviews is an important consideration; Vinay Kamat (2008) conducted interviews in people's homes where they were most comfortable, while Banerjee et al. (2000), Ngang et al. (2007) and Menegoni (1996) conducted interviews at the clinic sites of their research with patients and health care staff. Hammersley and Atkinson (2007:116) echo this position by further stating that interviewing individuals "on their own territory" allows them to organize the context of the interview in the way they wish, permitting them to relax and provide "insight into their sense of themselves and their world."

Despite the fact that Angola has equal tuberculosis incidence rates for males and females³, this research focuses more specifically on the experience of Mumuila women with tuberculosis. Though studies of women and infectious disease are common

³ World Health Organization

²⁰⁰⁷ Global Tuberculosis Report. Electronic Document, www.who.int/tb/publications/global report/2007/pdf/afr.pdf Accessed January 16, 2009.

(particularly as they relate to gender and public health research), the choice to focus on women reflects both the practical desire to further limit the variability in the information gathered, thus rendering it more manageable in light of the scope of research, and the attempt to heed the narratives of women experiencing TB. This research is therefore intended to focus on women's experiences rather than an attempt to explicate the differences in the ability to access services between men and women common in numerous "gender" studies (see, for example, Weiss et al. 2008; Caldwell and Caldwell 1994).

As the focus is on women's experiences with TB, the use of ethnographic methodology situates this information within the anthropologic literature on women's health. As Inhorn (2006) points out, the use of ethnography in creating anthropological knowledge allows for the unique perspectives of women to emerge: ethnographic investigation allows for the determination of women's own health priorities by listening to women through participatory forms of anthropological research.

The women interviewed all made decisions to receive treatment at Rio da Huila. The women therefore represent, in methodological terms, a clinical population, one often used in anthropological studies (Pelto and Pelto 1996). Because so much of the illness experience and the construction of knowledge about TB takes place in the clinical encounter, to conduct research within this setting is most efficacious for gathering the information necessary to explicate the nature of this interaction and how it shapes the experiences of women and the construction of their illness. More than the doctor-patient relationship, however, to take the clinic setting and its "population" as the unit of analysis

takes into account larger networks which situate the clinic interaction within global political, economic, and ecological spheres (Pelto and Pelto 1996).

Selecting the clinical population as the unit of study does necessitate certain methodological considerations, as does the specificity and generalizability of the information produced through this focus. Foremost, a clinic population should never be considered as representative of the general (community-based) population. Further, Rio da Huila and any other clinic setting receives only a selected and non-random portion of the population (those who have chosen treatment at the clinic), a population of individuals generally isolated from their families and communities, therefore extracting them from their normal social networks (Pelto and Pelto 1996). The collection of information is therefore limited by and sensitive to these constraints.

Methodology

The goal of this research is, in broad terms, qualitative in nature, the major aim of which in medical anthropology is to develop a sense of local vocabulary in relation to health problems (Pelto and Pelto 1996). As outlined by Hammersley and Atkinson (2007), this was achieved through ethnographic methodology, the interest of which is in how people construct situations and their own identities within such situations, all while pursuing their interests and goals within institutional contexts. Since the research focuses on women's experiences with tuberculosis within a clinic (an institutional context), qualitative ethnographic methodology was employed, as the accounts produced from such methods can "be read for what they tell us about the phenomena to which they refer, [and] can be analyzed in terms of the perspective they imply, the discursive strategies

they employ, and the psychosocial dynamics they suggest" (Hammersley and Atkinson 2007:97). Though many techniques for qualitative ethnographic analysis exist, because the research question posed in this proposal is "exploratory" in nature (Marshall and Rossman 1989), interviews and participant/direct observation strategies are most appropriate to "share in the understandings and perceptions of others and to explore how people structure and give meaning to their daily lives" (Berg 1995:7).

Though surveys are often another potent tool for gathering data similar in nature, in this case surveys (or formal interviews) would do little for an examination of complex social relationships or more elaborate patterns of interaction, such as those between staff and patients in the clinic setting (Marshall and Rossman 1989), or to understand the personal meaning structures of women's experiences. The selection of both patients and staff at the clinic as interview participants was therefore fundamental to this research. Further, Marshall and Rossman (1989) suggest that to access "meaning structures" in a research setting, certain types of data must be examined: the form and content of verbal interactions between participants and between the researcher, non-verbal behaviour, and patterns of action and non-action.

Meaning structures often become evident through the interview process, where such methods elicit qualitative data which reflects the understandings and meanings of those being studied – their "subjective worlds" (Layden 2005). Since the goal of the research was to understand how women formulate and experience tuberculosis in a particular clinical context, other quantitative methodologies that examine relationships between preconceived variables would have been less successful in determining an individual's interpretation and meaning of their experience (Layden 2005). The

utilization of semi-structured interviews (as opposed to more structured interviews) allowed for the creation of experiential data; flexibility in the interview schedule allows the elicitation of views or accounts in relation to quite specific questions, the ability to vary the wording or order of questions to encourage greater participant involvement, and provides the freedom to pursue themes which emerged in the interview (Wooffitt and Widdicombe 2006).

The strengths of ethnographic methods in medical anthropology are therefore numerous, providing detailed descriptive data, placing illness within larger social, cultural, and economic contexts, and using inductive approaches that allow the exploration of unexpected results (Bhattacharyya 1997). While useful for collecting anthropological data, however, the information gathered by medical anthropologists is often utilized by public health programmers merely because of common research subject interests. Though anthropologists recognize the value in placing disease and illness phenomena within social and cultural contexts (necessitating the use of ethnographic techniques), the methodology employed is often scrutinized by public health programmers for taking too long (and therefore often not timely enough for program planning), it is highly subjective, not generalizable, and data is not focused to program-specific needs (Bharracharyya 1997).

Analysis of Data

The data collected through interviews and observations at Rio da Huila was analyzed based on the concept of grounded theory, as outlined by Corbin and Strauss (2008). They propose that theoretical constructs must be grounded in the qualitative

analysis of data; data must be analyzed for context, concepts, and process, or "the flow of action/interaction/emotions that occurs in response to events, situations, or problems" (Corbin and Strauss 2008:87). The development of theory emerges out of the analysis of the data, while further data collection is guided by the theory that has developed from analysis (Hammersley and Atkinson 2007). In this way, the grounded theory approach "stresses the role of systematic theory-building as an integral element of research" (Layden 2005:54). As suggested by Layden (2005), other theoretical or analytical approaches are either descriptive in nature and therefore not grounded in theory (and are therefore not explanatory), or are better suited for theory-testing research aimed at gathering information to confirm previous findings or investigate social problems, neither of which are effective in garnering the desired information for this research.

Methodological Considerations

Regarding the nature of the interpretation of ethnographic information, Crawford (1985:63,64) explains that:

Interpretation is not an account from a privileged position of neutrality of how people "think" about health. It is an attempt to discern meaning from what people have chosen to tell this particular researcher in the context of an interview, with all its distinct properties as a special kind of social interaction. The study of meaning is riddled with problems of shared and opposed assumptions and categories as well as dangers of unconscious, personal projections.

As with any research methodology, the interviews and grounded theory approach adopted in this research project need consideration as to their limitations, many of which Crawford highlights. Just as the grounded theory approach to analysis stresses a relationship between data and theory in which one informs the other and vice versa, so

does the relationship between the interviewer and interviewee. This relationship proved to be simultaneously the most significant methodological challenge to capture "authentic" data out of the interview process, and also the most generative in terms of creating knowledge about local women's encounters with "Western" medical practice and institutions. As Robben and Sluka (2007:63) suggest,

Fieldwork is not a detached activity carried out by an objective observer but that subjective experiences and selfhood are part and parcel of fieldwork and its results. The ethnographer's multiple social identities and his or her dynamic self may be liabilities but also research assets.

The most obvious methodological "issue" in conducting research at a rural clinic in Angola was the researcher's status as a (very noticeable) outsider; this indeed did seem to be simultaneously a liability and an asset.

Certainly the idea of the "position" of the research in relation to the "subject" of research is prevalent in more recent ethnographic literature, embedded in the idea of anthropology as a reflexive exercise (Robben and Sluka 2007, Hammersley and Atkinson 2007). Such "social identities" are forged in part through positioning as "insider" or "outsider" in relation to the group, each with associated liabilities and assets. In particular, one of the main methodological issues with the interviews at Rio da Huila included what Wooffitt and Widdicombe (2006) describe as "interpersonal issues," and notably a certain keenness on the part of respondents to "please" the researcher because of her (perceived) higher status. Such issues in the dynamic of interviews are not uncommon, and Kitzinger (2006:155) suggests that:

The problem for researchers...is that what people say in interviews may not accurately reflect the reality of their lives. Peoples may deliberately lie or exaggerate, they may forget information that the researcher thinks

important, or they may try to give the sorts of answers they think the person asking the question wants to hear.

"Pleasing" a visitor by responding to a question in a way that the visitor is presumed to want is quite common in Angola (Dr. Karen Henriksen, personal communication), and to speak the "truth" or true information, regardless of whether or not it will please another person, is not necessarily universally valued. In the interview setting, the questions which were subject to the most "exaggerated" or "false" responses were those focused on the etiology of tuberculosis. None of the women stated the cause of sickness to be related to witchcraft, for instance, something they would perceive a foreign, educated interviewer to not understand – a more appropriate answer would involve talk of germs and "natural" causes. It is therefore difficult to discern to what degree they "actually" felt TB to be caused by witchcraft, if at all. Such situations therefore need to be understood with sensitivity towards the underlying interaction taking place within the interview, the power dynamics within the interaction, and the expectations of both the interviewer and interviewee in how knowledge is created.

Just as the interview itself represents a specific context which shapes the production of information, the clinic setting and utilizing the "clinical population" also warrants methodological consideration. The utilization of this particular population is limited, as Pelto and Pelto (1996) point out, since the clinic receives a selected, non-random portion of the population. At Rio da Huila and for this research, this portion is represented by women with tuberculosis who have chosen to get treatment at the clinic. Though this may seem obvious, it has profound repercussions for the kinds of information produced.

Because all the women interviewed have chosen to treat their sickness with biomedicine and view this treatment as efficacious, their narratives are probably compromised in terms of generating general knowledge about Mumuila beliefs about TB, the perceptions of causes or the effectiveness of traditional healers. This information is also too subjective to create a generalized "explanatory model" of tuberculosis for a large population. By examining such a clinical population, however, unique themes emerge from the data – themes relevant to Mumuila women that highlight "their own subjective experiences of sickness and health, pain and suffering, oppression and resistance, good health and occasional joy that are part and parcel of women's health experiences around the globe" (Inhorn 2006:367).

Chapter 4 – The Embodiment of Tuberculosis

Tuberculosis as Disease

From a biomedical perspective, tuberculosis is an infectious disease caused by the genus *Mycobacterium* which includes a number of species that are regularly pathogenic to humans. The bacteria are transmitted to humans by infected droplets (the respiratory route) into the lungs of another human, where the bacteria are caught (Roberts and Buikstra 2003). Only a small number of bacilli need be inhaled for initial infection to occur, which becomes known as the primary infection (Gandy and Zumla 2003; Roberts and Buikstra 2003). Once in the lungs, the bacilli are surrounded by human immune cells (alveolar macrophages), subsequently limiting the spread of the bacteria. This locus eventually forms a cluster of both macrophages and bacteria surrounding an infected area. The bacteria produce chemicals toxic to the body, resulting in the production of lesions which surround the pathogen clusters to contain the infection (Pratt et al. 2005; Gandy and Zumla 2003). This occurs most often in the lungs. Infection with *Mycobacterium tuberculosis* in healthy persons is likely to be asymptomatic, with the lifetime risk of developing clinically evident TB after infection only 10% (Hopewell and Jasmer 2005).

A major and highly problematic feature of tuberculosis can be the reactivation of an infection caused by the tubercle bacilli which remain housed in the lesions formed from the primary infection (Daley 2004; Roberts and Buikstra 2003). Re-activation of the dormant bacteria is caused by the breakdown of the lesions due to compromised immune function, more and more commonly due to co-infection with HIV. This discharge of infective material from the lesions into the rest of the body is known as secondary

infection, which also leaves cavities in the lung tissue, inhibiting its function. It is also during this time when individuals with secondary TB infection are the most contagious (Pratt et al. 2005; Gandy and Zumla 2003).

Secondary infection usually occurs in adults five or more years after the primary infection (Daley 2004). This characteristic latency and potential for reactivation means that tuberculosis epidemics are slow and tend to occur over hundreds of years due to the resulting accumulation of a large number of people with latent infection. This is evident in the lag in the visible effects of infection control (Roberts and Buikstra 2003). Typical symptoms of active tuberculosis infection include coughing, difficulty breathing, weakness and lethargy, loss of appetite and weight, hoarseness, chills, night sweats, irritability, pallor, amenorrhea (in women), impotence in men, and fever (Roberts and Buikstra 2003). Initially, the cough associated with pulmonary TB may be "unproductive," but as inflammation and necrosis of lung tissue develop as the disease progresses, the cough may result in the production of sputum. Diagnosis of pulmonary TB therefore relies on culture tests that identify specific *M. tuberculosis* DNA in the sputum.

Tuberculosis, though often generalized as a lung disease, can also affect the entire body. In non-HIV involved patients, 85% of reported TB cases worldwide in 2005 involved the primary site as pulmonary, while the remaining 15% were extrapulmonary or both. With HIV co-infection (an increasingly common occurrence), the body's ability to contain the TB infection is compromised, so the tuberculosis bacilli are more widely disseminated throughout the body and the incidence of extrapulmonary TB is higher (Hopewell and Jasmer 2005).

Extrapulmonary TB can be disseminated throughout the body as the bacilli are carried through the lymphatic system. This is known as miliary TB, and due to a compromised immune system in HIV positive patients, the incidence of miliary TB is becoming more common. The bacilli spread throughout the body forming small nodules or lesions most frequently on the liver, lungs, bone marrow, kidneys, adrenals, and spleen. Symptoms of miliary TB are systemic, and non-specific: fever, weakness, and weight loss (Hopewell and Jasmer 2005).

The bacilli can also gather in more specific locales, causing lymph node, pleural, genitourinary, central nervous system, abdominal, and pericardial TB. Skeletal TB is also common, with spinal TB making up from 50-70% of reported skeletal cases. Due to the spread of bacilli from particular lymph nodes, spinal TB most often affects the lower thoracic and lumbar vertebrae, causing deformation of the spine. Other skeletal involvement includes localization in the metaphyses of the long bones, postulated to be due to their rich blood supply (Hopewell and Jasmer 2005).

Tuberculosis as Illness

Globally, only AIDS is responsible for more deaths than tuberculosis, and the highest TB mortality rates are found in sub-Saharan Africa, representing some 29% of tuberculosis cases worldwide in 2005⁴. Tuberculosis also holds the rather unfortunate designation of having been responsible for more morbidity and mortality than any other bacterial pathogen worldwide (Corbett and Raviglione 2005; Roberts and Buikstra 2003)

⁴ World Health Organization

²⁰⁰⁸ Tuberculosis. Electronic document, www.who.int/mediacentre/factsheet/fs104/en/index.html, accessed May 21, 2008.

despite an overwhelming mid 20th century optimism surrounding the effectiveness of public health measures and the pharmacological eradication of tuberculosis and infectious disease in general (Mayer 2000).

