

**AN ANALYSIS OF THE CONTACT PATTERNS PERPETUATING
THE TRANSMISSION OF TUBERCULOSIS IN TWO HIGH
INCIDENCE COMMUNITIES IN THE CAPE TOWN
METROPOLITAN AREA.**

by

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Submitted in partial fulfilment of the requirements for the degree of
Master of Arts in the Department of Anthropology and Sociology,

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November 1997

ABSTRACT

Biomedicine positively maintains that tuberculosis transmission occurs due to close contact with a diseased individual (Coovadia and Benatar, 1991). Consequently, this refers to a direct mode of transmission where individuals are at direct risk of becoming infected.

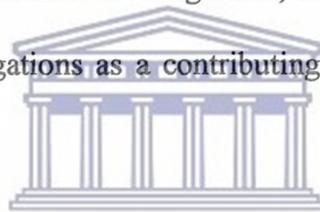
It is often taken for granted that when one speaks of contact within the context of tuberculosis, one is necessarily referring to contact or interactions among tuberculosis patients and people in the community with whom they have contact of any nature. It is then assumed that tuberculosis is transmitted in this manner. However, there are also indirect modes of transmission which are often neglected to be explored, but have an equally serious effect on transmission in high incidence areas. This paper also addresses other contact patterns that are also role-players in the tuberculosis epidemic.

This study explores the negative interaction that sometimes occurs between the biomedical paradigm and tuberculosis patients in the community, contributes to, or perpetuates the transmission of tuberculosis. Persons who sometimes do not complete their six-month treatment course of anti-tuberculosis drugs as a result of bad communication, once again become infectious (this being that they are again able

to transmit the disease to other individuals), being characterised as being non-compliant.

Therefore, non-compliance should as far as possible be prevented because it also contributes to the tuberculosis epidemic.

This study has also explored the contact patterns that occur within the clinics between biomedicine and patients. It found and found evidence indicating that these interactions have an effect on the aspect of non-compliance. This indicates that when undertaking tuberculosis contact investigations, the biomedical domain should also be included in these investigations as a contributing factor perpetuating tuberculosis in high incidence areas.



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Furthermore, by determining what the patients and community themselves perceive as close contact simultaneously indicates where transmission is occurring as certain types of contact occurs in specific places. In so doing, a working definition of contact has been provided that can be used by health care workers as part of a multidisciplinary team to enhance their idea of where and how to implement eradication control programs that are less invasive and intrusive to patients.

ABSTRAK

Bio-medici verklaar dat die oordrag van tuberkulose die gevolg is van noue kontak met 'n besmette individu (Coovadia en Benatar, 1991). Dus verwys dit na 'n direkte manier van oordrag waar individue wat aan 'n besmette persoon blootgestel word, die siekte kan opdoen.

Daar word algemeen aanvaar dat as daar gepraat word van “ kontak” in die tuberkulose-opset, dat daar noodwendig verwys word na enige kontak of interaksie tussen tuberkulose pasiënte en persone in die gemeenskap. Dit word dan aanvaar

dat tuberkulose op hierdie manier oorgedra word. Tog is daar ander faktore wat indirek die verspreiding van tuberkulose kan aanhelp, maar waaraan daar nog min aandag gegee is. In hierdie studie word gepoog om van die ander faktore uit te lig wat 'n rol kan speel in die tuberkulose-epidemie.

Hierdie studie het die interaksie patrone (kontak) wat in die klinieke tussen biomedici en pasiënte voor kom, studie en het bewyse gevind dat sommige negatiewe interaksies 'n effek het op die aspek van onvoltooide behandeling. Dit toon aan dat wanneer tuberkulose kontak-studies gedoen word in 'n gebied, die biomedici se

optrede ook ingesluit behoort te word as 'n moontlike bydraende oorsaak dat tuberkulose bly voortbestaan in daardie gebied.

Daar word gekyk na negatiewe optrede en interaksie wat soms tussen die biomediese paradigma en die tuberkulose pasiënt bestaan, wat 'n bydraende faktor kan wees waarom tuberkulose nie in 'n gemeenskap totaal uitgeroei word nie. Soms voltooi tuberkulose pasiënte nie hulle behandeling nie as gevolg van swak kommunikasie of -interaksie met die mediese personeel. Persone wat nie hul ses maandelikse anti-tuberkulose behandeling voltooi nie, raak weer geïnfekteerd. (Dit beteken dat hulle weer aansteeklik is vir ander individue). Hulle staan dan bekend as persone wat nie hulle behandeling voltooi ~~het nie en moontlike~~ verspreiders van die siekte. Nie-voltooide behandeling moet so ver as moontlik voorkom word, omdat dit 'n bydra lewer om die tuberkulose-epidemie te laat voort bestaan.



Verder, deur vas te stel wat die pasiënte en gemeenskap verstaan onder “noue kontak” word terselfdetyd vasgestel hoe en waar oordrag plaasvind, aangesien 'n sekere manier van kontak op spesifieke plekke voorkom. Deur hulle siening vas te stel, word 'n definisie vir “kontak” voorsien wat deur beide gesondheidswerker en die gemeenskap gebruik kan word om programme daar te stel wat minder inbreuk sal maak op pasiënte, maar die uitroei van tuberkulose kan bewerkstellig.

DECLARATION

I declare that: An analyses of the interaction patterns perpetuating the transmission of tuberculosis in two high incidence communities in the Cape Town Metropolitan area, is my own work and that the sources I have used or quoted have been indicated and acknowledged by means of complete references.



A handwritten signature in blue ink, appearing to read 'C. Classen'.

COLLETTE NATASHA CLASSEN
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DEDICATION

To all in Uitsig and Ravensmead who allowed me a glimpse of their lives.

Thank you for making me feel that I actually made a difference.



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ACKNOWLEDGMENTS

Without the help; both physically and emotionally, of the following people, this thesis would never even have been started or successfully reached completion.

Firstly, to all the people of Uitsig and Ravensmead who granted me a free passage into their communities and lives. By merely having remembered my name, you gave me the encouragement I needed to persevere, and so be able to tell your stories.

To all the volunteer workers who accompanied me on my initial visits to their communities, making me known to everyone so that I had a safe passage in and out of every nook and cranny of Uitsig and Ravensmead. Thank you so very much for everything.

To Glaxo Wellcome for financial support.

To Dr. James Ellis, better known as “Uncle Jimmy”. Besides being a completely understanding and non-pressurising and extremely helpful supervisor, thank you for having given me the opportunity to become part of the Action TB Research Team.