The pharmacological possibility of the eradication of TB led to a major transition in how Western society viewed the disease, suggesting that far from being a meaningless disease phenomenon restricted to bodily experience, tuberculosis carries tremendous meaning and metaphor not restricted to its cellular makeup or biological characteristics. In their discussion on measuring tuberculosis morbidity and mortality, Roberts and Buikstra (2003) point out that the confounding factors associated with TB occurrence are difficult to measure, wide ranging, and hard to partition. As they suggest,

Tuberculosis is immense, and of as much importance to society today as it was in our ancestor's world... Its epidemiology is a complex mix of many variables: the young, the old, and the malnourished are susceptible; poor environmental living conditions, high population density, certain occupations, the co-occurrence of HIV, and the lack, or crumbling of, public health infrastructures in some countries are some of the main factors to consider in its occurrence (Roberts and Buikstra 2003:11).

Part of the "importance" of tuberculosis therefore lies in its social and cultural construction, particularly because of its historical depth in the Western imagination. This historically-situated spectre still looms large in biomedical programming around the globe, influencing how TB treatment is carried out and how individuals with TB are enfolded within biomedical discourse. Susan Sontag (1979:5), in highlighting the role of both TB and cancer in our collective Western medical imagination, suggests that "the fantasies inspired by TB in the last century, by cancer now, are responses to a disease thought to be intractable and capricious – that is, a disease not understood – in an era in which medicine's central premise is that all diseases can be cured."

An examination of tuberculosis as metaphor and cultural construction, as Sontag pursues, highlights those aspects which have worked to produce TB as something "immense" in our cultural consciousness (Roberts and Buikstra 2003). Working primarily from European literary sources, Sontag (1979) suggests the earliest interchange of the words "consumption" and tuberculosis – the most prevalent metaphor for TB – occurred in 1398. "Consumption" referred to the physicality of the disease, that TB makes the body transparent, that you can see its effects through wasting away, literally the consumption of flesh; TB is disintegration and dematerialization. Because of this sense of wasting away, it also became important *who* got TB as it was also seen as a disease of poverty and deprivation, resulting in and deriving from thin bodies, unheated rooms, poor hygiene, and poor nutrition (Sontag 1979).

Tuberculosis took on different meanings during the Romantic period of the 1700s, however, and was expressed in the literature and cultural consciousness in new ways. Though tuberculosis dissolved the physical body, it "etherealized the personality" and "expanded consciousness" in death, and led to a new sense of death as aesthetic (Sontag 1979:18). The sense of "etherealizing the personality" in a death from tuberculosis was linked, again, to the physicality of the disease. The fevered flush of the patient suffering from TB arose out of passion – TB became romantic, a disease of the sensitive person who only grows more sensitive through suffering. It further became an index of one's gentility, delicacy, and sensitivity concurrent with the shift in European social worth and status becoming asserted (rather than given) with the increase in geographical and social mobility in the 18th century. The assertion of one's status required an upkeep of appearances, evidenced through fashion and physical thinness. The "consumptive"

appearance," a physical measure of one's social worth, became a manner of appearing – appearing to not eat heartily, and to look sickly for the sake of glamour. The "tubercular look" symbolized "an appealing vulnerability, and a superior sensitivity," especially for women (Sontag 1979:29).

The look of TB, ascribed with aesthetic value and imbued with meaning, made sick people "interesting," arguably the highest ambition for the Romantics (Sontag 1979). Tuberculosis, with its construction as a disease of interesting and sensitive people, became a disease of the creative personality, of novelists, poets, and artists in which their illness fuelled their creative consciousness. This idea was also congruent with the notion of tuberculosis as a mysterious disease which afflicted individuals, not an illness of epidemic proportions like the plague, cholera, or typhus. Neither did the other scourge of the time period, syphilis, possess the mysteriousness of etiology which contributed to the construction of TB; syphilis was seen to have a fairly direct cause and effect link to particular types of sexual relations, therefore imbued with stigma and shame (Sontag 1979).

The treatment for TB was also related to dominant modes of thinking in the Romantic period, particularly evident with the emerging idea of anti-urbanism. Cities were seen as dirty and generally insalubrious, so a "climatic cure" for tuberculosis became popular, especially as it was congruent with the broad get-back-to-nature sentiments of the Romantic period (Gandy 2003). Even the medical discourse surrounding tuberculosis at the time emphasized the relationship between climate and pulmonary TB; wealthy Europeans thus embarked on voyages to sunny and warm locales (Gandy 2003, Sontag 1979) and sanatoria developed in places with pleasing climates and

beautiful, natural, settings – an association which persisted well into the 20th century (see, for example, Adams and Burke 2006)

With the advent of structural changes to European social organization through the adoption of a capitalist system, biological metaphors about bodies became increasingly economic, reflecting men's movement to paid work in the public sphere, and women's role as wives and mothers in the home (private sphere) (Martin 1989; Sontag 1979). Economic metaphors were imbued in medical terminology not just regarding the body, but 19th century images of disease. Tuberculosis as consumption, for instance, echoes capitalist images of loss and gain inscribed within physiological processes: "one has a limited amount of energy, which must be properly spent... Energy, like savings, can be depleted, can run out or be used up, through reckless expenditure. The body will start 'consuming' itself, the patient will 'waste away'" (Martin 1989:34; see also Sontag 1979).

Treatment of tuberculosis also echoed changing medical and cultural discourse in general towards the beginning of the 20th century. The sanatoria movement shifted from treating TB with pleasing scenery and climate – a "change of air" – to one meant to institutionalize segregation. With such rapid industrialization and urbanization, the geography of tuberculosis became located in poor loci. The metaphors about TB came to reflect the disease as a "disgusting stigma of poverty" (Gandy 2003:22).

Tuberculosis and the Body

The power of a metaphoric analysis of tuberculosis within medical anthropology lies in its embodiment, that is, how it is understood in relation to the body. The

metaphors of tuberculosis changed and are changing now both because the etiology and treatment of TB is no longer shrouded in mystery, and because of the dynamic nature of the body in different cultural contexts and how illness is understood in relation to that body. For the Romantics, the look of TB on the body reflected character, temperament, and social identity. Further, the bodily experience of tuberculosis becomes the physical site for the classification of illness, and subsequently the site for choosing therapy. Metaphors of tuberculosis are therefore intimately connected with discourse about the body, whether it is a 19th century European or modern Angolan body.

The medical anthropological literature on the body is quite rich: Emily Martin (1989), for instance, suggests that the development of medical metaphors of women's bodies and menstruation, birth, and menopause, result from the history of scientific knowledge production, and the rise of economics, industrialization, and capitalism. In her argument, she turns the anthropological gaze onto science, suggesting that the production of scientific and medical knowledge can (and should) be analyzed as arising from a cultural context, thereby subverting its claim to neutral, objective, and natural "truth." As Lock and Kaufert (1998:6) echo, "The claims of medical knowledge to a privileged status depend on the belief, shared by medical professionals and the public alike, that scientific knowledge, being factual, cannot be subject to epistemological scrutiny." This naturalizing of scientific knowledge as truth is the result of discursive strategies and metaphors which, far from remaining neutral, are imbued with cultural values and must be contextualized within a wider historical setting and social systems and networks, and are therefore "subject to discursive negotiation" (Lock and Kaufert 1998:6).

In their discussion of medicalization in Europe and North America, Lock and Kaufert (1998) suggest that Foucault's idea of "biopower" must first create its own objects of analysis to which it must subsequently respond. As cited by Lock and Kaufert (1998:7), Foucault asserts that biopower functions in a way that

Bodily states are labelled by experts as diseases; certain behaviours are defined as deviant, unnatural, immoral, opening up the way for systemic and legitimized attempts at medicalization of both body and behaviour.

Bodily states, more particularly, are "key markers in which are invested the social definitions of the self – not only regarding role, but normality and abnormality, inclusion and exclusion, domination and subordination" (Crawford 1985:60). The "body" becomes the object of interest, and certain "bodily states" are classified as illness or sickness and labelled as diseases by experts, thereby creating a specific domain of expertise.

In a broad sense, our bodies are always mediated by culture, defining our social roles, and defining us in relation to others through categorizations like kinship, sex, age, or race (Crawford 1985). The bodily experience is also structured through the symbolic category of health, grounded in the experiences and concerns of everyday life (Crawford 1985). In his study of views of "health" in North America, Robert Crawford (1985) suggests that the "healthy body" is tied to a sense of self-control, that to be healthy takes work and self-discipline. The value of discipline becomes synonymous with the value of work, both bestowing a sense of self-worth to the person who can physically show their self-discipline through their fit, youthful, and therefore healthy, body.

Health, therefore, becomes a goal achieved through particular acts of maintenance and enhancement of biological functioning (like excessive exercise). The act of

promoting health, Crawford (1985) asserts, is subsequently integral to an encompassing symbolic order in which the individual body, separated from society and the mind, becomes managed by biomedical criteria. Crawford further emphasizes that one very distinct way of experiencing our bodies is through the internalization and reproduction of such biomedical discourse, or medical knowledge. As Lock and Scheper-Hughes (1996:44) suggest,

Medical knowledge is, of course, also constrained (but not determined) by the structure and functioning of the human body [and] the notion of 'embodied personhood': the relationship of cultural beliefs and practices in connection with health and illness to the sentient human body.

For the women who experience tuberculosis and come to Rio da Huila for treatment, their construction of, and medical knowledge about, tuberculosis is also "constrained" by the structure and functioning of their bodies, and experienced through sickness. Present in all of the interviews and numerous informal conversations with staff at the clinic was an implicit description of a non-sick body, a body (and in particular, that of a woman) that was able to fully participate in expected Mumuila social relations and economic activities.

This idea was evident throughout the women's narratives in talk of the appearance of the non-sick body. Most frequently, and most explicitly, this was explained by the women as a decrease in strength, and specifically the inability to walk, or walk long distances. When asked how they felt when they first knew they were "sick," most women responded with descriptions of a cough that would not resolve, and weakness. One woman stated her decision to seek treatment was because

I couldn't walk... and also, I had a big body, I was really big and strong... but [not] now... it's because of the sickness.

Other women, in remarking about how they knew the medication/treatment was working, stated they were "feeling better" as expressed through a renewed ability to walk:

I'm feeling better because in the past I couldn't walk a long distance, but now I can walk a good distance.

For the Mumuila who are not reliant on cars and telephones for communication, it is no wonder that the ability to walk, to move one's body, was a prominent feature of the idea of what constituted a state of "abnormality" – of sickness.

The idea of a previous state of being "big and strong" was also echoed by others. The communication style of Angolans appears to include very little in the way of gesticulating; hand gestures and extreme or dramatic body movements were not observed very often. This was particularly true for the women during interviews. In the few common gestures, however, women would either wave their hands generally in front of their chests or stomachs to indicate a degree of discomfort located there, or wave a hand over the opposite arm, over the bicep. The infrequent use of "body language" in descriptions of symptomology both gave a false sense that these women were not, in fact, that sick, and a sense of prominence of the hand gestures they did use. When the translators were asked what the particular motion of the hand over the opposite arm meant (as it was not clear in the translation), it was suggested that the women were articulating the loss of muscle, that they were weaker and it was physically apparent.

The idea of a "strong body" as important for social relationships and economic necessity became somewhat of a theme in the interviews. Following each interview, permission was requested from the women to take their picture. The intent, it was explained, was not to include such photographs in any written work, but for myself only,

to remember their faces after returning to Canada. For several women, they gave consent but with much embarrassment. There was often a shy smile and averted eyes with such a request, and when asked if they would rather not have their picture taken, the women would reply that they were embarrassed with the thinness of their appearance or the skinniness of their bodies. Such a response would therefore suggest there is significant value – both aesthetically and practically – for women to have big and strong bodies. A thin, weak looking body was experienced as an embarrassment, a sign of sickness.

The physicality of a healthy body, of cultural values of a woman's body for the Mumuila, was also evident in comments directed at me regarding my appearance, my perceived health, and subsequently my social position. In one instance near the beginning of my stay at Rio da Huila, an Angolan who remembered me from my last visit remarked that I was looking fatter than before – a common observation made when seeing someone again after a long period of time. Initial thoughts included, "Excuse me?" then, "Have I really gained that much weight?" and finally, "I should probably lose that weight if people are noticing." In all likelihood, these thoughts were most evident on my (somewhat horrified) face, and my Canadian companion, knowing how such a comment would be negatively received in Canada, said not to worry - in Angola, it's a compliment meaning I'm looking healthy. Nevertheless remaining not-quite-reassured and extremely conscious of my weight, it became an interesting lesson in how body image is both constructed physically and discursively in North America (considering my horrified reaction that I may have gained weight) and the image of "health" for Angolan women in having a big, strong body.

Another incident occurred during a conversation with staff members, insistent upon discussing my age and marital status. Marriage and child-rearing among Angolan women was a normal and inevitable life stage, and something to be embarked upon generally before the age of 20. My own situation was therefore somewhat anomalous; I was in my late 20s, and still unmarried. And perhaps worse, had no children. I was excused, however, since I was not Angolan, and because they assumed that this was "normal" behaviour for a Canadian. One further comment suggested that the appearance of a woman's body was also related to the cultural expectations of a woman. After stating yet again that no, I was not married, a staff member reassured me that this was okay because I was still big and strong, and still looked healthy. This was explained in comparison with a description of an Angolan woman in her 30s who also was not married; she had lost a lot of weight, and her face looked thin, drawn, and "old." While I retained marriage potential at my advanced age, the thin and drawn look of the woman not much older than I, did not retain the necessary "look" to maintain such potential.

My involvement in the descriptions of what a healthy body is certainly shed light on the relationship between the body and health for Angola women, and represents the power of discourse in producing social knowledge about the body, and in this case, a healthy body. A healthy body is big and strong (able to undertake physical work) and attractive (creating a gendered female body). Because I was perceived to still be big, strong, and "animated," there was still hope for me – I retain the potential to get married, and therefore could still secure a proper place in society. In other words, the way a body (Angolan or Canadian) looks creates identity. Though researching the topic of sexuality and gender in sociological perspective, Amanda Coffey (2005:415) discusses the

widespread interest in the marital and sexual status of the fieldworker in an ethnographic setting. She suggests that such interest "demonstrates a key way in which identities are established and maintained... they provide first-hand, 'stranger' accounts of how sexual mores, status, attachments and marriage are accomplished in the cultural setting."

A healthy Mumuila woman's body is therefore both mediated by and a mediator of culture, creating identities based on its appearance (Crawford 1985). This is also exemplified in Lock and Scheper-Hughes' (1996) idea of "embodied personhood" relating cultural beliefs and practices to the human body. Further, the functioning of the human body in part contributes to the creation of medical knowledge. At Rio da Huila, the appearance of a body established an immediate sense of health in relation to others, and creates an identity in sickness which, embodied, contributes to medical knowledge, particularly regarding when and from whom to seek treatment.

In interviews, it became apparent that the decision to seek treatment came about most often when a particular, self-defined threshold had been met, particularly when symptoms progressed from normal to "abnormal" and interfered with daily functioning. In addition to losing strength, to looking "thin" and sick, further symptoms cited by all the women included weakness, feeling soreness or pain, and were often extremely vague in description. One woman suggested that "I can feel it in my whole body, it's very hard for me to do different kinds of things." Another woman stated that she "felt weakness, I felt sore in my body," and another felt pain in the stomach area, moving up to her chest, and then throat. When she coughed, she said, "it's like my heart is going to burst."

This is an example of what Nichter (2008:26) terms "ethnophysiology," the focus of which is the examination of understandings of bodily processes cross-culturally, and

how such understandings may influence perceptions of health, physical development, illness, medicines, and diet:

Perceptions of bodily processes influence what physical symptoms are deemed normal and abnormal at particular times and which ones are deemed serious enough to warrant treatment... [it] contributes to the meaning accorded to particular symptoms and plays an important role in determining thresholds of symptom tolerance.

Coughing was another prominent symptom, again only becoming problematic after a certain threshold was reached, when it warranted treatment. In some cases, the cough became "abnormal" because it did not resolve. In the most extreme case, one woman was coughing for three years, until she felt the cough "getting into her," and therefore becoming problematic. Another woman said at first she thought what she was feeling was a normal cough, but the duration of it (over a year) made her suspect otherwise: "it wasn't a normal cough because when I started coughing I also felt sore in my body, that I wasn't okay." The pain and cough that is problematic is so because, as one woman stated, the pain was such that it "stopped me from doing those things that I normally do."

The beginning stages of "feeling sick" for many of the women was marked by coughing, but was typically perceived as "normal" coughing. One woman described the "normal" cough getting "deeper" accompanied by a soreness in her throat after 5 months. The "deepness" of the cough spurred her to get treatment, to go "see someone." Another woman remarked on the "deepness" of her cough, and when it finally got worse, and she began to feel tired and experience pain, she came to the clinic for treatment.

Though all the women interviewed ended up at Rio da Huila for treatment, what precisely does "treatment" mean for these women, and why did they come to Rio da Huila? The decisions around seeking relief from suffering, for medical treatment, are

perhaps best expressed in the concept of one's "health belief model" (Rubel and Garro 1992) and the multiplicity of factors which surround medical decisions, including possible anxiety associated with taking medications, the perceived impact of side effects of these medications, health beliefs, the complexity of the treatment regimen, poor clinician-patient relationship, issues around control, and personal attempts to deal with the illness (Pratt et al. 2005). A health belief model is mediated by culture; do individuals believe themselves susceptible to tuberculosis, and how severe do they perceive it to be (Rubel and Garro 1990)? If the decision is made to seek assistance for this condition, what benefits do they see in taking preventative action, and how costly do they perceive the barriers to obtaining that assistance to be (Rubel and Garro 1992)?

Rubel and Garro (1992) go on to suggest that the motivation to seek treatment for illness is grounded in the interpretation of the meanings of symptoms and what such interpretation implies for a functioning social life. This is certainly the case at Rio da Huila; when the pain/cough/weakness interferes with daily life, when "it stopped me from doing the things I normally do," or the body looks thin and unhealthy, action must be taken to return to "normal" bodily function.

The treatment decisions the women discussed related directly to their bodies, particularly when discussing self-medicating. The woman who described pain in her stomach, chest, and then throat thought the onset of pain was the result of something she ate; she subsequently stopped eating, and only drank water and sugar. This did indeed make her feel better for a time, but when the pain returned and was accompanied by a cough, she made the decision to come to Rio da Huila. All but three of the women had lengthy tales of where they went for treatment, all involving various medical clinics or

hospitals in the area, and all seemingly unsuccessful. Two of the women first began to treat their chronic cough by increasing their consumption of a traditional alcoholic drink, and in both cases that made them feel better for a period of time, but not sufficiently to return them to their desired state of normalcy.

Decisions around treatment are, as Rubel and Garro (1992) point out, related to the meanings of symptoms, and further, what the cause of those symptoms appear to be. Though much literature on tuberculosis in Africa and Asia focuses on the etiology being "spiritual" in nature (witchcraft, for instance) this was (surprisingly, because of the literature) not found to be the case at Rio da Huila, possibly because this was a case of telling the interviewer what she wanted to hear, and possibly because TB was simply found not to be caused by witchcraft. It could also be the case that those individuals who believed TB to be caused by witching simply sought alternate treatment that was congruent with their experiences and etiological knowledge base. In one interview, when a woman was asked why she did not try going to a witch doctor first, she responded simply, "it's never going to make me feel better."

In her study on conceptions of tuberculosis at a rural hospital in the highland Chiapas region of Mexico, Lorenza Menegoni (1996) found that upon conversion to Protestantism, people with tuberculosis increasingly rejected the belief that it was caused by witchcraft, instead attributing causation to "natural" causes like getting wet, or drinking too much alcohol. Similarly, Ngang et al. (2007) found that the causes attributed to tuberculosis in rural Rwanda ranged from distinctly biomedical (germs or worms), environmental (seasonal changes), cultural or socio-economic (hard work, malnutrition), to ideological (witchcraft). The symptoms subsequently reflect the source of illness; if

witchcraft was the cause, the symptoms were blood in the sputum and abdominal distension. The body in this state therefore becomes the site of therapeutic decisions – symptoms which suggest witchcraft to be the cause require the body to be treated differently. Promptness in seeking treatment from capable healers is necessary so the infection does not "form roots" in the body, as a tree might (Ngang et al. 2007). In this case, discourse about the physical body, and metaphors about the "infection" abound, generating knowledge about how to treat, when, and from whom.

In another study from Tanzania, Vinay Kamat (2008) looked at narrative representations of "degedege," an illness that inflicts mainly children and which parallels the symptoms of cerebral malaria. Through examining how mothers of children who died represented the symptoms and experiences of their illness through narratives, it was found that "hybridization" (Escobar 1995) was occurring in relating experiences with degedege. Kamat (2008) suggests that the characteristic symptoms associated with cerebral malaria (seizures, high fever, rigidity of the body) had been incorporated into the cultural repertoire of the mothers to varying degrees; the etiology centred around a spirit/bird's shadow under which a child fell. To fall under the bird's shadow and become ill occurred randomly and without intention, further shaping how the illness was experienced and where and from whom treatment was sought (Kamat 2008).

Similarly, at Rio da Huila, how illness was experienced influenced from whom treatment was sought. Though none of the women interview stated their sickness was caused by witchcraft, on two occasions women explained differences in symptoms between their illnesses and family members who had been witched. One woman had a highly complex etiology for both her tuberculosis and an illness her son was suffering

from, exemplifying the 'hybrid' nature in which medical knowledge is created. Her son, she explained, was suffering from heartache, which eventually moved into his head, causing him to feel pain and act in a strange way. This, she stated, was caused by him being witched by other family members. When asked later on in the interview what caused *her* sickness, she said that she knew tuberculosis was caused by bacteria so she was supposed to cough with her mouth covered. Still later in the interview when asked what she's going to do when she feels better, she offered that she is going to have to sit and relax, because if she started working the way she did before she got sick, it will happen all over again – the hard work she had to do caused her to become sick.

The observations made at Rio da Huila suggest similarities to the studies by Menegoni (1996), Ngang et al. (2007) and Kamat (2008). Like the setting in Highland Chiapas (Menegoni 1996), the majority of patients that utilize services at Rio da Huila have been influenced by Protestantism and biomedicine, which subsequently shapes their worldview and how disease phenomenology is understood. The woman who had an ill son described models of illness based on different ideologies and based on certain symptoms; her son's condition, she reasoned, was due to witchcraft, while the cause of her own sickness resulted from both bacteria and too much work. Another woman, when asked about the cause of tuberculosis was, initially responded that she did not know.

After a pause, however, she replied, "I heard it was caused by bacteria."

In their study of etiological beliefs of TB in Vietnam, Long et al. (1999) found that generally, "beliefs" about tuberculosis were in agreement with biomedical knowledge: TB is contagious and transmitted through the respiratory route. In addition, it was found that four types of TB were understood – hereditary (passed down from one's

parents and therefore present in childhood), physical (caused by hard work), mental (due to worrying too much), and lung (the contagious form, and present in the lungs). It was further found that men were thought to get tuberculosis more often because the activities they participated in as males put them at greater risk. Male activities such as drinking alcohol, smoking, eating out, heavy work, and numerous social contacts put them at risk. Women, who were perceived to worry too much, were more susceptible to the mental form. In Vietnam, as in Angola, it is evident that biomedical knowledge is integrated and changed to create a new understanding of sickness and how that sickness is embodied.

At Rio da Huila, there is no consistency regarding an understanding of tuberculosis etiology, but rather a hybridization of information from various sources used to create a narrative of causality that, in turn, influences how to treat the perceived illness; in other words, the health belief model (Rubel and Garro 1992). This is not surprising, for though the discursive practices of biomedicine function to maintain hegemony (tuberculosis is caused by bacteria), the anthropological literature shows that its unquestioned acceptance seldom (if ever) occurs, even in North America (Lock and Kaufert 1998, Escobar 1995, Martin 1989, Hepburn 1988). The complex causality narratives presented by the women interviewed reify this view.

Lock and Scheper-Hughes (1996) point out that the mind-body dichotomy as outlined by Rene Descartes is at the root of biomedical discourse and medical knowledge. This dualism also fosters the diagnostic techniques of biomedicine, and establishes disease etiology as biologically based and having nothing to do with unhealthy relationships, for instance. In cultures and societies with an articulated conception of the "body-self," a self-identity lacking the separation between the mind (where the "self" is

understood to be situated) and the physical body characteristic of Western culture, sickness is often explained or attributed to malevolent social relations (sorcery), breaking of social codes, or to disharmony within a family or community. At Rio da Huila, the relationship between social interactions and sickness is evident, but the etiology of tuberculosis is less clear, with numerous hypotheses provided by the women as to why they became sick.

The causality and treatment narratives therefore also exemplify the idea of socially generated knowledge regarding specific illnesses, and TB in particular. Such knowledge is characterized by dynamics of change and influenced by new ideas (Kamat 2008). The knowledge that is culturally-mediated, produced and reproduced through social interactions become patterns of medical knowledge. Such patterns are then "articulated within the framework of culturally embedded ethnomedical systems" and are termed "health culture," incorporating the information and understanding gained from family, friends, and neighbours regarding the nature, cause, and implications of a health problem (Vecchiato 1997:186). A "health culture," however, is in no way static, instead characterized by dynamics of continuity and change, and therefore influenced by new incorporations of ideas and practice (Vecchiato 1997). Not only is the process by which this knowledge is created culturally-mediated, but such belief models are inherently negotiated in the cultural arena as well (Vecchiato 1997).

At Rio da Huila, both Protestant Christianity and biomedicine have been significant influences on "health problems" (Vecchiato 1997), but, as is evident, to varying degrees. Two women interviewed said quite specifically that they felt their sickness to have a "natural" cause, that it was a disease of nature. The categorization of

"natural" causation implicit in such comments suggests views in opposition to sickness asserted to be caused "unnaturally" or by witchcraft. When further pressed to clarify why tuberculosis was "natural," one woman responded:

I didn't think it [her sickness] was anything, I just thought it was a sickness of nature, that it was nature, and I'm not the only one who has it. Many in our community have it.

Fully expecting the response to include an explanation related to biomedicine, the answer was somewhat surprising but nevertheless shed light on the complexity of the construction of TB causation. The prevalence of tuberculosis in this woman's community, the commonality of its occurrence, aided in constructing her health belief model, and produced social knowledge regarding it. Because she knew of so many people afflicted by TB and the success of their treatments, she subsequently made decisions regarding her experience with tuberculosis.

In one interview, a woman, describing how she initially knew she had to seek treatment, stated it was her neighbours who told her she had TB and that she should go to Rio da Huila. In this case, the woman's compromised ability to function as she did before she became sick meant her illness experience became social – she relied on information and support from her neighbours to identify her sickness, its severity, and where and from whom she could receive relief. Similarly, a woman who is no longer "big and strong" cannot complete the tasks necessary for her to sustain herself and her family; she is compared physically to the woman who has not gotten married, therefore becoming thin and drawn. These are women whose physical states have rendered them "abnormal," and for the women who have TB, provide them with the impetus to seek treatment.

The fact that TB etiology is explained in such myriad ways, defying the expectation that sickness should be attributed relationally (sorcery, disharmony, or breaking social codes) (Lock and Scheper-Hughes 1996), would suggest that perhaps it is not tuberculosis that women are experiencing. In looking at medical knowledge in an African context, Pearce (1993:160) suggests that "the assumption that one is physically well is also dependent on how the body feels... the stress on *strength* and activity will influence the types of symptoms recognized as important."

The symptoms described by the women in the interviews suggest a similar pattern focusing on physical strength, the decrease of which causes a shift in a woman's ability to maintain her identity within her community. As Nichter (2008:69) points out, "regardless of their biomedical significance, symptom sets accorded cultural importance flag local health concerns." The symptoms of TB recognized as important were cough and a wasting of the body, those that influenced a woman's place in her social world. It would seem, therefore, that women sought treatment not because they knew they had TB, but because they wanted to return to a previous physical state of normalcy.

In this way, the bodily experience of tuberculosis, whether during the European Romantic period or in modern-day Angola, emphasized more than mere physicality, more than a bacterial infection. The bodily expression of TB (the "tubercular" look) both in Western history and Angola reifies certain cultural values, impacting on both identity and social relationships. The body as cultural construction is again exemplified, that the ways in which the body is conceived, its internal processes, and its ideal configuration are products of culture and history (Inhorn 2006). The "healthy" body is equally subject to construction: "health, and more specifically, health ideals are rooted in cultural norms and

values that permeate and define – yet extend beyond – the state of the physical body" (Adelson 2000:9).

Chapter 5 – Encountering Biomedicine

I drove in with the truck and up to the *chefe do posto* 's office and home, which was located high on a hill and under the shade of many eucalyptus trees... Drinking red wine is a favourite pastime with a Portuguese and he indulges this pleasure by taking wine in his coffee in the morning, in his soup at noon, and with hors d'oeuvres at night. He was a bachelor with an avid interest in anthropology. He told me that his natives around here are secretive and hide their rituals and ceremonial dances... "There is a very picturesque and interesting primitive tribe which dances under the leadership of its medicine man whenever the bad or good spirits run amuck," he continued over another glass of wine. "If anyone is sick, some individual is always the cause of it. Natives do not accept natural causes for illness or death." (Laszlo 1955:91) [Andreas Laszlo, an American medical doctor, related his adventures travelling through Angola in the early 1950s in his memoir published in 1955. He frequently comments on the nature of the interactions between the "whites" and the "blacks," especially as they relate to medical care of Angolans by Portuguese doctors and their respective perceptions of the causes of sickness.]

Tuberculosis Control Programming in Africa

Currently, Sub-Saharan Africa bears the brunt of the world's tuberculosis burden (Corbett and Raviglione 2005; Enarson 2004). This particular geographical area also has the highest rates of multi-drug resistant TB (MDR-TB) and dual infection with HIV. MDR-TB, in fact, has become a significant health problem in the space of one generation (Harries et al. 2003), and Enarson et al. (2004) suggest that high rates of HIV, poverty, crowding and homelessness, malnutrition, and poor disease control have all contributed to these developments. Looking historically, however, the high rates of TB in this area are also situated both in the historical relationship between Africa, its people, and biomedicine, and the relationship between infectious disease (and specifically tuberculosis) and global health policy in the 20th century.

The history of European colonialism in Africa is long. The creation of modern Angola, for instance, is both situated in relation to the political history of Portugal and within the entirety of the colonial enterprise on the African continent. In looking particularly at South Africa, Jean Comaroff (1993) suggests, in fact, that this colonial history and ideology shaped the European view of the body (in relation to the African body) and the development of medicine and public health. Nineteenth century European thinking focused on man's place in nature ("man" meaning specifically male), and the human species in relation to the rest of the world. Reason, it was supposed, uncovered man's "essence" or human nature which separated human from object and human from animal (Comaroff 1993). Knowledge therefore lay in man himself: "the essence of life was in the unplumbed depths of organic being, to be grasped through the invasive thrust, the looking and naming, of the new biology (Comaroff 1993:307)." This way of seeing, this "invasive thrust" equated with the body, was produced and reproduced in discourses about the "discovery" of Africa by European explorers (Comaroff 1993).