To Dr. Nulda Beyers - “the Aunty”, your kind nature, keen interest in, and absolute determination to help those less fortunate than yourself, was my unquestionable inspiration throughout my fieldwork and the writing of this thesis. Thank you for having faith in me as a researcher and making me feel that had indeed contributed to the fight against tuberculosis.

To Meldrick. Even though you were busy with your own final examination, you always found the time to mirror my ideas so that I could put my thoughts into perspective. Thank you so much for remaining by my side and helping me keep my sanity at the risk of almost having lost your own. Your love, dedication and constant encouragement gave me the strength to carry through to the end.



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To my parents. Thank you for leaving me completely to my own devices through the entire process of completing my research. It must have been terribly hard to ignore my mood swings and the acting out of my frustrations, while continuing to support, encourage and most importantly, believe in me. Thank you also for unselfishly allowing me to often carry your grocery cupboards to my respondents and run up the electricity bill as I sat through many nights working with the computer you bought especially for the convenience of writing my thesis, thank you mommy and daddy.

To my sisters, Bronwyn and Lanna. Bronwyn, thank you for cheerfully bearing with a moody, sometimes nasty and often unreasonable big sister when you had much greater troubles of your own. And Lanna, who was always at my every beck-and-call without a single sigh of discontent. Thank you for the back rubs and hugs of “I love you” when I returned from a long day of fieldwork. Knowing I could count on the two of you for anything, made my agonising task so much easier.

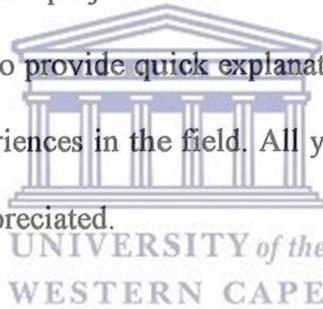
To Diana. Although you were not directly involved in the writing of this thesis, you were nevertheless directly involved in moulding me into a medical anthropologist. I will always be indebted to you for giving me a taste of what fieldwork was all about. Had it not been for your dedication and mentorship as a lecturer, I would not even have gone through with the honours course - Who would have guessed I would be writing a masters thesis, and planning for a Ph.D. too? Thank you for having believed in my abilities and refusing to take “no!” for an answer.

Dr. Gie. Thank you for just being yourself and so taunting me into being a feminist. You reminded me of what I always knew: women rule the world! In

essence, you actually taunted me into always wanting and trying to do the best I can, and be the best I can be.

Mrs. van der Merwe. Thank you for being a much needed shoulder to cry on when things were not going too well. You really were my rainbow at the foot of every cloud. Thank you also for all the constant translations with which you so generously aided me.

To the “ Mildred” Sisters - Danita, Priscilla, Helen and Susan. Working with you all on this project was most interesting. Thank you so much for your willingness to provide quick explanations of medical jargon and share in your patient experiences in the field. All your contributions were a great help and was much appreciated.



To all of you.... THANK YOU

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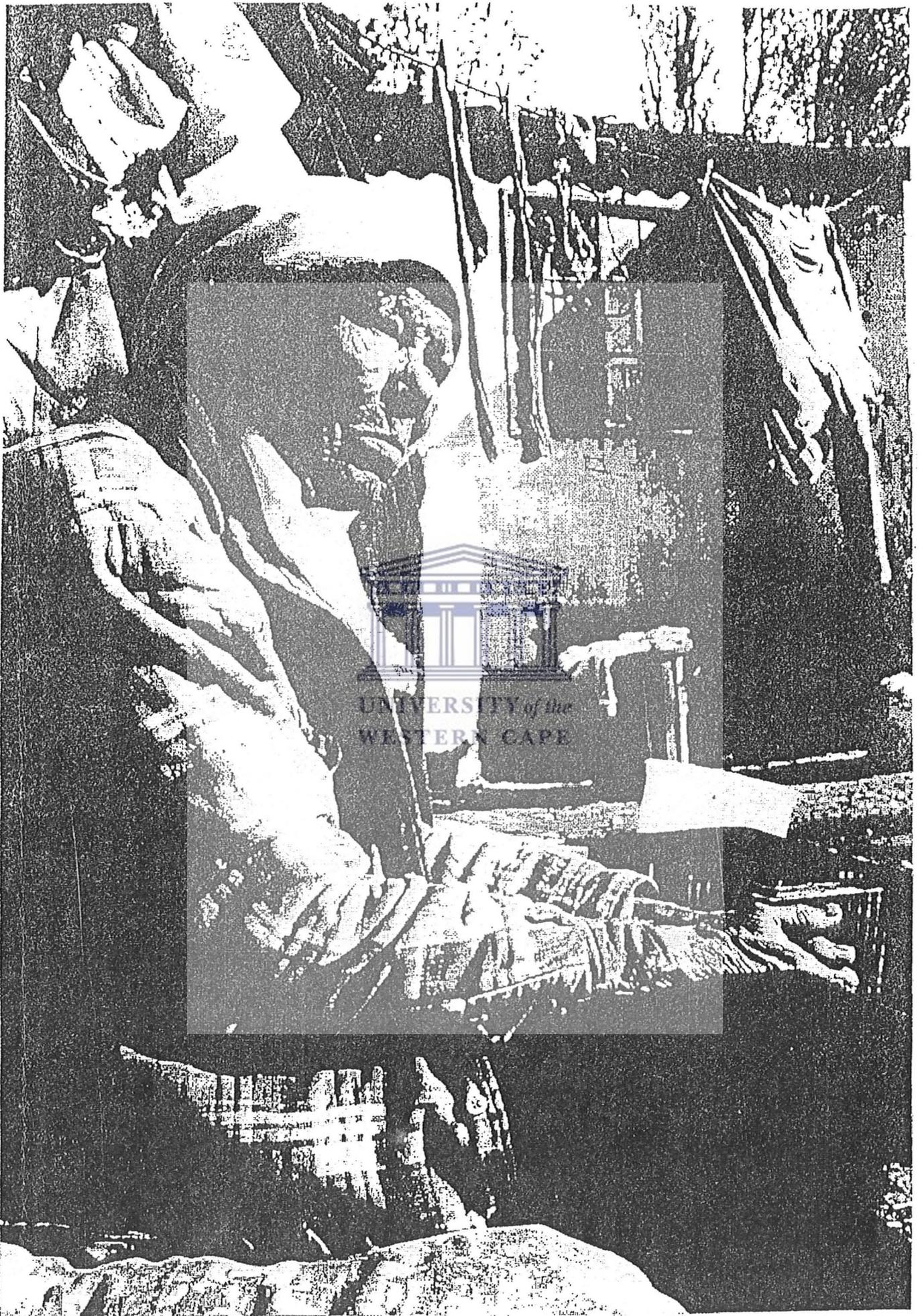
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AN ANALYSIS OF THE CONTACT PATTERNS PERPETUATING THE TRANSMISSION OF TUBERCULOSIS IN TWO HIGH INCIDENCE COMMUNITIES IN THE CAPE TOWN METROPOLITAN AREA.

**CHAPTER 1
INTRODUCTION**

1.1 BACKGROUND

Already during 300 BC. Aristotle hypothesised that tuberculosis was transmitted due to certain substances found in an infected persons' breath (Medical Students Conference, 1982). Transmission was thus accepted to be airborne. Today, we are sure that this "certain" substance that causes tuberculosis, is the tubercle bacillus, *Mycobacterium tuberculosis* which Robert Kock discovered only in 1882 (Bass et al, 1990). *Mycobacterium tuberculosis* is an intracellular facultative parasite whose growth depends on favourable host conditions such as alcohol and drug abuse, malnutrition, and other factors associated with poor socio-economic conditions (Youmans, 1979), and is transmitted by diseased individuals during coughing or sneezing (Bass et al, 1990). Logically then, identification and consequent eradication of these favourable host conditions would denote considerable preventative treatment for tuberculosis disease. However, judged by the high incidence rates of tuberculosis throughout the world, there seems to be a gap in existing knowledge of the transmission of tuberculosis and the favourable host conditions in which it is being perpetuated. This is derived from the fact that all patients treated with anti-tuberculosis drugs are able to recover completely from the disease if they continue treatment uninterruptedly for six months (Reichman, 1997), yet we continue to have such high incidence rates throughout the world.

1.2 INCIDENCE OF TUBERCULOSIS WORLD-WIDE

The seriousness of the tuberculosis situation may be understood better by an explication of incidence figures throughout the world as listed below:

1.2.1 The World Situation ✓

According to estimates from the World Health Organisation (WHO), approximately 7 537 000 new cases of tuberculosis have occurred in 1990. This number is expected to increase globally to 10, 2 million new cases by the start of the 21st century (Dolin et al, 1994).

As estimated by Dolin, et al (1994), 2,9 million deaths occurred from tuberculosis in 1990. Except for 40 000, all these deaths occurred in developing countries. Tuberculosis is considered to be the largest cause of death from a single pathogen (Snider, in Porter and McAdam, 1994).

The harrowing news though, is that during the current decade, approximately 30 million people will die from tuberculosis at the present level of intervention (Dolin et al, 1994). Even more alarming is that Dolin, et al (1994) purports that these figures are based on notification data, and because of under reporting of tuberculosis cases, the incidence and mortality rate could be much higher.

Furthermore, in view of the fact that tuberculosis is the major cause of death throughout the world¹, we have to really think and act seriously and swiftly on tuberculosis eradication strategies, starting at grassroots level in home communities such as Uitsig and Ravensmead.

1.2.2 Tuberculosis in Africa ✓

With 272 new cases of tuberculosis per 100 000 population per year, Africa has the highest incidence of tuberculosis in the world. (Beyers et al, 1996). As noted by Snider (in Porter and Mc Adam, 1994), in 1990 there was an estimated tuberculosis case rate of 229 per 100 000 in Sub Saharan Africa, and in the WHO's African Region, Kochi (1991) estimated a case rate of 272 cases per 100 000 population.



1.2.3 Tuberculosis in South Africa

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In 1993 the overall incidence of tuberculosis in South Africa was 366 new cases per year per 100 000 population (Thierry et al, 1980).

In 1996, the Department of Health estimated that nearly one out of every twelve South Africans would become diseased with tuberculosis. The present death rate resulting from tuberculosis each year is approximately 10 000, implying that without immediate eradication plans, by the year 2005 a minimum of 90 000

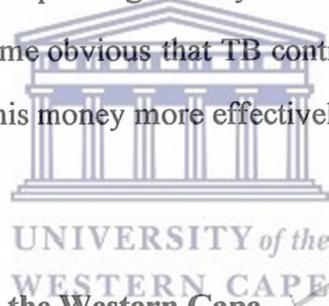
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Centres for Disease Control (1993).

people will die from tuberculosis with 3,5 million becoming diseased (Singer, 1996).

The alarming news though is that almost two thirds of the country's population is affected with the bacillus. Due to this, 160 000 people in South Africa become diseased with tuberculosis yearly. And in view of this alarming figures of tuberculosis disease and deaths in South Africa, we are faced with the cruel reality of tuberculosis in South Africa that:

“Unless treatment programmes are improved now, the number of annual TB cases in South Africa will quadruple over the next 10 years. Since this country has been spending a hefty 500 million rand on TB control every year, it has become obvious that TB control activities need to be refocused in order to use this money more effectively.” Fourie and Weyer (1996).



1.2.4 Tuberculosis in the Western Cape

In 1996 the estimated cases of tuberculosis was 559 per 100 000 population. Here, more than 20 000 people become diseased with tuberculosis (Singer, 1996). Due to this alarming incidence, the M.E.C. for Health in the Western Cape, Mr. Ebrahim Rasool declared tuberculosis an emergency. This emergency was declared at a tuberculosis summit where more than 80 people from various health organisations gathered to discuss the improvement of present control programmes. It was decided at the meeting that Guguletu, Paarl, Ravensmead and The Hex River Valley be demonstration areas for the implementation of the Directly Observed Therapy shortcourse (DOTs) programme. An amount of R2 million was

allocated to tuberculosis eradication programmes; the implementation of the DOTs programme and the training of tuberculosis care-givers.

1.2.5 Uitsig and Ravensmead

In Uitsig and Ravensmead, where this study was undertaken, the incidence of Mtb is more than 1 000/100 000 within a surface area of 2,42 km² and a population of 34 294 (Beyers et al, 1996). Within the past ten years, of the 5345 dwelling units in both communities, 1 835 had experienced at least 1 case of tuberculosis (Beyers et al, 1996).

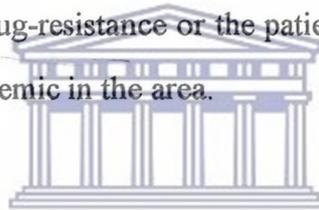
1.3 SCOPE OF THE STUDY

The harrowing statistics of the tuberculosis epidemic in the world, let alone so near to home, is clearly indicative of the inadequacies of medicine alone to the tuberculosis epidemic throughout the world. My study aims through the ensuing chapters to bring into greater perspective the need for further social scientific research on tuberculosis, and the complementary nature thereof to the biomedical sciences.

The importance of social science for medicine has been illustrated by this study by having identified contact patterns that are possibly perpetuating the tuberculosis in Uitsig and Ravensmead. These contact patterns are manifested at two levels viz. community contact and biomedical contact.