This exploratory endeavour by Europeans involved the creation of discourse around the "natural hierarchy" in which Africans were placed lower on the evolutionary ladder and thus closer in relation to animals than white Europeans. In Angola, these ideas solidified the Portuguese colonial enterprise within the country. The Portuguese settlers who felt looked down upon in Europe came to Angola perceiving themselves as superior to the Africans, therefore developing an entrenched and significant classist and racist legacy in their attempt to "maximize their own security at the expense of others" (Clarence-Smith 1979:57; Wheeler 1971).

At the beginning of the 19th century, European colonial officials sought to ensure the well-being of both government employees and expanding European-majority communities. In South Africa, (and Angola) the functioning of these communities was dependent on African labour. The contradiction of Africans being both central to the new colonial economy and yet marginal to its political and moral community was, according to Comaroff (1993), built into the constitution of South African society. The public health project meant to ensure the well-being of Europeans therefore also functioned to maintain control of Africans, situated within existing ideologies of colonialism and "man's place" within the natural order.

The African body, along with the African continent, was viewed as infectious and dangerous (Schoepf 1998; Comaroff 1993). Viewing Africans themselves as "dirty" was congruent with the idea that they were, in evolutionary terms, closer to animals than the white settlers. This is particularly the case regarding the discourse of HIV and AIDS in Africa because it is also entrenched within Western ideas of African sexuality. As Schoepf (1998) points out, biomedical accounts of AIDS in Africa are overtly racist, characterizing African sexuality, and particularly that of women, as "promiscuous." Such labelling is an example of the metacommunication of biomedical discourse regarding African cultures and sexuality. When disease control policies are enacted through cultural politics in the context of the history of relations between the West and Africa, as is the case with HIV/AIDS and TB, hegemonic biomedical discourse can function as a conduit for racism (El-Bayoumi and Morsy 1993).

As is evident with the discourses surrounding HIV/AIDS in Africa, the idea of Africans being somehow "dirtier" (both sexually and as "impoverished") in contrast to

Europeans has not been completely lost to history, nor has the popular early 20th century idea that TB was a disease of poverty. This became evident on my voyage to Africa during a conversation with a white South African man en route to Johannesburg. After he inquired as to what I was doing in Angola, I explained how I was researching tuberculosis. This seemed to pique his interest, as he then went on to describe how his father was a physician familiar with TB in an African setting. After remarking about the increasing incidences of HIV and TB among "the blacks," he snidely concluded by saying, "black people... they're different than you and me. They think about things [sickness events] differently."

In the global public health arena, these entrenched views of "Africans" is further evidenced by the sudden renewed interest in tuberculosis in the 1980s as a "re-emerging" infectious disease, though incidence rates had been climbing in certain geographical areas since the mid-century. As Corbett and Raviglione (2005:3) explain,

Tuberculosis was catapulted back onto the centre stage of international health at the beginning of the 1990s, when New York City and Miami were affected by multiple institutional outbreaks of MDR-TB, mainly affecting hospitalized HIV positive persons and associated with extremely high case fatality rates... once international attention had refocused on TB, it became apparent that renewed efforts were required worldwide.

These authors highlight the view that TB infection as an international problem came about only as high case fatality rates were recognized in American cities. Tuberculosis in Africa (a disease of the poor and deprived) was thus not addressed in global health until the 1980s when it became "problematic" in Western countries (Roberts and Buikstra 2003).

Lewontin and Levins (2003) suggest that this is broadly due to the failure of public health researchers to foresee the re-emergence of TB because their reliance on science (and biology in particular) meant the neglect of other factors in infectious disease incidence. The historical period in which the relationship between TB and humans that was analyzed was too short, and such research did not take into account the major demographic, ecological, and environmental changes that affected human populations globally. Other studies, however, focus more specifically on the failure of "Third World" biomedical systems for the continued application of long-course (12-18 month) treatment regimens without the appropriate supervision or necessary laboratory facilities, thereby generating "epidemiological chaos" (Sbarbaro and Spinaci 2006:491). Those more critical of public health bureaucracy suggest the focus on TB as a "re-emerging" disease came about primarily because increasing incidence in the United States, Canada, and Europe brought the disease far too close to home (Roberts and Buikstra 2003; Mayer 2000).

The increasing global disease incidence and the emergence of multi-drug resistant TB have become part of what is known as the "new" tuberculosis, derived from what some posit as the interaction of different developments such as collapsing health care services, shifting patterns of poverty and inequality, and the spread of HIV (Lewontin and Levins 2003). As Zumla and Gandy (2003:237) describe:

No longer a 'tropical disease' of merely historical or scientific curiosity, TB has had a resurgence that has become global in scope, ranging from schools in the UK to prisons in Russia, from refugee camps in central Africa to North American suburbs.

Additionally, in 1991 the WHO identified major "programmatic deficiencies" leading to the complications which characterize the new TB, like inadequate treatment leading to

high failure rates, inadequate resources for programs, and inadequate government commitment to and insufficient funding for program management, laboratories, and drug supplies (Sbarbaro and Spinaci 2006).

Recognizing the significant disease burden this places on sub-Saharan Africa's infrastructure at every level, the WHO has, through implementation of an intensive control programme, attempted to alleviate this burden in accordance with its goals to eliminate tuberculosis as a global health problem by the year 2050 (World Health Organization). The WHO's Stop TB programme tailored for sub-Saharan Africa seeks to address some of the exceptionality of the region, taking into consideration that growth in GDP per capita lags behind every other country in the world, and poverty as measured by the number of people living below the \$1 a day line has increased from 44.6% in 1990 to 46.4% in 2003. Demographically, Sub-Saharan Africa is also considered to be the youngest region in the world with the highest global fertility rate and 44% of its population under 15 years of age (Baingana and Bos 2006).

The WHO's statistics on Angola in particular exemplify the "impoverished" nature (according to development agencies) of the region. Life expectancy, for instance, is 38 and 42 years for males and females, respectively, compared to 78 years for males and 83 years for females in Canada, while the maternal mortality rate (as measured per 100 000 live births) has risen from 1300 to 1700 in the years between 1995 and 2000 after falling from 1500 in the year 1990. Such statistics represent a significant barrier to the

United Nations Millennium Development Goals, considering a major goal to be met by 2015 is a drastic reduction in maternal mortality.⁵

According to World Health Organization statistics, while out of a population of about 16.5 million the prevalence rate (the proportion of individuals infected) of HIV is 3.9% (relatively low for the region), it is on the rise, as is the incidence rate. ⁶ In 2003, the prevalence and incidence of TB were 310 and 259 per 100 000 people, by 2006 the rates increased to an incredible 344 and 285 for prevalence and incidence respectively.

Treatment success was 72% in 2005. In Angola, health care services are provided primarily by nurses who make up 79.1% of the health care work force, while there were 1165 physicians in Angola in 2004, or 8 physicians per 100 000 people. Since the end of the civil war in 2002, however, access to biomedical health care services and pharmaceuticals is improving according to the WHO. ⁶

The "centrepiece" of global efforts to control TB is the DOTS (Direct Observation Therapy, short course) strategy, initiated by the WHO and the International Union Against Tuberculosis and Lung Disease (IUATLD) in the early 1990s, intended to reduce mortality, morbidity, and transmission of tuberculosis worldwide (Lewontin and Levins 2003; Lienhardt et al. 2003). Because the treatment of tuberculosis is based on lengthy multi-drug therapy, the DOTS strategy was developed as a means of assisting TB patients in following the regimen (Garay 2004).

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⁵ United Nations Millennium Development Goals

²⁰⁰⁸ Electronic Document, www.un.org/millenniumgoals Accessed March 31, 2008.

⁶ World Health Organization

²⁰⁰⁸ The Stop TB Strategy. Electronic document, www.who.int/tb/strategy/en/index.html, accessed September 23, 2008.

The first drug to be utilized in curing TB was streptomycin, developed in 1944. Though it initially cured patients, the tuberculosis bacilli were not eliminated and subsequently became drug resistant (Hopewell 2006; Garay 2004). Paraaminosalicylic acid (PAS) was then used, but was found to be more efficacious when used in conjunction with streptomycin. Another drug, isoniazid, was developed in 1951, but also did not work on its own. It was successful, however, when used in conjunction with PAS and streptomycin, suggesting that resistance was reduced when multiple drugs were used and treatment (up to two years) was prolonged (Garay 2004). Eventually, ethambutol was used with isoniazid, and, with the advent of rifampicin, the short-course therapy was developed with treatment with isoniazid, rifampicin, ethambutol and streptomycin. The modern core regimen utilized by DOTS for previously untreated patients with pulmonary or extrapulmonary TB includes isoniazid and rifampicin for four months, supplemented by pyrazinamide and ethambutol for the initial two months (Hopewell 2006).

The WHO's Stop TB Program functions as the main rubric within which programming takes place, its goal being the dramatic reduction of the global TB burden by the year 2015 through ensuring that all TB patients access diagnostic and treatment services⁷. This strategy is highlighted by six characteristics: the pursuit of high-quality DOTS expansion and enhancement, addressing the relationship between TB and HIV/AIDS and drug-resistance, contributing to the strengthening of health systems, engagement of all care providers (public and private), empowerment of people with TB

World Health Organization
 2008 The Stop TB Strategy. Electronic document, www.who.int/tb/strategy/en/inc

²⁰⁰⁸ The Stop TB Strategy. Electronic document, www.who.int/tb/strategy/en/index.html, accessed September 23, 2008.

and their communities, and the enabling and promotion of research (Dye et al. 2006). Further, the DOTS strategy focuses on five major components – government commitment to TB control, diagnosis including bacteriology with an effective laboratory network, short-course chemotherapy with a four drug regimen, an uninterrupted supply of quality assured drugs, and the consistent recording and reporting of patients (Chauhan et al. 2005). By the end of 2004, the core DOTS strategy was available to 84% of tuberculosis patients in Africa because of WHO implementation plans (Dye et al. 2006).

It is important to consider, however, that there are obstacles to realizing the WHO DOTS coverage potentials. As was explained to me, Huila province receives 100% DOTS coverage according to the WHO, but the clinics (one being Rio da Huila) are at a sufficient distance from one another to render them inaccessible to much of the population (Dr. Karen Henriksen, personal communication). Therefore, though DOTS may be providing complete coverage according to WHO standards, in actuality these statistics do not take into account the differing abilities to access health services in various contexts. Though distances between clinics in one area can be covered easily by car, in settings like Rio da Huila, these distances may pose significant issues in accessing these services.

Barriers to Control Programming

The domain of global public health has largely been in the hands of the World Health Organization, but Gandy (2003) points to significant changes in the economy of biomedicine that limit the availability of public health measures. It is suggested that in

the last thirty years, advances in biomedicine have led to a shift away from collective forms of health care to health as one dimension of personal development:

The historical synergy between health reform and social justice has been displaced by an increasing emphasis on the individual patient (or consumer) rather than the wider social and political context of disease (Gandy 2003:22).

Because of this restructuring of health-care-for-profit, technological or pharmaceutical advances are not available to those most affected by poverty (Gandy 2003).

Equally unfortunate for those suffering from TB in Africa is the underfunding of TB control worldwide compared with other infectious diseases. For each patient death, for example, \$8 US of external aid was spent on TB, compared with \$137 for malaria, \$925 for AIDS, and over \$38000 for leprosy (Gandy 2003). Pharmaceuticals to treat TB were developed as early as the 1940s and remain highly effective, but the completion of a course of treatment is lengthy and defaulting is frequent. In 1998, the WHO attempted to persuade pharmaceutical companies to collaborate over the development of a combined drug for TB which would make public health campaigns simpler and more cost effective. This failed, however, because the potential profit margins were too low (Gandy 2003).

Such obstacles therefore meant that a seemingly thorough strategy of disease control as developed by the WHO was not as effective as anticipated, despite the fact that since the 1960s, national control measures sponsored by the WHO revolved around long-term strategies of improvement of socioeconomic conditions, increased case-finding and treatment, and use of the bacille Calmette-Guerin (BCG) vaccine (Chauhan et al. 2005; Vecchiato 1997). In fact, it was found that DOTS programmes were only reaching 45%

of infectious tuberculosis patients globally, and "success" of the strategy in Africa was well below WHO targets (Chauhan et al. 2005).

Lewontin and Levins (2003) suggest that this "non-success" is due, in part, to larger global development practices, and the fallacy of the expectation that "development" would lead to worldwide prosperity and major increases in resources applied to health improvement. In looking at more epidemiologically-oriented literature, there has been widespread recognition of so-called barriers to effective tuberculosis control programming, which, depending on one's professional bias, places the responsibility of constructing these barriers on a multitude of complex variables.

Most of the academic literature on the "problem" of tuberculosis in sub-Saharan Africa comes from the disciplines of epidemiology or public health, while an extensive amount of literature also exists on program development and management for control of tuberculosis, courtesy of the World Health Organization and World Bank (see, for example, Dye et al. 2006; Chauhan et al. 2005; Turshen 1998). It has been reasoned that if better chemotherapeutic agents were available that eliminated the need for short-course therapy and combated the threat of multi-drug resistance, issues of access and patient (non) adherence, in this system, the most troublesome barriers to effective programming would be eradicated (Dye et al. 2006; Pratt et al. 2005; Liefooghe et al. 1997).

The barriers often cited in epidemiological and public health literature highlight the key attitudes and practices of a particular ethnomedical knowledge base, including certain unhelpful assumptions regarding patients and African people in general (Schoepf 1998). When examined in totality, the multiple barriers identified through different levels and perspectives of study move into tighter and tighter spheres of identification from the

more general (like access and poverty) to more specific (patient adherence or consultation with traditional healers). Within the biomedical belief system, attempts are made to rationally assess why the implementation of a seemingly coherent control program is not functioning, most often focused at the "patient" level. Poverty and other socioeconomic factors function on a larger access level, while practitioners of such a model enter into a patient-clinician relationship with "cultural baggage" and assumptions about education levels of their patients and mistrust about patient "compliance."

Studies on patient adherence to tuberculosis treatment in North America seem to take into consideration a multiplicity of factors related to an individual's "health belief model" (Rubel and Garro, 1992) and their choices around "compliance," or to what degree they follow the instructions and recommendations of their physician. These factors include possible anxiety associated with taking medication, the perceived impact of side effects of these medications, health beliefs, the complexity of the treatment regimen, poor clinician-patient relationship, issues around control, or personal attempts to deal with the illness (Pratt et al. 2005). Pratt and colleagues (2005:179) suggest that adherence, the degree to which the treatment regimen is followed, is "therefore dynamic, changing and varying within the life of an individual patient according to circumstances at given points in time."

The women that were interviewed at Rio da Huila also exemplified such varying "adherence patterns," with the longest default period being one week. The dynamism of adherence to treatment which Pratt et al. (2005) discuss is echoed by Farmer (1997) in his study of TB beliefs in Haiti. After interviewing one hundred TB patients, it was found that many believed their TB to be caused by sorcery. Both medical anthropologists and

physicians predicted these patients to be the ones most likely to abandon therapy, as the etiology and treatment were seen to be incompatible. After following these patients for 18 months after diagnosis, it was found that etiological beliefs were not a predictor of "compliance" with chemotherapy. Therefore, though one's "health belief model" may relate disease etiology models with compliance to treatment, the example provided by Farmer (1997) shows the dynamism of this relationship, that it is continually subject to negotiation within the treatment setting.