The study approaches the transmission of tuberculosis within poor socio-economic conditions from the point of view that it is not this conditions per se that drive the epidemic. However, it contends that it is the social contact relations and interactions that are perpetuated in the midst of such appalling living conditions

that may in fact be a major driving force in the transmission of tuberculosis in Uitsig and Ravensmead. Within these poor socio-economic conditions, contact patterns that have been established are those among community members and patients. These contact patterns have been found to occur predominantly in places where alcohol is consumed on a regular basis. The second kind of contact that has been established, is biomedical contact. This type of contact occurs within the clinic where there sometimes seems to be some negative interrelations between the clinic personnel and some patients. These negative relations are manifested with patients' reactions to the side-effects of anti-tuberculosis therapy, patients' personal hygiene and their alcoholic tendencies. The study has established that these negative interrelations leads to patients terminating therapy themselves before the recommended six-month period has expired, which could lead to the phenomenon of multidrug-resistance or the patient becoming infectious again and so perpetuating the epidemic in the area.



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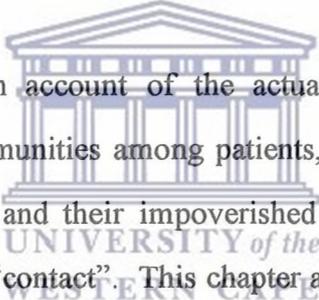
Furthermore, this study has aimed to show how important phenomena like contact patterns that impact on tuberculosis transmission, but are often overlooked by the biomedical domain, may be easily identified with the aid of social scientists as part of a multidisciplinary research team in the community. The importance of a research team of this nature is further emphasised by the positive impact that it will have on patient-centred care in general.

1.4 ORGANISATION OF CHAPTERS

Chapter Two serves as a baseline review of existing literature pertaining to this study in order to illuminate the role that my research may play in contributing to the existing field of knowledge on tuberculosis. This chapter also explores the

inadequate exploration of the phenomenon of social contact patterns perpetuated by “poor socio-economic” conditions which in effect perpetuates the transmission of tuberculosis.

Chapter Three provides an ethnographic explication of the Uitsig and Ravensmead communities where the study was undertaken and a description of my introduction into the field. It then goes on to describe the difficulties I encountered being a social scientist in a biomedically dominated multidisciplinary research team and how I dealt with these obstacles and was finally accepted as a complimentary team member.



Chapter Four yields an account of the actual social contact patterns that I encountered in the communities among patients, as well as their encounters with the biomedical domain and their impoverished living conditions. Included, are patient perspectives of “contact”. This chapter also contains an explication of the realisation by the biomedical team of the need for social science to the tuberculosis epidemic in Uitsig and Ravensmead.

Chapter Five consolidates the findings of the project. As well as exploring the usefulness of this study to other research of this nature, providing suggestions for further research and multidisciplinary teamwork.

CHAPTER TWO LITERATURE REVIEW

2. INTRODUCTION

Literature abounds with studies conducted on aspects of contact as pertaining to tuberculosis (Small, 1994; Alland, 1994; Chapman and Dyerly, 1963). The ensuing chapter thus looks at the main themes in the literature relevant to the present study of contact patterns.

2.1 NOTIONS OF CONTACT

When one person with active tuberculosis disease transmits the disease to someone else, both will have identical strains of mycobacterium tuberculosis (Warren et al, 1996). Conversely, if two individuals have the same strain of tuberculosis, it is assumed that they had had contact with each other. However, whether two such people have in fact had contact of any nature with each other, is not definitely known. Furthermore, because contact occurs between people in the community, the biochemist team members² requested that persons trained in interviewing and fieldwork techniques collect information in the community to determine whether contact had in fact occurred between certain individuals with identical strains of mycobacterium tuberculosis. While determining whether people had contact, I simultaneously had to determine the type of contact that occurred between them.

² These individuals were those members of the team who conducted the DNA fingerprinting that determined strain relatedness.

Strain relatedness was established with new available technology of strain typing³, successfully differentiating strains by DNA fingerprinting. Since evidence suggests that is a relatively stable DNA element, patients from whom cultures which are apparently identical are derived, are assumed to have had contact with each other or with a common source of infection; this is thought to be indicative of recent transmission (Warren et al, 1996). From this, and a number of other studies (Small, 1994; Alland, 1994; Warren, 1996), it is known that less than half of the tuberculosis cases are due to transmission, and in less than half the cases of people with tuberculosis who share the same strain of mycobacterium tuberculosis, social contact could be proven. However, the above studies could not determine the nature of contact and thus did not accurately define the closeness of contact between people with the same mycobacterium tuberculosis strain. It is at this point that the present study bridges this gap in existing knowledge of the closeness of contact necessary for the transmission of tuberculosis to occur, by explicating on the nature of contact among tuberculosis patients. By taking into consideration, as this study does, patient perceptions and experiences of close contact, will reduce the aforementioned gap while simultaneously making the process of “contact tracing” easier.

Contact tracing is an important phenomenon in the prevention of tuberculosis transmission because it is the process whereby the contacts of tuberculosis

³ DNA is extracted from TB culture and exposed to a restrictive endonuclease that separates the DNA at specific sites. The IS6110 is a 1355 base pair segment of DNA that binds the complementary DNA fragments. The IS6110 is linked to a number that enables the identification of various strains according to number and electrophoretic mobility (genomic location) (Hayward, 1995).

patients are traced by tuberculosis care-givers and their sputum tested for the mycobacterium tuberculosis and given treatment if they have tuberculosis disease. These contact tracing methods can become questionable though, because if patients' and doctors' perceptions of "contact" differ, then the incorrect contacts will be traced. In this instance, people who were possibly infected may not be traced and so not been tested for infection and so become diseased, and so perpetuating transmission. Therefore this study provides a working definition of tuberculosis contacts where patient notions of contact are recorded and taken into account.

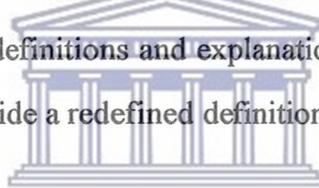
One may actually go on to argue that the above mentioned research studies do in fact stipulate what they mean by close contact; as Donald (in Coovadia and Benatar, 1991) indicates viz., "sharing a house or bedroom". What is not noted though is the fact that in practice when patients are questioned as to whom they have had contact with, they are not asked in terms of whether they have slept on the same bed, or sleep together, etc.

2.1.1 Household Contact

According to Coetzee, Yach and Joubert (1988) the sharing of households with tuberculous persons is a risk factor for transmission. They note sharing of a household as being a setting for close contact. This phenomenon is assumed to be a great risk factor for transmission because it is logically the place where close contact supposedly occurs. However, within medical literature, there even seems to be an inconsistency as to what constitutes a household. As noted by Lomnitz (1977) a household is "a social group of all individuals who share the same

residence and who also share the same entrance or access to a residential unit” (Lomnitz L, 1977: 99). In Uitsig and Ravensmead though, this definition does not apply, as the majority of the supposed household members do not share the same access or entrance to the residential unit in which different families live. There are numerous other residential units with independent entrances.

One therefore needs to define a household relative to the present socio-economic situation in the above mentioned areas. Hussain, Watura, et al (1992) use the notion of households freely as a place of close contact and familial relationships, but preliminary research in the area has indicated that “household” members often do not even know each other as they live in different structures on the same plot. What kind of contact thus occurs between these people? This research has aimed to compliment present definitions and explanations of contact conditions in a high incidence area and provide a redefined definition therefore.



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This study therefore re-examines the household as an actual place of close contact and transmission and provides a baseline for the comparison of contact within different areas and communities. It is not the aim to use the results as a generalisation for other communities but merely to indicate that differences exist in differing communities which in effect highlights the limitations of Hussain, Watura, et al’s (1992) study as not bringing this to the fore.

Hussain, Watura, et al (1992) go on to classify contact in terms of close and casual contact. Close contact is defined as being members of the same household sharing kitchen and bathroom facilities or very close associates viz. courting couples. Every other kind of contact is referred to as casual contact. This is a limited view as it leaves such questions as where one would thus classify persons who do not

share a household, but who meet regularly and often intimately in the neighbourhood bar and share drinks?

A study undertaken by Chapman and Dyerly (1963) indicates that one risk factor for the transmission of tuberculosis in terms of contact is intimacy of association with source case (Chapman and Dyerly, 1963). This implies that the contacts do not necessarily need to be living in the same household as per Hussain, Watura, et al (1992). There thus seems to be an inconsistency in the literature as to the closeness of contact necessary for the transmission of mycobacterium tuberculosis. This study hopes to determine this phenomenon which may be of a complimentary nature to existing research on notions of contact.

These notions of contact all point to the fact that in order for transmission to occur, one has to be in contact with someone with active tuberculosis. In other words - direct transmission. All fail to note anything on the notion of indirect transmission where contact does not directly cause transmission as that mentioned above, but where the contact leads to the perpetuation of transmission. It is argued that the nature of contact through attitudes of health-care workers may indirectly contribute to transmission. This will now be explored.

2.1.2 Biomedical Contact

In the light of the observation above, that the attitudes of health-care workers has an impact on the transmission of tuberculosis, this section depicts the contact that occurs between patients and biomedical care-givers and impacting on transmission.

Literature does not stress the impact of patient contact with biomedicine that may lead to non-compliance. Being non-compliant, patients are returned to a state of infectiousness and are once again able to transmit the mycobacterium tuberculosis in the community, and may even develop multi-drug resistant tuberculosis that can be fatal (Singer, 1996). Thus, as opposed to contact in the community being a direct impact on transmission, contact with biomedicine may have an indirect impact on transmission, but both perpetuate the epidemic.

Paul Shears (1985), in his discussion of tuberculosis control programmes in developing countries, purports that these programmes should essentially be planned and implemented to the patients' convenience so that it does not interfere with the daily running of their lives. The programmes should thus not be determined by what and when may be convenient for the health service. In the same light, Friedman, et al (1994) quote the sentiments of a tuberculosis patient who attended a clinic in 1948:

“[The nurse was] tight-lipped, unsmiling, unfriendly.... She gave me a stony stare and motioned me to one of the benches.... Apparently she hated people with TB the way some people hate liver”

(Friedman et al, 1994:893).

Although this is a phenomenon that I have observed in the clinics serving tuberculosis patients in Uitsig and Ravensmead, Freidman does not explicate any further on the effect that this kind of treatment actually has on the patient and their feelings of wanting to return to the clinic the following day and thereafter, to continue with and complete their medication. They also do not propose any alternatives to this kind of treatment of patients. Ellis, et al (1997), however, brings to our attention a very important aspect in tuberculosis care that is not sufficiently addressed by many authors. This relates to the observation that the

terms “disease” and “illness”⁴ are not synonymous, as commonly used, which in effect poses grave difficulties for the biomedical care of tuberculosis. They proposed the incorporation of what constitutes differences in perception between patients and biomedical care providers into each other’s perspective. They also propose a “team strategy” where patients, members of the community and other professions unite with their expertise in the fight against tuberculosis on an equal level. This may essentially be a strategy where patients are given control of their own disease and given a part in the management thereof.

Accordingly Grange and Festenstein (1993) refer to tuberculosis control programmes as lacking in what they call the “human dimension” of the disease. This view I support. Researchers continually look for answers to the world-wide increasing incidence of tuberculosis in medicines. They do not however ponder on the notion of why the medications do not always have optimal functioning within epidemic areas. This is also typical of the biomedical paradigm where the body is seen purely as a mechanical object, continually being acted upon. It is this dimension that is lacking in almost all literature explicating on causes for the increased incidence of tuberculosis world-wide, and which this study wants to address.

2.2 SOCIO-ECONOMIC CIRCUMSTANCES

“To be poor in South Africa is truly to be exposed to the threat of ill health and premature death”.

(de Beer, 1984:12)

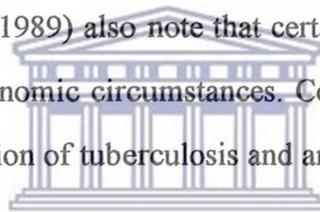
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As opposed to disease which is merely the presentation of a specific physiological disorder, illness is the embodied experience of that specific disease (Baer, 1987).

Tuberculosis is basically referred to as a disease associated with poor socio-economic circumstances (Olver, 1984). In South Africa, socio-economic factors are noted by Strebel and Seagar, (in Coovadia and Benatar, 1991) as being the primary cause of tuberculosis disease.

These studies have focused predominantly on the socio-economic risk factors that perpetuate tuberculosis transmission and infection. They do not address the actual contact that in fact causes transmission in any great detail, if at all. Socio-economic factors are very important determinants of susceptibility for tuberculosis disease (Wilson and Ramphela, 1989) but once again, one ultimately has to come into contact with a diseased individual in order for tuberculosis to be transmitted.

Wilson and Ramphela (1989) also note that certain social tendencies occur within impoverished socio-economic circumstances. Consequently these tendencies also impact on the transmission of tuberculosis and are therefore examined below.