The Clinical Encounter

The choices around where to go for treatment are as subject to negotiation as choices of compliance or adherence to treatment. Because the most cost-effective strategy for the detection of TB cases is based on early passive case-finding (meaning voluntary presentation to TB care facilities), diagnosis requires early symptom recognition and appropriate actions to seek medical treatment soon after (Long et al. 1999). In most cases, however, the time between symptom development and "appropriate action" is lengthy, evidenced by the woman interviewed at Rio da Huila. Diagnosis of TB requires the recovery of the *M. tuberculosis* organism from the body in secretions, body fluids, or tissues, and assessment of their presence through staining and microscopic examination, an easy and low cost technique with a "reasonable diagnostic yield" (Garay 2004:359). At Rio da Huila, patients with suspected TB who arrive at the clinic are initially seen by a nurse. Doctors would see patients with drug reactions or complications (often cardiac), and all extrapulmonary cases (Dr. Karen Henriksen,

personal communication). All those interviewed were seen by a nurse, identified by most of the women by name.

For all but one woman, the treatment journey to Rio da Huila was a lengthy one. This exceptional woman had the benefit of neighbours who were knowledgeable about tuberculosis and staff members, so she came to Rio da Huila. Other women, however, all used the services of various other medical clinics, some after treating themselves at home. It seems evident from the interviews that, though fairly straight forward, misdiagnosis or incorrect treatment of TB is quite a common occurrence in the clinics in the Lubango area. One woman stated she went to a particular hospital over fifteen times before she came to Rio da Huila and was given TB medications that were making her feel better. The possibility of narrative exaggeration aside, missing and mistreating TB, however often it occurs, is a significant danger for TB programming, and one not often discussed in public health literature. Other women went to hospitals in larger centres, or clinics in their home communities.

The experience of tuberculosis for the women interviewed was therefore significantly affected by their encounter with biomedicine, and through their "therapeutic journeys." Indeed, it would seem that tuberculosis does not exist for these women outside the biomedical encounter. In her study on leprosy in Brazil, Cassandra White (2005) found that at the time of (biomedical) diagnosis, patients will often have formulated ideas about their condition based on their personal experience of symptoms, "folk models" of health and illness, and conversations with family or friends, therefore producing socially-generated medical knowledge about their condition (Kamat 2008). White (2005) further asserts that it is important to recognize cognitive models of illness, but equally important

is the manner in which the clinic interaction shapes and transforms how patients conceptualize their illness.

The question which elicited the most discussion in relation to social knowledge of tuberculosis was regarding how tuberculosis information (what it was, how to treat it, precautions for contagion) was relayed by health care workers following diagnosis. All of the women responded with a list of proscriptions reflective of the biomedical interest in preventing behaviour that may lead to infection of others. Interestingly, when a few women were asked directly, "what did [this nurse] tell you tuberculosis is?" one woman responded, "they told me that I had TB, that I had a cough, which is TB." She then went on to list the things she was told not to do. The other women mentioned nothing about "what TB is," but only what the health care staff told them to do or not to do. The women did not refer to themselves as having TB, rather stating they were either told their cough was TB, or they relied on the health care staff to give them information.

In her study on Hansen's disease in Brazil, White (2005) found that once physicians articulated the disease process to patients in biomedical terms, the patient began to modify the components of his or her "personal explanatory model" to incorporate medical explanations. The list of proscriptions that were provided by the women interviewed when asked what information was given by the staff also reflects this pattern of incorporation, sometimes leading to somewhat surprising responses. For example, two women stated they were told to eat healthy food and not drink alcohol; what "healthy food" was, specifically, was not mentioned. One woman stated she was told not to eat dried fish, a rather common food staple. Again, it was not understood by the respondents why this was the case.

While several women mentioned they were not supposed to eat with others or share utensils like cups or spoons, one woman said that she was told she could eat with her family. The incongruence of responses also reflects social knowledge production. According to biological principles, TB is not spread through shared use of utensils, which the staff at Rio da Huila, all knowledgeable in biological matters, would doubtless be explaining (Dr. Karen Henriksen, personal communication). Most women, in addition to stating the above information, said they were told to: cover their mouths when coughing/do not cough on others/if you have to spit on the ground, cover it up or use a cup so that you can dispose of the contents. Sometimes this was understood as necessary in order to avoid infecting others, but not consistently – the woman with extrapulmonary TB was not contagious (i.e. did not have pulmonary involvement), but still understood she was not supposed to cough on others, and cover her spit.

The modification of biomedical information was also exemplified in some cases at Rio da Huila where the responses provided to queries regarding information from health care providers were related to how the women formulated disease etiology. One woman mentioned several times that she was told by staff at the clinic not to "do anything," specifically meaning not to lift heavy things, to "work hard." She understood why they said this, she explained, because lifting heavy things and working hard was the cause of her cough. In this case, the biomedical encounter could have, through the recommendation to rest, provided a plausible cause of this woman's illness consistent with her own suspicions of etiology. Her perseverance on the prohibition on hard work could also have arisen out of her own belief that too much work had caused her to become sick at the outset.

In looking at representations of infectious diseases and their intersection with biomedicine, Nichter (2008:42) states that "even when health-education efforts are successful in helping people recognize that a vector or 'germs' are the cause of illness, pre-existing representations of causality are not necessarily replaced or superseded." Nichter (2008) found, for instance, that mosquitoes could be associated with causing malaria, but in ways that diverge from biomedical thinking – mosquitoes carrying spirits which cause infection, for instance.

At Rio da Huila, this was not consistent for all the women or within individual narratives: one woman explained she knew coughing and spitting on the ground could cause others to become sick in case someone should happen to step in it. The reason, it was stated, was that the spit was contagious. When asked if she meant contagious as in 'full of germs,' she said she did not really understand about germs, also explaining the cause of her illness as due to too much drinking. The complexity of her "explanatory model" as an indicator of correct behaviour does suggest that the biomedical encounter is a powerful producer and mediator of medical knowledge. How someone will understand and incorporate medical information into existing modes of knowledge is not predictable, but rather complex and dynamic.

Interestingly, in responding to questions regarding the information given about TB by the staff to the women, all responded not with a description of what the disease is, but with action; what do I do now that I have this disease. For this, the women seem to rely completely on the information given by the health care providers. All the women at one point in the interview responded to a question with, "I don't know... but they [the staff] tell me [this]..." Many interviews also included statements like "The doctor (meaning

doctors from various clinics) told me to (not eat this/go to another doctor/stop doing this), so I did." Invariably, when asked if they understood why the doctor/nurse told them to act that way, they did not know why. The following is part of an early interview, and exemplifies the reliance on information from health care workers:

I: And what did the nurses tell you about tuberculosis... about what causes it?

P: The nurses told me to eat... to eat healthy food, to not drink alcohol.

I: So some people think, for example, that TB is caused by spirits or witchcraft, and some people think it's caused by germs. What do you think about that?

P: I don't know. I don't have any information about tuberculosis. I depend on the nurses for information, so when I had this disease I didn't know anything about it. I don't know what the cause is.

Another theme that emerged in the interviews involved the idea of a "solution."

Three of the women's treatment journeys, for instance, were expressed with the idea that these clinics had no "solution" for them:

There is a clinic in my village I went to. And then I went to a clinic in Lubango, and then nothing was being solved and then I came here.

At first I went to Chibia for help, but they said we have no solution. So then the doctor told me to go [to Rio da Huila].

I went to the hospital [in Lubango] right away. At first I went to Lubango to the [hospital], but... they didn't see any difference. And then I came [to Rio da Huila].

Later in the interview, when asked how the nurses explained TB to her, the woman said, "They said that this is a sickness and you don't have to worry because there is a solution, you're going to be okay." The frequent use of the term "solution" would suggest that instead of looking for a "cure" for a perceived disease, these women were looking for a solution to a problem that intersected numerous aspects of their experience, a problem which affected more than their physical being rather than "tuberculosis." The variety of,

or inconsistency in, responses provided for what the nurses "told them to do" (eat with separate utensils, stop drinking) also suggests that these actions are imperative to the health care providers in treating *tuberculosis*, but were not necessarily related to the "problem" the women perceived themselves to have.

Though the identification of what constitutes "the problem" differs, how staff members relate to and view the patients themselves also has a bearing on the biomedical encounter, how information is received and communicated, and what assumptions are made. Significant differences exist between the health care providers at the clinic and the women interviewed; the education levels of the staff members directly involved in tuberculosis care were appreciably higher than the interviewees, they had paying jobs and therefore financial security, and, of the three staff members most directly involved in the TB program, none were Mumuila. These differences, embedded within Angola's colonial history, ethnic relations, and demographic shifts due to recent warfare, would suggest that ethnic perceptions of staff by patients and patients by staff does indeed shape the nature of clinical interactions.

For the staff that were interviewed, there seemed to be a general frustration with the length of time it took for individuals with cough to come in to the clinic – a frustration shared by many medical practitioners involved in TB programming and public health initiatives in Africa (Montgomery et al. 2006). One nurse suggested that what needs to happen is more education, as people generally do not realize a persistent cough could be significant and require treatment. Frustration was also expressed at the lingering idea that tuberculosis is caused by witchcraft, inevitably leading to mis-treatment by a witch doctor. This route then only exacerbates the problem, causes other problems, or, at the

very least, not help at all and waste more time – all of which impact on the health care providers at Rio da Huila.

The significant number of defaults also was a point of frustration. When asked why they thought so many patients had lapses in their TB treatment regimen, one staff member remarked, in exasperated tones, that they say they forget to come to the clinic, or couldn't make it. With no phones and little contact information, the logistics of communicating the importance of continuing treatment for those deserters, or reminders to come to the clinic, become quite complicated. The frustration regarding defaulting behaviour was also evident when patients with large stretches of defaults on their medical charts resumed treatment. Though most of these encounters were observed in Lumuila (without a translator), the annoyance with the patients on the part of staff members was evident, leaving most of the patients without excuse and smiling apologetically at the floor.

The frustrations expressed by the staff are quite understandable. Tuberculosis control, diagnosis and treatment based on DOTS would be quite simple and 100% effective if all patients with TB followed the DOTS "rules." Interestingly, several studies place the responsibility of successful therapy on those supervising the care of the patient because of the public health considerations related to TB (Hopewell 2006), or negligent care (Squire et al. 2005; Buu et al. 2003). The fact that DOTS therapy requires unwavering devotion to treatment regimens and early voluntary case detection means there is no room for flexibility in adhering to treatment. The frustration on the part of staff members, the regulation of DOTS therapy in a standardized way, and the construction of TB from a medical perspective all influence how knowledge about the

disease is imparted to those being treated for TB (encountering biomedicine) at Rio da Huila. As Montgomery et al. (2006) point out, such interactions between patients and staff are not always positive.

As is evident in the interaction between patients and staff, the construction of tuberculosis, as is the case with Hansen's disease in Brazil (White 2005), is created in part by the medical encounter. This encounter is also premised to a certain degree on the tenets of biomedicine. In Lupton's (1994) paraphrase of Michel Foucault's arguments regarding the history of biomedicine, she suggests that the medical encounter is, in essence, surveillance. Patients must revel the secrets of their bodies, both through the giving of their medical history under a physician's questioning, and by allowing a physical examination. The patient gives up jurisdiction of his/her body as the doctor investigates, questions, and touches the exposed flesh of the patient; the body is an object for prodding, testing, examining (Lupton 1994).

Crawford (1985) further suggests that the hegemony of biomedical idioms and modes of thought (such as the view of the body) in Western contexts has rendered social and emotional aspects of health (as experienced bodily) inexpressible:

The experiential meaning and the cultural capacities that enable us to understand and confront the social and emotional dimensions of our health and illness experiences are diminished in the medical encounter and by the dissemination of medical modes of thought (Crawford 1985:65).

The idea of medical surveillance put forward by Foucault and the critique of Western medicine's focus on health as a project of self-discipline enacted on the body and separated from the social or emotional by Crawford, are both part of larger historically-situated systems of colonialism and development (Comaroff 1993). Arturo Escobar

(1995), for instance, offers that the same problematization of phenomena by "First World" experts functions within the processes of development and the creation of the "Third World." The need for resources for the capitalist-industrial system which fuelled the superpower status of the United States after the second World War required the creation of a "domain of expertise" to control and manage the resources of the rest of the world. Just as medicine as science was seen as objectively describing reality and therefore not influenced by social processes (Martin 1989; Hepburn 1988), development became an economic and market-driven enterprise that was based on objective scientific fact, ostensibly legitimating it because of its removal from cultural context (Escobar 1995). These are the processes which inform DOTS programming in Angola, and are entered into during the therapeutic relationship when women seek treatment at Rio da Huila.

In Africa, the history of European colonialism has created a situation of incredible medical pluralism, with Western medical and economic systems vying for control. As Lane and Rubenstein (1996:421) point out,

Just as the general area of development studies has evolved in a way that is consistent with the concerns of development professionals, so the development of international health programs takes place in an arena in which the concerns of the First World provide the major imperatives for action.

Though the WHO waited an unacceptably long time to address the alarming increase in TB in Africa (until it concerned the First World), the DOTS strategy is the only treatment plan for tuberculosis (Gandy 2003). This pharmaceutical regimen is effective in curing TB, but through its deployment, such a treatment strategy is subject to transformative engagement with various cultural contexts.

Therefore, far from achieving hegemony, biomedicine, placed in various contexts, is encountered in highly transformative ways. This engagement takes place in the biomedical encounter, where medical knowledge systems, illness semantics, and social actions are negotiated in complex ways (Nichter 2008). The notion of therapy management as outlined by Janzen (1978) is a helpful model in uncovering the nature of this negotiation. The process of making choices and decisions around when and from whom to seek therapy for a perceived illness occurs in society and in relation to others, providing the latitude to allow individuals to interpret their roles within this society, and manage their social relationships. As Janzen (1985:76) illustrates,

The therapeutic process is a series of actions occurring in a social context in which individuals (usually in groups or sets), living in ordered relationships or roles, make decisions about their own welfare, often in closely related sequences, on the basis of partially shared classifications and values (culture), social structures or roles (society), and protagonists' assessments of the effectiveness of the therapy.

One woman, in describing how it "felt" to have TB, described the following:

I noticed a difference [in how she felt] because before I started to come here and when I went to [another] hospital. I tried everything, but nothing was working. There was no solution. My husband, my neighbours, said maybe I have this kind of disease that is really common in our community.

This woman's community represented her therapy management group, creating knowledge about tuberculosis (known, in this case, as "this disease that is common in our community") and how to treat it. Further, because so many members of her community regarded it as a common occurrence, she understood TB to be caused "naturally," not supernaturally. In particular, her sickness was caused "naturally" by excessive drinking. Then, after receiving treatment at Rio da Huila, she was told not to spit on the ground as it could cause others to become sick; her illness was thus also related to bacteria. She came

to understand, through myriad encounters, the nature of her sickness, what to do about it, and how it affected her social interactions, subsequently shaping her health belief model of TB.

The therapy management model is often focused on so-called "advocates" of the patient, including their neighbours, friends, and family. Indeed, Janzen (1985) suggests that in an African context, kin are the ones who make critical health-related decisions, with medical professionals/healers serving as informational resources. This is also true at Rio da Huila as is evident by the comments by the patients who suggest they do not know anything about TB, but rely on the nurses for information. "Therapy" for tuberculosis is not an isolated event – one check-up, or one prescription – but a lengthy therapeutic process that occurs over several months, as does the management of this therapy and the choices and decisions necessary. The women's therapy management groups therefore also included the staff at Rio da Huila, and how their cognitive models of sickness were transformed within the clinical encounter.