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2.2.1 Substance (Ab)use

Numerous research studies have noted the susceptibility for the development of active tuberculosis in alcohol and drug users (Yach, 1988; Enarson, Wang and Dirks, 1989; Bloch et al, 1996 and Coetzee, Yach and Joubert, 1988). However, they do not explore the alcohol phenomenon any further than stating its effects on susceptibility for infection.

The social contact situations within which alcohol and substance abuse occur are normally not addressed. Being aware that there is a surplus of shebeens in the research areas, this study has explored in detail the kind of contact that occurs in shebeens. Here my interest was in the social patterns by which alcohol is consumed. Substance (ab)use was explored as having a twofold effect on

transmission in the community. The aforementioned studies have focused on the effect of alcohol on the immune system whereby persons who drink for example, are at greater risk of becoming diseased, as their immune system is suppressed (Nelson, et al 1995) by over-use of alcohol; this being physiological immunosuppression. These studies fail to mention the phenomenon of “social immunosuppression” whereby the individual, by merely being in contact of an alcohol-related nature, is put at risk of infection. Literature does not explore the fact that although the alcohol decreases the immune system’s defence mechanisms, one has first to be infected in order to get the disease. And, it is through contact that occurs at alcoholic interrelations that one may become infected.

Unlike de Beer (1984) who has noted that alcohol abuse is a result of the psychological stress of living in impoverished and overcrowded conditions, writers like Burman, et al (1997) note alcohol abuse as being one of the leading determinants of non-compliance in the city of Denver. They focus primarily on the failure of therapy viz., non-compliance rather than on the reason for the person's alcoholic tendencies in the first place.

2.2.2 Poverty and Overcrowding

Although overcrowding has often been identified as a risk factor for tuberculosis infection (Coetzee, et al, 1989), medical researchers approach the aspect of overcrowding from the perspective that it is the apt environment for close contact to occur. Social science researchers like de Beer (1984) take a different stance on overcrowding. They note the ensuing psychological strains that are coupled with the stress of living in overcrowded conditions, as well as the fact that it is the actual stress of the overcrowded conditions that makes people more susceptible to diseases. De Beer (1984) asserts that these psychological strains may be noted in

the high levels of alcoholism and crime. And it is because of factors like these that are often not addressed in biomedical research, but have a grave impact on tuberculosis and other diseases, that multidisciplinary teamwork needs to be given extensive attention.

Appropriately so of medicine, de Beer purports that:

“ Yet this scientific approach to disease, although bringing many benefits is marked by certain inadequacies. Concentrating as it does on the diagnosis and treatment of individuals, it makes illness appear to be a random event, which strikes down those who have been ‘unlucky’ enough to be exposed to a hazardous extrinsic factor. In fact though, we know that this is not the case and that different groups of people show different patterns of disease.”



de Beer (1984:1)

Therefore, although inadequate however, biomedical intervention does play an important role in the eradication of tuberculosis. Thus, instead of having searched for an alternative to medicine, this study has opted for a complementary model to medicine, i.e. an anthropological/sociological model in the fight for the eradication of tuberculosis in Uitsig and Ravensmead, using a team work strategy.

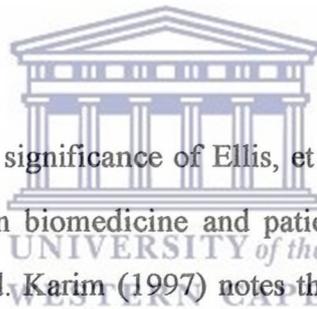
2.3 MULTIDISCIPLINARY TEAMWORK

The implementation of the aforementioned “team strategy” proposed by Ellis, et al (1997), is often mentioned, as the answer to the eradication of illnesses like tuberculosis. However, there is hardly mention of the execution of such teams, less so its functioning in many studies calling for the eradication of tuberculosis.

Although biomedical care-givers are able to competently treat tuberculosis - the disease, they do not possess all the skills to treat tuberculosis - the illness. Therefore there is the need for the skills of other care-givers in the treatment and eradication of tuberculosis which signals the need for the implementation of a team approach for tuberculosis care.

Being a relatively new team, this study will show the effectiveness of a multidisciplinary team approach to disease such as tuberculosis in high incidence areas.

Weyer (1997) purports that although there has been extensive explication of the biomedical aspects of the DOTs strategy, there are insufficient studies exploring its social and behavioural domains. This study heeds her call for extensive research in these areas.



Karim (1997) notes the significance of Ellis, et al's (1997) study that focuses on the relationship between biomedicine and patients, where patients' perspectives are actually documented. Karim (1997) notes the importance of such research to the greater comprehension of the aforementioned relationship that has an impact on achieving a larger degree of adherence which is ultimately the aim of in the eradication of tuberculosis. In accordance with Karim's assertion, this study also highlights this relationship and patient perspectives, showing how these perceptions can be used for effective tuberculosis treatment in areas such as Uitsig and Ravensmead.

Rene Dubos (1992) notes that "tuberculosis is a social disease", and the social problems presented by the disease are outside of the understanding of the biomedical domain. He in effect highlights the holism that exists between mind and body, purporting that socio-economic factors have as great an impact on the

human body as does the actual bacteria that cause disease. So too, my study illustrates the importance of a phenomenological approach to tuberculosis care as noted by Edington (1997).

This study illustrates the workings and complimentary nature of a multidisciplinary team by attending to both medical and social issues and the use of people trained in both disciplines in one team and the expectation that different individuals will perform interrelated roles in a team and cannot function in isolation of each other if their common goal is to be achieved.

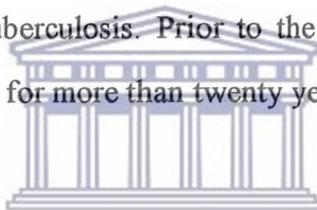


CHAPTER THREE

RESEARCH METHODOLOGY

3.1 THE RESEARCH SETTING

The study was undertaken in the Western Cape Province of South Africa where the incidence of tuberculosis in 1996 was 559/100 000 (Singer, 1996). The two suburbs studied (Uitsig and Ravensmead) are in the Cape Town Metropolitan area. Health care to the communities is provided by two local authority clinics and a tertiary care referral hospital (Tygerberg) where health care workers including volunteer community workers are involved in the Directly Observed Treatment (DOTs) programme implemented in the hope of improving cure and therefore transmission rates of tuberculosis. Prior to the DOTs system though, there had been supervised therapy for more than twenty years.