As Janzen (1985) further asserts, the idea of therapy management is both cognitive, involving the production of medical and therapeutic knowledge of tuberculosis, and social – the relationships and interactions in which this knowledge is created, or what Kamat (2008) terms 'socially produced knowledge.' Ellen Lazarus (1988) echoes the assertion that the social space in which the biomedical encounter takes place is highly transformative. She further highlights two major theoretical perspectives in the anthropological literature on the doctor-patient relationship, an interaction that has been consistently characterized as problematic.

One approach is looking at "explanatory models" to assess the reasons why these relationships are seen as problematic. These models cognitively examine what sickness and health mean to patients, and why people act in the ways they do. Doctors, through the negotiation of both their own explanatory models of sickness and health and that of their patients, can therefore eliminate problematic discrepancies and miscommunication in the interaction (Lazarus 1988). Lazarus suggests, however, that this approach tends to ignore how the doctor's explanatory model has been constructed, despite the same dynamism which characterizes the construction of their patient's models of illness. It further focuses on the health and illness beliefs of *individuals*, not on the interaction itself and its critical social engagements (White 2005).

Another approach is provided by critical medical anthropology, which incorporates the political and economic determinants of society into studies of health and medicine. This approach further highlights the role of societal power structures based on differential access to knowledge and technology (Lazarus 1988). The doctor-patient relationship is an extension of power relationships present in wider society; this relationship is therefore asymmetrical because of the possession of medical knowledge by the physician. Lazarus points out, however, that this approach, in focusing on the power dynamics within the relationship, ignores the role of human agency, that patients "take action" despite restrictions by systems of power.

To address the shortcomings of these two approaches, an examination of the social interactions between the doctor and patient needs to occur (Lazarus 1988). At Rio da Huila, this would include the social interactions between the health care staff and the patient as part of the process of therapy management. Socially-situating the biomedical

encounter rather than focusing exclusively on "explanatory models" or "health belief models" is perhaps even more pertinent at Rio da Huila or in an African context than in Western settings. Pearce (1993:160), in describing the construction of lay medical knowledge in Africa, suggests that for Africans,

Emotions such as fear, shame, anxiety, guilt, hope, trust, confidence, feelings of being in the right, and so forth are meshed with reasoning. These feelings affect the review of received tradition, the ordering of incoming information, and the assessment of possible lines of action by all persons. Both the afflicted person and significant others are affected.

Implicit in these comments is the importance of relationship, often not addressed in explanatory models. In one study, for instance, which addresses the reasons provided why biomedicine may *not* be chosen for therapeutic purposes, Christakis et al. (1994) suggest that poor and inadequate medical practice, "noncompliance" for a variety of reasons, distance/access, better availability to traditional healers, and patient's personal attributes (age, sex, education, residence, occupation) all influence decision making. Nowhere is it suggested that social relationships may equally influence these decisions, despite the acknowledgement that illness itself is socially situated, and significantly impacting the nature of one's relationships.

The choices and decisions women make in how and when to treat and from whom to receive treatment are all made within their social context, how their illness will affect their relationships, and their ability to relate to others in their communities. Most telling, perhaps, is the fact that all of the women interviewed came to be treated at Rio da Huila because they knew a staff member or other members of their therapy management groups were connected personally to the clinic. This is particularly significant considering that all government health clinics and hospitals were providing *free* services during 2008, an

election year. In this case, having a social connection with a staff member influenced the treatment plan to a considerable degree. The examination of the transformative power of the biomedical encounter in the women's experience of tuberculosis is therefore intimately and inextricably connected with their relationships, situated within the social fabric of their communities.

Chapter 6 - Women's Work: Politics, Ecology, and Economy

In a community such as this where the rules were, or are, based on needs of its members, everything will run pretty smoothly until foreign ideas and strange laws upset this equilibrium. Apparently their conduct is not haphazard. On the contrary, it is well calculated and the result of reason and purpose. Polygamy is not an immoral act, but an economic necessity. In the faraway bush country where there is hardly any contact with the white it will change only as the emancipation of the primitive woman takes place. She is the "beast of burden" and her lot is hard and her endurance taxed to the utmost. She is the one who tills the ground and toils on it from morning to night. The miserable return of a small mound of beans, manioc, maize, and sweet potatoes ground in poor soil must feed her, the children, and her husband from one season to the next. The man does not work, seldom hunts, and certainly does not put himself out to assure food for his wife and children. It is the woman's chore and her responsibility (Laszlo 1955:47).

Tuberculosis and Gender

There is no shortage of academic literature on the effects of tuberculosis on women. So much, in fact, that research on its effects (both biological and societal) on men is lacking: according to Allotey and Gyapong (2008), there are hardly any studies in health and gender research that do not focus on women. This overcompensation has arisen out of both a feminist critique of male-centric social science research, and attempts at redress for the biomedical knowledge base understood from a male anatomical paradigm which limits an understanding of the scope of physiological effects of TB on various bodies. The majority of these studies seek to demonstrate differences in experiences of women versus men in accessing health services, unequal distribution of resources, and inequalities in capacities, vulnerabilities, and power. They are, in essence, "advocacy studies, accounts of victimhood and vulnerability" (Alloytey and Gyapong 2008:833); the "women" in these studies are victims, vulnerable to a host of structural and biological factors which render them incapable of accessing services.

One recent study, for example, attempted to explain the cultural epidemiology of TB as it was related to gender (Weiss et al. 2008). In looking at tuberculosis patients in Bangladesh, India, and Malawi, the researchers were attempting to locate cross-cultural similarities in the experience of tuberculosis in order to improve treatment plans for DOTS services and thus reduce defaulting tendencies due to stigmatization. This particular study was undertaken to determine whether or not experiential differences existed between men and women, with their findings showing that, indeed, a difference in treatment trajectories existed between them. Women, for instance, present with "atypical" TB symptoms such as lack of blood in the sputum as compared with men. Further, though both male and female patients experience significant psychological and emotional distress associated with TB, its nature, according to the authors, is genderspecific (Weiss et al. 2008). More men, it seems, worry about the financial burden of TB, leading to psychological distress. The authors conclude by suggesting that:

Health systems benefit from classical sex-disaggregated epidemiological data complemented by cultural epidemiological study, which together clarify the role of gender and contribute to the knowledge base of TB control programmes at various levels (Weiss et al. 2008:845).

This study, however, highlights some problematic tendencies of gender and health research, the most problematic being the tendency to treat "women" as a homogenous category (Allotey and Gyapong 2008). The example by Weiss et al. (2008), in fact, treats the categories of "men" and "women" in three very different contexts (Bangladesh, India, and Malawi) as homogeneous groupings, without explanation on what basis these categorizations were made. It is assumed, therefore, that these are biologically-based ("natural") categories. Though identifying cross-cultural similarities/comparisons is often

used in anthropological studies, basing TB programming on supposed similarities (determined through surveys, a methodology poorly suited to uncovering social relationships or constructions) (Marshall and Rossman 1989) is unhelpful for DOTS treatment regimes. Seeking to make the DOTS program even more uniformly applicable does not account for contextual differences that exist. The major predicament with application of DOTS over the globe is its inflexibility – it is not tailored for specific situations, for specific people. Research which provides shallow evidence for crosscultural similarities between the manufactured and supposedly homogeneous categories of "men" and "women" only reproduces the Western gendered notion of two biological sexes in a context in which it may be incompatible.

Further, by focusing so extensively on the categories of 'women' and 'gender,' other societal or cultural divisions are disregarded, though such divisions may contribute equally to differential access to resources or the inability to complete treatment (Allotey and Gyapong 2008). Part of the problem is the frequent misuse of the term "gender" in much of the literature and a misunderstanding of the relationship between gender and social categorizations, as understood by those within the society or culture under investigation. As Weiss et al. (2008) explain, epidemiological data is often preferred when it has divisions of incidence and prevalence based on sex – male or female. Again, it is taken as "natural" to segregate the sexes into two biological categories, reifying the biomedical model in a context where it may not be congruent. As Allotey and Gyapong (2008:832) helpfully point out, "differences in health outcomes are not solely biological."

The conflation of epidemiological data based on "men" and "women" with the social construction of gender in literature such as Weiss et al. (2008) highlight becomes

confusing; it reiterates biomedical (physiological) categories of what constitutes a man and a woman and cannot account for the experience of tuberculosis encountering the social construction of gender. The categories of "men" and "women" then become equated with other "stigmatizing metadiscursive" practices of biomedicine, like labelling "target groups" or "cases," serving to maintain the hegemony of the biomedical system (Schoepf 1998). When looking at the nuances of the construction of gender, how does a woman act that makes her a woman? What are role expectations of women in a specific context? These are gender aspects that are not necessarily uncovered in "gender and health research," but nevertheless influence how women (as they are understood in whatever cultural context) experience disease, experience tuberculosis. For the women interviewed at Rio da Huila, for instance, the expectations of how they, as women, were to perform tasks and how to act in relation to others significantly shapes their experiences and worries about TB.

The approach of ethnographical fieldwork in medical anthropological research as it relates to women's health is also quite extensive. As Marcia Inhorn (2006:346) suggests, "a specifically ethnographic approach to women's health leads to a particular set of insights that are important, timely, and quite different from the women's health research agenda currently being promoted within biomedical and public health circles." Just as biomedicine cannot ascribe Western meaning onto a culturally contextualized understanding of gender, Inhorn (2006) observes that ethnographic methods document the fact that women around the globe do not define their health problems in the same ways that the biomedical community does.

Ethnographic literature has also highlighted the exertion of biomedical hegemony over the women of the world, to the point that it is now the default and most prestigious form of women's health care (Inhorn 2006). As numerous authors point out, however, biomedicine is seldom accepted without question or translated "whole," (Lock and Kaufert 1998; Hepburn 1985) and part of its translation to various cultural contexts includes its interaction with "structural" factors related to economics, the environment, and the political landscape as it encounters gender.

Women's Work

Also evident in the biomedical literature is the idea of women doing "health work," or the ways in which women work to produce healthy family members (Inhorn 2006). This idea of health work, of women's health work, was very evident in the interviews at Rio da Huila. Often, the subject of "women's work" came out through discussions about worry, and the hardships of remaining for long periods of time at the clinic while their families had to function without them. Also embedded in discussions about worry were larger themes of economics, ecology, and the political history of Angola. These themes all contributed to the ability of women to access care, determine whether or not they were sick, and construct an understanding of tuberculosis.

As is evident from the quote opening this chapter, Andreas Laszlo could not help remarking on the social system of the Humbe people (which include the Mumuila) in his travels to southern Angola in the 1950s. Commenting on practice of polygamy, he was apparently shocked to see it "work." Its success he attributed to women, who work daily to ensure the survival of their families. Though the author offers this opinion as proof of

the "backwardness" of the Angolan social system (men don't work!), and suggests later that if they only had proper agricultural techniques, such a system would be unnecessary, it nevertheless highlights the expectations of all that everyday "women's work" entails.

Environmental constraints make agriculture in the surrounding area a difficult process, and subject to devastating climatic changes. The area, as previously discussed, is semi-arid and best for raising cattle. Corn is the major crop, and the majority of agricultural work is done by hand; agricultural work, according to the interviews, often takes up the majority of a woman's day. The rainy season was at its beginning at the time the research took place in November and early December, and over the course of one month, it became noticeably greener as trees unfurled new leaves and grass began to grow again. This is the time for planting, when fields are tilled and families are waiting for adequate rainfall to begin.

Agriculturally speaking, 2008 proved to be a rather difficult year, however. In June, a killing frost destroyed many crops and fruit trees, thereby putting pressure on food reserves for those who relied on subsistence agriculture. Due to its geography, frost is not unknown on the high plateau, but its effects are usually quite devastating. During the research period in November and December 2008, the rains were beginning, but not in earnest – there was not enough rain yet to begin planting, adding more stress to an already nutritionally stressed population who could not begin to grow their food. Particularly affected were those women who, knowing it was time to begin agricultural work, had to remain at the clinic to receive treatment for tuberculosis.



Figure 4: Millet crop during dry season. Photograph by Rebecca Plett, 2007.

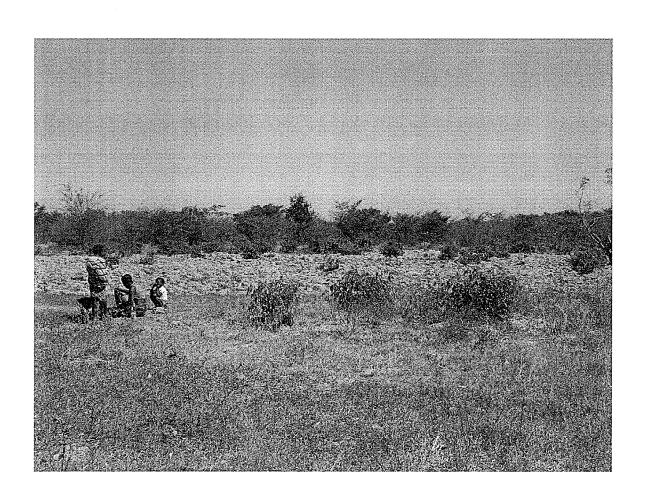


Figure 5: Mumuila girls with tilled field in the background. Photograph by Rebecca Plett, 2007.

Agricultural work was necessary to sustain those whom the women are responsible for, most often their families. All of the women interviewed were responsible for their children, and sometimes grandchildren. Some women had small children at home, parents or in-laws, other middle-aged women were accompanied to the clinic by their older children, or had older children (and their families) at home. But as is evident from the interviews and in conversations with other Angolan women, whatever the household structure, the everyday tasks of caring for a family are numerous. When asked the question "what do you do on a daily basis to care for your family," most women explained how they had to work in the fields to get food, or supplement their income in order to buy food. They wash clothes, prepare and process food, and if their children attend school, find money to pay for supplies and books.

Women on staff at the clinic also shared their narratives regarding the tasks of everyday life. One woman in particular offered her perspective on the "plight of the modern Angolan woman" one morning by sharing her own story. She was a fairly recent nursing graduate in her early 20s, had a six month old baby (her first), and her husband was a teacher. They lived in Lubango, and she commuted to the clinic for her shifts which included some 24 hour overnight stays at the clinic. Education for Angolans does not come cheaply, and the completion of a nursing degree takes some investment by one's family. Then there was the care of the household, tasks that usually fall under a woman's role in Angola. This particular woman had a rather unusual arrangement, one in which her husband was as likely to cook and care for their baby as she was. They were, after all, both employed full-time. In her conversation, however, she recognized the exceptionality of this arrangement, explaining both the grief they got from both his and

her family ("how can you let him cook?"), and how her husband stood in contrast to other Angolan men. After commenting on how Angolan women do so much physical labour, I inquired what Angolan men do. The response: "nothing," an observation remarkably similar to that made by Andreas Laszlo in 1955.

Other staff members at the clinic shared their stories as well. One woman had five children at home, and carried her three month old baby on her back for the majority of her day ("maternity leave" is a little shorter than in North America). Her position was full time, and she also went to school (paying for books and supplies) along with her schoolaged children. The school "semester" was ending during the time the research was taking place, so there was a two-week exam period for which many staff members that were going to school had to study. Women were also responsible for shopping for food and clothing, washing their family's clothing, and preparing food. I was assured that they did, in fact, sleep.

The lives of these women, particularly the nurse – an educated, financially secure urbanite – stood in contrast to the women interviewed, who were uneducated rural agriculturalists. This nonetheless highlighted some of the difficulties women face in navigating the modernization of a country with nearly 500 years of war. The patients that were interviewed, differing in socio-economic position, created divergent narratives of everyday work but were nevertheless under tremendous pressure to provide care to their families. Interviews generally began with inquiries about the household, who the women live with, and who they are "responsible" for. Most frequently, the women's households were made up of several generations, sometimes adult children and their spouses,

sometimes small children. Two women were widows, and seemed to function as the "heads" of the household. One woman lived with her husband and their nine children.

Household questions were usually followed by inquiries regarding the nature of their "responsibility," and then with questions of who is taking care of the tasks while these women are staying at the clinic for treatment. Those with older children felt confident that their responsibilities would be taken over. One woman, for instance, explained that "normally I do all the work, but when I'm here, my daughters do my work." When asked if this caused her to worry, she laughed, stating she does not worry because she trusts them – and maybe when she returns, her daughters will do everything and she can rest.

Other women were not so reassured that their children were being taken care of adequately, or that their children could do the work to sustain themselves. Some had husbands that worked to provide financial resources to care for everyone. One woman expressed concern for her children at home by explaining how, since her own mother was dead, the only person left to care for the children was her husband through his financial support. A family member was also sick at home, which increased her anxiety: "I'm worried because I'm here [at Rio da Huila] and I do not know how they are being fed. I'm here. I'm worried." Another woman had to decide whether or not she would remain at the clinic for her treatment or return home; it was very expensive to take a taxi during a lean financial time, but there was no one at home to care for her small children.

Another woman who was just a few weeks into treatment (and was feeling only marginally improved) presented a much more despairing tone in her interview. She was worried about the delay in rain and the pressure of having to buy food with little money

until it was time to harvest the corn. At the time of the interview, it was difficult to find enough food to feed her nine children, and having to remain at the clinic thinking about her children was worrisome: "I miss my little son, and my other children. I think when I'm hungry, my kids are also hungry."

In addition to inquiring after the nature of such everyday tasks, the other questions which elicited information about care were those centred on seasonal work, and getting to the clinic. Some women were asked whether the season (dry or wet) impacted on their decision to seek treatment because of the different nature of agricultural work. In the dry season, harvesting and processing of the corn takes place, while the beginning of the rainy season (when the research took place) heralds the beginning of planting. Agriculturally speaking, the women did not suggest a huge difference in work load between the seasons; with the rains came intense planting, and during the dry season it was time to harvest. When the rains were delayed like in 2008, and food was short, it became a matter of being able to supplement the family's income in order to afford to buy staples like oil or dried fish.

In order to supplement their income, women would engage in various activities—
the majority being the resale of various and sundry items in nearby markets. One woman
would supplement her income by burning trees and selling the charcoal in bags at a local
market or at the side of the highway. Another woman would buy beer from the
manufacturer (in Lubango) and re-sell it; other women would work in other people's
fields and thus generate income that way, and yet another helped people at the market
carry their purchases to earn extra money. Though these are common means for women

to procure funds, they are time consuming and do not generate that much income. For women afflicted with tuberculosis, these tasks become even more onerous.

Illness Construction, Ecology, and Economics

The narratives of these women would suggest that the experience of disease is tied to ecology and the environment in ways that extend beyond its relationship to microbiology. McElroy and Townsend (1989) importantly suggest that the environment is associated directly with the relative health of a population, and that the distribution of disease across geographic space and over time is also related to a population's role in its ecosystem. For the Mumuila, this would mean their nutrient-poor diet is constrained by the ability to grow nutritious food, leading to an increased susceptibility to disease.

Though this is perhaps true, and the exhortations by staff members for the TB patients to "eat healthy" reflects the importance of nutrition to TB treatment and "health" in a biological sense, the relationship between TB and ecology and subsequently economy is much more intricate and complex. An ecological approach to understanding a disease like TB therefore also must recognize the social component of human/disease/ecological interactions that influence both the treatment of an illness like tuberculosis and create structural barriers to accessing treatment.

For some women, the environment also contributes to the conception of what tuberculosis is. While the seasons dictate women's work schedules of planting and harvesting, times of bounty and times of famine, some patients recognize a congruence between seasonal changes and the tubercular cough. One woman, who explained the high incidence rate of TB in her community, described the cause of the disease as "natural,"

precisely due to the high incidence. Members of her community refer to this disease as "Ngolowilo," which, she explained, specifically referred the tubercular cough. None of the other women interviewed knew this word in relation to any illness, and the woman who called tuberculosis "Ngolowilo" knew nothing about it beyond its name. A Mumuila staff member later explained that "Ngolowilo" translated as "cloud cough," referring to the observation that most people get this sickness when the clouds arrive at the beginning of the rainy season.

The metaphorical history of TB in Europe highlights myriad cultural values that become reflected in constructions of disease, like romanticism, capitalism, and increasing urbanism and industrialization. These metaphors then centre on bodily appearance; TB as "consumption," for instance. Though not particularly widespread, the construction of TB as Ngolowilo – the cloud cough – is significant in that it is tied to the seasonal changes of the environment which dictate the yearly work schedule of planting and harvest. It is therefore not surprising that when women describe their illness experiences in relation to how they knew they were sick or how their bodies felt, they often focused on the loss of strength, and the inability to walk long distances in addition to prolonged cough. Again, it would seem that cultural values (the agricultural cycle and the relationship with the environment) partly creates the construction of TB that was then understood in relation to the body, and in relationship to certain cultural values – those symptom sets which flag local health concerns (Nichter 2008). For the Mumuila women interviewed, TB was a problem when their bodies could not do women's work in the expected or necessary way.

Tuberculosis is therefore also a problem of economics. For women to sustain themselves and their families, the ability to work is critical both to provide food and to

generate income to pay for services. For all but two of the women interviewed (who lived within walking distance of the clinic), getting to the clinic meant paying for a taxi and also consultation fees at the clinic. When money and food is in short supply, accessing clinic services becomes a major consideration in treatment decisions (Pearce 1993). Further, because so many women had consulted other various clinics (up to fifteen, apparently), it is a wonder how these women made it to Rio da Huila at all.

The issue of access to health care services is common in public health research and anthropological literature, as it relates to reasons why individuals are not "compliant" with DOTS treatment regimens. It has been reasoned that if better chemotherapeutic agents were available that eliminated the need for lengthy therapy and combated the threat of multi-drug resistance, issues of access and patient (non) adherence, in this system the most troublesome barriers to effective programming, would be eradicated (Liefooghe et al. 1997; Pratt et al. 2005; Dye et al. 2006). Farmer (1997), in citing the anthropological literature on accessing care, states that the focus of most studies on noncompliance as an ideological problem stemming from cultural constructions of etiology ignores the practical aspects of access, that TB does happen to be a disease of poverty.

In the interviews at Rio da Huila, issues of the practicality of accessing medical services were overt. When asked, "how far away do you live from the clinic" and "how did you get here," all the women not within walking distance took taxis, and without prompt, added how much it was to take the taxi to Rio da Huila and back to their homes. It becomes quite hard to imagine how so much research, according to Farmer (1997), ignores the tremendous impact of something as simple as not being able to a) afford a taxi

to a clinic or b) not be able to walk to receive treatment because of TB. As Farmer (1997:353) explains,

Strenuous insistence on the causal role of culture or permissibility in explaining treatment failures runs the risk of conflating cultural (or psychological) difference with structural violence... throughout the world, those least likely to comply are those least able to comply. In theory, it would be necessary to ensure full and facile access to all persons before ascribing failure to complete treatment to patient-related shortcomings.

The idea of "structural violence"— those structures of a particular culture or society which work to prevent or limit access to health care services or adherence to therapy and work especially against those in more vulnerable positions (Pratt et al. 2005)— are seen to affect women to a greater degree than men, and thus gets placed under the rubric of "gender and health" studies. "Women" as a homogeneous category become the persons in "vulnerable positions" who are subject to the most violent results of poverty in some studies, and personally non-compliant in others (Montgomery et al. 2006).

The position of the vulnerable woman is, in part, created through the intersection of poverty and the stigmatization often resulting from a TB diagnosis. In a study from Pakistan, for instance, it was found that females (this time not referred to as women) experienced the detrimental effects of tuberculosis more so than men because they are affected to a greater degree economically; loss of the ability to work because of illness leads to divorce and broken engagements in women's relationships (Liefooghe et al. 2005). A recent study by Dodor et al. (2008) regarding TB stigma in Ghana further suggests that it is stigma, and specifically a fear of infection, that impacts on one's ability to access health care services, and health care behaviour through non-disclosure of symptoms. The issue, they suggest, is that you can see the effects of tuberculosis (the

"consumptive appearance") on a body, especially when one is infected with HIV as well. When someone therefore appears to have TB, a fear of infection causes avoidance of that individual.

The issue of stigma was addressed in the interviews with patients and staff members, sometimes expressed quite overtly, other times more indirectly. Part of the information patients relayed from what the staff had told them about TB related to the (potentially) perceived stigma of eating with others who are seen as sick. The fact that some women stated they had been told not to share utensils, others that they could eat and sleep with family members, and still others to cover their coughs and not spit on the ground suggests that the cause of "infection" or "contagion" is not understood in the biological sense (or does not matter). Stigmatization of those with tuberculosis may therefore not be related per se to a fear of infection as in the study from Ghana by Dodor et al. (2008). In fact, the presence of stigma was only acknowledged by nurses expressing frustration at those who delay in presenting their symptoms (a prolonged cough) because of perceived stigma.

In interviews, those that were asked directly if they found their families treated them differently with a diagnosis of TB all replied in the negative. Various comments included:

I do not need to separate myself because they are my family, they are my friends. I do not need to be separate.

I don't have a problem [with people treating me differently]. If other people think they should treat me differently, that's their problem.

Yet another woman suggested that her family does not treat her differently, and that when they eat, they all eat together. This concept of eating together was echoed by one woman who explained that the patients staying at the clinic (at Sanzala) for the duration of their treatment lived as a family; food was made together and shared.

This theme of eating together becomes a powerful image of the importance of relationships in overcoming stigma. Indeed, it was somewhat surprising to hear positive narratives of women talking about infection or contagion not interfering with familial relationships considering the prolific literature on the detrimental effects of stigma on TB patients. The explanation that family relationships are more important than perceived contagion speaks to the nature of family for the Mumuila women, echoed in the construction of a familial situation for those women staying at the clinic. It is a positive image, and one that bespeaks affirmative support networks for those undergoing treatment for TB. If health care staff are keen on "proper" education of tuberculosis infection, the prevalence of the idea of not being allowed to share utensils should be changed to one of positive interactions – yes, eating together is good.

It is these positive images provided by the women themselves, rather than the negative language of stigmatization, which would seem to challenge the prevailing theme in gender and health research that women are the vulnerable victims of structural violence and uncontrollable cultural forces which limit their ability to get better if they feel sick. The nurse whose husband assists her with housework was chided by her family: "you let your husband work in the kitchen?" the connotation being that women should not be allowing men to do "their" work, a source of identity formation. It is perhaps too easy to assume that women are "relegated" to doing household chores and caring for their families, thus becoming victimized and powerless. This, like the assumption that sex is

dualistic in all settings, unfairly suggests Western cultural constructions as uniformly applicable to all contexts.

Though it is unhelpful to view Angolan women as powerless victims, it does not diminish the difficulty of everyday life for these women. The structural violence which they encounter creates a framework on which decisions and choices are made – how to make money, where to get food, how to care for sick family members, when to seek treatment for a prolonged cough. For Angolan women, this framework is politically situated within the history of colonialism in Africa. Nearly five hundred years of Portuguese influence and thirty years of recent warfare have created a unique and often difficult social situation in which women must negotiate their actions and relationships.

Education is costly, and therefore not accessible to all. With education comes paid employment and financial security within a nation without a government social safety net after a decimating civil war. The infrastructure to care for Angolan citizens is simply not there. Access to health services if one becomes sick is therefore somewhat dependent upon whether a family can generate sufficient funds. The fact that many women who struggled to finance their treatment plan had to visit numerous clinics due to misdiagnosis or incorrect treatment is not helpful, particularly when the effectiveness of the DOTS program relies on early case detection.

Historically, the geographical layout of Angola (specifically southern Angola) influenced the spread of the Portuguese colonial enterprise, determined economic development, and the distribution of services. Considerations of the modern Angolan political landscape cannot be extricated from its geography and ecology. The Mumuila, who were (and are) considered "backwards" by Europeans and other Angolan ethnic

groups, maintain strong ties to an agricultural lifestyle while most of the country is going through an intense transition towards modernization. Due to the shifting political milieu, Mumuila women must engage with the dynamic nature of such a lifestyle, subject to ecological shifts, in their task of sustaining themselves and their families, and in so doing engage in the everyday tasks of living and performing women's work.

When encountering tuberculosis, a woman's ability to work is depleted. Her body, that which engages the political, economic, and ecological realms, becomes incapable of normal engagement. Inextricable from the wider structures of politics and environment and economy is a woman's body, one that is big and strong and able to perform the tasks necessary to relate to others as a woman. Gender, how a woman is understood to be in a physical sense as well as a social actor, is therefore also linked to these wider domains. If a woman becomes sick with tuberculosis, her ability or inability to "access" treatment encompasses numerous factors, from colonialism to the amount of rainfall one November. Indeed, all these factors intersect social relationships, and, as a result, "it is more important to understand women's responses in medical settings as reflecting their daily experiences as part of a domestic group, community, or society" (Lock and Kaufert (1998:19).

The embedding of illness experience within cultural or social interactions often stands in contrast to the biomedical model, which tends to focus on the individual's experience with disease. This idea of "the making social of disease" is highlighted by Soheir Morsy (1996) as increasingly necessary for medical anthropology as part of the approach of political economy. This approach further attempts to situate medical

anthropology within the context of the processes of development – evident within the narratives of the women interviewed.

Additionally, political-economic models assist in relating macro-scale political and economic forces to the biology of disease transmission and frequencies, highlighting how human cultural practices influence disease transmission, where "disease expresses a temporary maladjustment between human host and their environment" (Inhorn and Brown 1997:39). At Rio da Huila, relationships also exist between politics, economics, and ecology, but in ways divergent from the disease ecology perspective outlined by Inhorn and Brown (1997). Most importantly perhaps, is that the environment/ecology of the area not only affects the biology of the organisms which cause disease, but intersects culture itself, and the formation of identities within that cultural space.

As Adelson (2002) points out, for example, the Cree living around James Bay in Canada do not have an understanding of their own health apart from the health of the land on which they live and derive their Cree identity. Similarly, Mumuila women derive identity from their work which is dependent (in large part) on environmental conditions. Therefore, in addition to the model that suggests macro-scale political or economic changes influence cultural practices which influence disease frequencies or disease transmission, these macro-scale changes influence the cultural production of identity and social relationships. These processes highlight, as Morsy (1996) describes, the "making social of disease."

The examination of the macro-scale factors such as politics and economics which influence the experience of tuberculosis necessitates situating such analysis within processes of development (Morsy 1996). This becomes most evident by relating TB to

poverty. It seems that as often as women become powerless victims due to structural forces beyond their control, people living in poverty are subject to the same discursive tendencies (Escobar 1995). Farmer (1997:349) suggests, in fact, that anthropologists, in focusing to such a great extent on the "ideological" problems of non-compliance, ignore the practical aspects of access, that TB is a disease of poverty and that "the poor have no option but to be at risk for TB."