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3.1.1 Ravensmead

There were approximately 2 500 “Coloured” people living in Parow (a so-called “White” area) until 1961. Many of these “Coloured” people were landowners, but due to the proclamation of the Group areas Act on 31 January 1958, all the Coloured families were removed from Parow. They were then re-located to Ravensmead (then called Tiervlei) where the Municipality provided them with housing. However, due to the numerous undeveloped plots and erection of informal housing, Ravensmead was declared a slum area in 1966. Today though, in accordance with Nyaoro’s (1992)⁵ definition of slum areas, certain parts of Ravensmead (as well as Uitsig), continue to be slum-like even though there are 1

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Nyaoro notes that lack of essential services among others, sewerage, drainage systems, garbage bins, poor housing and security is a characteristic of slum areas (Nyaoro, 1992).

165 flats and semi-detached houses, as well as 1 569 privately owned houses (Coert, 1994).

Furthermore, due to its central location, Ravensmead may be regarded as a semi-industrial area while it provides housing, several large industries, plants, factories, etc are surrounding it. (Coert, 1994).

3.1.2 Uitsig

The residential density in Uitsig is 31,2du/ha. The housing types are four-storey flats, free standing houses, semi-detached and row-type scheme houses and 458 backyard dwellings. According to 1991 census statistics, the population in Uitsig was 10 650 persons of which 6615 were unemployed. In 1993 the average number of persons per household was 6,6. (Elsies River Local Structure Plan, Volume 1, 1995). This is indeed an indication of the overcrowded conditions under which the residents of the community reside. Furthermore, the slum conditions that exist in Ravensmead, exist more so in Uitsig where there are no street lights and excessive dumping of refuse on open plots⁶.

From my interviews and observations I found that in a few cases as many as 25 people live on a single plot. There was even a house where, due to it being semi-detached and no other entry to the backyard, the family's horse had to be taken to the back of the house through the kitchen, at night. Although the owners were not very pleased with this phenomenon, they had no other choice as the horse was a means of income and the arrangement became a part of life for them. I even encountered one woman who literally lived in a chicken coup.

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Elsies River Draft Local Structure Plan Volumes 1 & 3.

3.2 ENTRANCE INTO THE COMMUNITIES

3.2.1 Being a multidisciplinary team member

At the time of my introduction to the community, the tuberculosis multidisciplinary research team of which I became a member, had already been conducting research in the area for approximately the past ten years. Permission to undertake research with human subjects had already been obtained by the medical ethics committee of the University of Stellenbosch, and the Uitsig and Ravensmead tuberculosis care groups for the larger research project of which I formed a part⁷. Thus, being a member of this team, I was able to cut through all the “red tape” that goes along with securing access and carrying out research in a community where research was already being carried out by other researchers. However, because I was not a nurse or doctor, i.e. a biomedical person, I had to obtain permission from the Cape Metropolitan Council for access to patients' files, where necessary. In this regard and concerning all other aspects of my research process, confidentiality and anonymity were maintained at all times.

I was introduced to the matrons and nursing staff at the clinics by the medical doctor in-charge of the research in the community. Upon the assurance that I would co-operate and respect the regulations inherent in the functioning of the clinics, I was allowed to proceed with my research and promised access to patient files and other information that I may have needed. I was usually well accepted, except if I happened to ask for assistance during lunch or tea times. In such cases I was severely reprimanded. One specific nurse was synonymous with scolding

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The Glaxo Wellcome Action TB Initiative.

me, even if I did not call during their breaks (which in most instances was my only break). She always seemed to receive me with contempt, as if I was looking for or doing unnecessary work. I became a very good and close friend with two of the nursing sisters on the team who were well known and liked by the staff of both clinics. They also introduced me to the other nurses, invited me to tea during breaks and I was later accepted as one of the “gang”. Thus when I needed to do or use anything in the clinic, I was treated as a staff member of the clinic who, like them, was just doing my job. This made for a rather amicable research environment that made up for the unpleasantness I experienced with that specific nurse, who I tried to avoid as far as possible in order not to get in her way.

I became acquainted with my informants through the tuberculosis treatment supporters in the community. I assisted volunteers with the preparation of food, which they distributed, to the community on a daily basis. I also attended regular gatherings and meetings and tried as far as possible to assist with community work in both areas. Through these activities, I became known to residents of the communities who then mostly accepted me quite readily when I visited them for the first time with the volunteers. However, this is indeed a grave generalisation as my initial interviews were not all met with participant enthusiasm. My initial interviews with those informants that I had not become acquainted with through the feeding scheme, were met with apprehension until I had built up sufficient rapport and trust with them. A common phrase upon first visits was: “Wat wil die mense nou weer hê?” (What do these people want now again?). While I was explaining that the purpose of my visit was research on TB, a few people even ran inside and came out with receipts saying: “Nee, nee, nee, u hoef nie hier om te kom nie, ons het al klaar ons TV lisensie betaal!” (No, no, no, you do not have to come around here, we have already paid our TV licence!).

3.3 THE SAMPLE

Over the past three and-a-half years, biochemist team members have conducted strain typing fingerprinting on mycobacterium tuberculosis of confirmed tuberculous patients. Through this process, they were able to identify the relatedness of certain strains of mycobacterium tuberculosis in the communities. These patients became the subjects of my research. In order to prevent bias in interviews as far as possible, I was not made aware of the results of this IS6110 results of strain relatedness at the time of conducting the social interviews.

Because I was examining the notion of social patterns, with close contact as the source of transmission of tuberculosis, my sample consisted of thirty four households in Uitsig and Ravensmead that have been recorded as having two or more cases of confirmed tuberculosis and whose cultures were submitted for IS6110 strain typing of Mtb. By using households where there were two or more cases of tuberculosis, I was better able to examine the closeness of contact and interaction patterns that occurs between tuberculous persons in the households and juxtapose this with general social contact patterns in the community as a whole.

The total number of households with two or more cases of tuberculosis was forty four, of which I was only able to interview thirty three as patients had either died, given clinic staff incorrect addresses, had moved, or had simply evaded being interviewed by not keeping appointments that had been made, even up to eight times. The problem of interviewing informants was further compounded by the fact that I was faced with the problem of the extensive use of aliases in the communities. For example, I would go to an address and ask for Johan⁸ upon

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A pseudonym

which the person who opens the door would reply that there was no such person there. And just as I was leaving, the person would call me back, saying that there might be a person by the name of Johan. Going into the back yard, she would call someone, asking what “Pampoen’s” name was. Pampoen would then end up being the person I had initially been looking for, i.e. Johan.

The sample consisted of both male and female patients over the age of sixteen. In only one of the thirty-four households a child was one of the interviewees, in which instance her mother assisted in the answering of questions.

Finally, there were no specific criteria⁹ by which I chose my respondents, other than them being able to converse in English or Afrikaans because in the initial stages of my project, I had interviewed a Xhosa speaking person who was very friendly and willing to assist with the interview, but we both became quite frustrated because we could not understand anything we were saying to each other. Consequently, I discarded this interview as part of my original sample. Fortunately though, all the other informants spoke Afrikaans, so language did not pose a problem at all.