At Rio da Huila, however, it is hard to classify the women interviewed as "impoverished" and therefore at higher risk for TB, as the Mumuila are continuing the agricultural lifestyle they have lived for hundreds of years. The idea of "poverty" is an idea of development produced within the last fifty years, classifying these women as impoverished based Western economic standards. Though it is true that the women interviewed had to work extremely hard, were worried for their families, and could often not generate enough income to pay for their health care needs, the problem, it seems, is not that these women are living in poverty, but that we have come to view these women as being "impoverished" and therefore more susceptible to TB.

Chapter 7 – Conclusion

The elucidation of the construction of culturally-situated epistemologies necessitates the examination of the myriad settings, interactions, networks, and spheres of human existence in which such constructions take place. For medical anthropologists, this work focuses on the body – how it is imagined, manipulated, constructed, discussed, and otherwise culturally situated (Lindenbaum and Lock 1993). This research represents an attempt to explicate the experience of women whose bodies are afflicted with tuberculosis, requiring the situating of that body within those spheres of human existence which impact the clinical encounter and create knowledge about TB.

The narratives presented by the Mumuila women interviewed over the research period suggest that the disease phenomenon known as 'tuberculosis' does not exist outside the biomedical encounter. There is, however, a perceived problem that creates symptoms, felt bodily, that precipitates the decision to seek treatment at Rio da Huila. These symptoms create a sense of affliction, both impacting a woman's social identity and impacted by her gendered body. This affliction places her outside the ability to function "normally" in necessary social interactions and compromises her ability to provide for her survival. This affliction is only given a name – tuberculosis – at the time of diagnosis, during the clinical encounter.

That women do not come to the clinic "with tuberculosis" to be cured is not unique to the Mumuila. Ethel Nurge (1977:145) suggests that,

Diseases do not exist as categories which can be identified, named, and brought for treatment according to the classification... the individual does not grapple with a disease, but with a discomfort or malaise which he may

describe as being itchy, disturbing or painful. It is not measles or bronchitis or tuberculosis but an unhappiness and a dis-ease which the patient brings to specialists and which the curer or medical doctor defines for the patient.

This also accounts for the numerous treatment options many of the women engage in.

Their perceived "dis-ease" causes them to seek relief from a variety of sources, from self-medicating, drinking more or less alcohol, to visiting various clinics, all seemingly offering "no solution" for their problem.

The experience of tuberculosis within the individual makes it an embodied experience. Therefore, though the infection of the human body with *Mycobacterium tuberculosis* remains consistently expressed, because the body itself is culturally mediated, tuberculosis as an illness will be embodied differently through space and time and in various human contexts. This notion is situated within the idea of embodied personhood, the relationships of cultural beliefs and practices in connection with illness and health to the human body (Lock and Scheper-Hughes 1996). In the clinical encounter, biomedicine brings with it the historical spectre of tuberculosis, so significant within European medical thought since the Middle Ages. TB as "consumption" worked both on a metaphorical level (reflective of early capitalist notions of loss and gain) and as an existential bodily process. The "tubercular look" became something entirely culturally situated, the body with TB being ascribed with aesthetic value and imbued with meaning (Sontag 1979).

In Angola, though far apart in time and space from Romantic Europe, the idea of TB as "consumption" works in a similar manner, with the "tubercular look" being ascribed value based on aesthetics and cultural meaning. Women formerly "big and

strong" succumb to the consumptive and disabling effects of the tubercular bacillus, becoming thin and weak and unable to perform the tasks of everyday life they once could. They enter a phase of abnormality, in which their bodily states render them subject to a change in their relationships and identity. It is for this sense of abnormality, experienced in their bodies, that women seek treatment at Rio da Huila – not for tuberculosis.

The embodiment of tuberculosis and its disabling effects are also therefore gendered. A woman's sense of becoming sick is dependent on her increasing inability to perform the tasks that a woman should be able to perform. When she becomes too weak to walk, to do agricultural work, or generate income to sustain her family, she seeks treatment – a solution. A certain body type (one that is big and strong) has both aesthetic and practical value, and a big, strong woman possesses the potential for both marriage and survival. The body in sickness is thus also situated within the wider spheres of economics and the environment: the environment which determines in part the successes or failures of necessary agricultural endeavours, which a woman must undertake to ensure her family's survival.

The experience of tuberculosis is subsequently also connected with ecological and economic contexts. For Angolan women, the political history of their country also shapes the ecology and economy of their illness experience – particularly the emergence of biomedicine. The years of Portuguese colonial rule and the recent conflict changed Angola's ethnic landscape with urbanization and mass displacement. Lack of infrastructure and a social welfare system has meant lack of services, food shortages, and ineffectiveness of public health care measures, created through processes of globalization

and development (Pearce 2006), the same processes which have created the modern concept of poverty itself (Escobar 1995).

This research is also further situated within the clinic context. This context elucidates the nature of the interactions that occur regarding TB knowledge production within the clinic, but is also constrained by the specificity of the population being studied. An analysis of the "biomedical encounter," however, is as quintessential a factor in the creation of explanatory models of illness as economic or environmental constraints. Further, as Lazarus (1988) cogently argues, explanatory models do not explicate the nature of the transformative engagements that occur in the clinic setting. In these engagements, both the staff and patients bring with them knowledge of tuberculosis as disease or "dis-ease," out of which patients create new understandings on which further therapeutic decisions may be made.

The biomedical encounter also becomes incorporated into the patient's ideas of therapy management process. Nichter (2002:82) offers that this process involves "engagements" of illness-related works, all evident in the narratives of women at Rio da Huila:

These engagements include the marshalling of material resources, the management of emotions, the performative aspects of 'being sick' and relating to the afflicted, participation in the co-construction of illness narratives, and provision of a space where healing or the management of sickness takes place.

Therapy management, though it may involve a diagnosis, does not necessarily mean that the women are seeking therapy for tuberculosis, nor does this mean that the etiologies of illness of the staff and patients must correlate. As Csordas and Kleinman (1996) suggest, what counts as therapy first depends upon what is defined as a problem. Therefore, staff

members attempt to relieve patients of tuberculosis by utilizing DOTS, while the women were seeking a return to the "normalcy" of a healthy body. Those women who had to seek treatment from up to fifteen sources did not receive the "solution" to their perceived problem until they arrived at Rio da Huila. The women did not talk about how these clinics misdiagnosed their tuberculosis, but had no solution for them, suggesting again that "tuberculosis" is created in the medical encounter.

What is therefore evident throughout the narratives is that an understanding of women's experiences with tuberculosis necessitates an examination of both macro and micro scale phenomena which impact a woman's life. Csordas and Kleinman (1996:11) state in relation to their discussion of the therapeutic process: "just as the therapeutic process extends beyond specific events in the broader social world of the participants, so also the world is embedded in the therapeutic process." Indeed, woven within the narratives of the women interviewed were descriptions of interpersonal engagements with staff members, their families and neighbours, as well as expressions of worries about the weather or the inability to collect enough money for a taxi to the clinic.

These comments, situated within the broader social world, were also informed by global scale TB programming and the history of colonialism and conflict within Angola. Tuberculosis is thus personal, experienced by individual bodies, while at the same time, as Roberts and Buikstra (2003) describe, immense. A woman's daily existence and the creation of her illness experience are influenced by these larger macro-scale forces, just as her everyday existence informs the process of illness control programming. As evident in the narratives of women experiencing TB in Angola as in Romantic Europe, tuberculosis

simultaneously encompasses the individual body, the social body, and the body politic (Lock and Scheper-Hughes 1996).

Sickness, or more specifically, being afflicted with TB is therefore both recognition of the physicality of sickness and situating that "feeling" within a larger "condition" needing treatment (Hepburn 1986). The integration of treatment into the wider sociocultural system is not the strength of biomedicine which perceives disease "as a specific entity independent of the patients' social circumstances and personal characteristics" (Hepburn 1986:61). DOTS programming has not been as successful as anticipated in part because treatment is not integrated within these cultural systems, with research attempting to address perceived cultural gulfs and how to effectively bridge them.

The narratives of the women at Rio da Huila, however, are suggestive of a different paradigm of effective treatment. Though this "clinical population" provides very specific information within a particular context, as Nichter (2008) points out, such research illuminates how people in various settings and circumstances solve problems, generating, in the process, new ways to think about similar problems in other contexts. If examined from the public health perspective, it is problematic that the women interviewed do not view themselves to have TB, as it suggests a failure in educational efforts; the women did not correctly identify the biomedically important symptoms and associate them with tuberculosis. This should not be seen as problematic, however. The anthropological literature (and this research included) suggests that biomedical encounters are transformative engagements, and that biomedicine rarely ever achieves hegemony in any cultural context. The strength of biomedicine is its ability to diagnose

symptoms, and in the case of tuberculosis, presents the only real possibility of its eradication (Pearce 1993).

That said, however, the women interviewed all came to be treated at Rio da Huila not because they correctly recognized the symptoms of TB, but because they had a social connection, a previous relationship with a staff member whom they sought treatment from regardless of their perceived disease etiologies, or how they may differ from the staff members who treat them. Therefore, while public health researchers, epidemiologists, and social scientists research reasons why TB continues to plague sub-Saharan Africa, here at Rio da Huila is a powerful example of how relationships — one's social networks — function to relieve these women's afflictions in ways that are both culturally appropriate to the Mumuila, and lead to curing TB.

Rasmussen (2000:252), in her study on Tuareg medicine, suggests that:

Kinship relationships and, more generally, close interpersonal relationships between the sick person and the healer are important in Tuareg healing. Friends and relatives often cure each other and are the preferred healers.

Similarly, in a study of patient's beliefs of TB in South Africa, Edginton et al. (2002) state that in some interviews, patients explain the difficulty in receiving treatment from a stranger for fear of being bewitched. The authors interpret these statements to mean the patients wish their support group to be comprised of a familiar network of people. The example provided by Rasmussen (2000) and narratives of the women at Rio da Huila would suggest, however, that the patients, rather than wanting merely their support group to be comprised of friends and relatives, desire to receive care from those with whom they have a relationship and therefore trust.

The initial Portuguese rendezvous with the Kongo of Angola was a positive and mutually beneficial relationship precisely because the Portuguese integrated themselves into pre-existing cultural systems: they merely added new networks to existing trade routes. In a similar way, at Rio da Huila biomedicine is most effective when women are able to utilize its strengths through relationships with its practitioners on their terms, through cultural networking systems familiar to the Mumuila. Community and relationships are important to the Mumuila and are reflected in their bodily experience of tuberculosis.

The importance of community within public health programming is becoming more prominent in the literature, especially when such movements arise out of the communities themselves, rather than as an imposition by health program planners (see, for example, Pratt et al. 2005; Maher et al. 2006). Health teams, notably the one at Rio da Huila, who participate in wider social networks and are part of the community are effective because health care providers become visible and relationships (and trust) are established. Recognition of the importance of culturally appropriate means of accessing treatment through social networks – regardless of what the perceived ailment is – is necessary as it both illuminates a particular way of solving the "problem" of tuberculosis, as well as generating new ways to think about the problems of effective TB control from a public health perspective in other contexts (Nichter 2008).

In his discussion of the concept of "health," Robert Crawford (1985:65) highlights the importance of the social and emotional experience:

Perceptions and beliefs about the physical experiences suggested by the word health are frequently vehicles for explaining social and emotional experience, just as social and emotional life provide explanations for the life of the body. Emotional and social well-being, in other words, find their confirmation in the body, and bodily states "make sense" in terms of social and emotional occurrences.

Just as tuberculosis became a representation of one's social status and identity in Romantic Europe, the Mumuila woman's affliction with tuberculosis, felt bodily, influences her social well-being and identity – that her bodily states make sense within her social world. Therefore, despite our knowledge of *Mycobacterium* and how to destroy it, the myriad spheres of a woman's life which are affected by and affect the construction of this illness, whether she perceives it to be *tuberculosis* or not, suggest that it is as immense as it was in Europe two hundred years ago.

Appendix A:

Interview Schedule - Patients

Before we begin the interview, I would like to stress that you (the participant) are not under any obligation to participate. Should you choose to participate, you do not have to answer any question you do not want to answer, and you are free to withdraw from the interview at any time. This interview should only take about an hour, and all responses will be kept confidential. I will not use your name in any written record. There should be no negative consequences to you, your family or friends, if you participate in this interview. If you feel any concern in this regard at any time afterwards, please contact me. Are you willing to proceed with the interview?

- 1. Do you have children? How many? Who all lives in your house? In your community? How many people are you responsible for/care for? How do you care for them/do on a daily basis to manage?
- 2. Where do you live? How far did you come to get to the clinic, and how? Was it difficult did it cost a lot of money? Who cares for your family if you're away?
- 3. What made you get help/how did you know you should see someone? How did you know something was wrong/what did it feel like? Did someone tell you to go?
- 4. Did you try other things before coming to the clinic/are there other options (e.g. "traditional healer")? How did you hear about Rio da Huila? Would you have come sooner/later if things had been different?

- 5. When did you get sick (rainy/cold/dry season, harvest/threshing/planting time)? Was it easier/harder to get to the clinic? Why?
- 6. How is your husband? Is he sick also? What does he think of your illness? Is this illness making a difference in your relationship with him?
- 7. Who did you see when you came to the clinic a nurse, a doctor? What did the staff of the clinic tell you about tuberculosis and about your tuberculosis? Did you understand them? What do you think tuberculosis is? Did you think it could have been something else?
- 8. Is it hard to stay on the program to keep taking your pills?
- 9. Did the clinic staff tell you/what advice did they give you about anything special you need to do at home/with your children/family now that you have TB? Will that be difficult for you to do? Why or why not?
- 10. Do you think that will make you feel better/are you feeling better? Are you worried about anything?
- 11. When will you be returning home? Are you looking forward to going home? What do you miss the most? What is the first thing you're going to do when you get home?

Appendix B:

Interview Schedule - Staff

Before we begin the interview, I would like to stress that you (the participant) are not under any obligation to participate. Should you choose to participate, you do not have to answer any question you do not want to answer, and you are free to withdraw from the interview at any time. This interview should only take about an hour, and all responses will be kept confidential. I will not use your name in any written record. There should be no negative consequences to you, your family or friends, if you participate in this interview. If you feel any concern in this regard at any time afterwards, please contact me. Are you willing to proceed with the interview?

- 1. How long have you been working at the clinic and in what capacity? What types of tuberculosis do you diagnose here (skeletal, pulmonary)?
- 2. How do you diagnose tuberculosis? How do women diagnosed with tuberculosis describe their symptoms? Do you rely mostly on how they say they are feeling or on diagnostic tests?
- 3. When a patient comes in, what is the procedure for who is diagnosed by a nurse and who gets to see a doctor? Why are some patients sent home right away and some keep coming back to take their pills?
- 4. A lot of people "default" on the program why do you think that is? Is there a difference between men and women?

- 5. Do many women come to the clinic alone, or do they bring their families? Are there more men that come alone? Do you think there are differences in how women deal with tuberculosis than men?
- 6. Do some women see "other" healers before they come to the clinic? Who accompanies them to the clinic? Who initiative/decision is it to go to the clinic or traditional healer? Is that usually helpful/unhelpful?
- 7. How do the families of women with tuberculosis see them/interact with them? Is there a difference between when the women are at the clinic or in their homes?
- 8. For women, what do you think the hardest part of living with tuberculosis is?

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