3.4 METHODS

3.4.1 Participant Observation

In order to make myself known in the community, I befriended some young adults introduced to me by volunteer workers. I also tried initially to always be seen with a well-known community worker in both areas.

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I had no specific criteria as my respondents were cases given to me by a biomedical team member who had fingerprinted the patients. One of his main criteria though was that they had in fact lived in the same household.

When I started the project, I did not possess a driver's licence and my friends I had made in the community through some of the volunteers would thus walk me to the station or wait with me at central taxi pick-up points. While I enjoyed the company for its own sake also, these friendships also served as a means for me to become part of the community, as well as a manner of observing normal daily community activities.

After becoming more familiar with the communities, I observed the kinds of interaction that took place in the community in general by sitting on street corners, visiting the shebeens, and just visiting with informants, their friends and family in their homes. In so doing I was able to observe social contact “outside” of an interviewing environment in which instance I could see what physical contact occurs as opposed to informant notions of social contact with each other.

I assisted in the daily preparation of food in the soup¹⁰ kitchen. This gave me the opportunity of informing residents in general that I was going to be in the community quite regularly and tell them what it was that I was going to be doing there. Because the one meal that they got at the kitchen was often the only meal they would have for the day, the residents were therefore very grateful and appreciative of the hands that had prepared it. Associating me with the kitchen, thus gave informants a sense of ease with my presence in the community. Furthermore, by assisting in the kitchen I was able to further observe contact among residents while they were standing in the queues waiting for their food to be served. In this manner, I hoped that residents would not perceive me in my status as an interviewer or researcher, but merely as one of the volunteers

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The kitchen is merely referred to as the “soup kitchen” although everyday different kinds of food are prepared, ranging from soup, to fish, to stews, etc.

preparing their meals. However, I was constantly aware of the fact that an ethnographer's presence invariably influences informant actions within specific situations (Lockwood, in Devereux and Hoddinott, 1993). Therefore no matter how “normal” informants went about their daily interactions, these interactions were perpetually governed by my presence in the community to a large extent.

3.4.2 Interviews

I acquired my information through informal face-to-face, in-depth interviews with informants. Open-ended questions with the following categories were used:

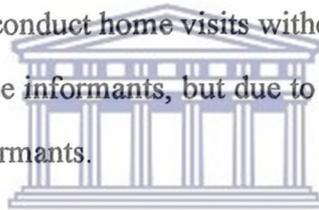
- (i) Perceptions of being a tuberculosis sufferer
- (ii) How they thought Tuberculosis was spread;
- (iii) What their daily activities entailed, their interactions with friends and family;
- (iv) Perceptions of contact;
- (v) Whether they have had contact with any persons they knew had or suspected of having tuberculosis;
- (vi) Whether they had previous contact with tuberculous persons prior to their residence in Uitsig or Ravensmead and the type of housing;
- (vii) Alcohol and drug use;
- (viii) Their experience/s with clinic staff;
- (ix) Perceptions of living in Uitsig and Ravensmead.

Our discussions were basically of a conversational nature where I would probe on the aforementioned items.

Where necessary for attaining particular statistical data, I employed the use of closed-ended questions. These were used for data such as determining population density per household. Here the exact number of persons occupying each room in

the household was required, as well as the number of rooms per dwelling per plot per household. I also enquired by means of closed-ended questions about regular social contact of informants in order to establish contact patterns that I could juxtapose with that of other informants in order to establish a possible common source¹¹ of transmission.

Initial interviews were conducted in the presence of volunteer workers. After being in the field for approximately five months, I conducted interviews alone, as I found that due to the fact that the volunteer workers were well-known figures in the community who often knew patients personally, there were certain aspects of their illness and lives that patients did not feel comfortable speaking about in front of the volunteers. Fortunately this realisation coincided with the stage when I felt comfortable enough to conduct home visits without a “chaperone”. I managed to go back to a few of these informants, but due to time constraints I was not able to go back to all these informants.



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I did not tape record the interviews because when I enquired about the use thereof, respondents replied: “Nee, skryf jy maar lieweste dan sal ek bieter kan praat” (“No, rather write down what I am saying, then I will be able to speak more easily). Others were so distracted by the tape recorder, almost as if I was conducting some momentous radio interview, that I decided not to even take it to the field any longer. Consequently I merely wrote what informants told me during interviews in a manner that did not distract them while they were talking. To counter memory loss of important information, I would dictate important parts of our interviews to my Dictaphone when I got back into the car.

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According to Warren et al (1996), if two people have exact banding patterns they have most likely infected each other.

Unfortunately this did not convey the real feeling with which informants spoke to me. This was something that would have aided me tremendously when I was writing up my research, to refresh my sense of the mood and emotions with which respondents had spoken to me.

A undertook approximately three interviews with individual informants¹². In most cases, I only needed to conduct one interview because these were informants with whom I had built up rapport much faster than others. Interviews were conducted in their homes or in a secluded part of the clinic. On a few occasions, I met informants in the shebeens where I was also able to conduct interviews, but this was done discreetly. In other words, informants were aware that I would be taking note of and writing down what they told me later on, but I did not make it obvious to other patrons of the shebeen that we were conducting an interview. In these situations though, I was saddled with a moral dilemma of whether I was taking advantage of my informants in their “drunken” state when their defences were not at their peak. But this was overcome by the fact that I had informed respondents that they might bump into me at the shebeens sometimes, where I would be doing observations, but did not tell them exactly when I would be doing so.

Respondents never left when I entered the shebeens though. They also knew that they might become inebriated and could say things they would not if they were in a sober state when we spoke. Furthermore, I asked informants if they could remember things that they told me at the shebeen. When they said they did, but did not want me to use the information, I respected their wish and discarded the

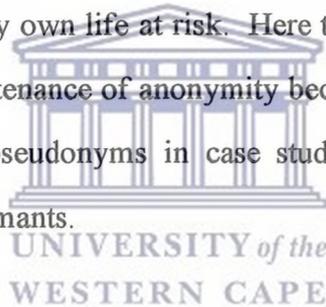
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Many times informants would become so engrossed in the fact that someone was interested in listening to their stories that they would go totally off the point of the specific categories that I wanted to explore in which instance the interview would be taken up by personal problems. I therefore had to go back for these.

information in my project. In so doing, making certain that I was in fact not taking advantage of them and what they tell me in confidence - under which all our interviews took place.

3.4.3 Anonymity

No information that would put informants at risk of being identified by any person inside and outside of the community was made available in any form. This was all the more important because there were informants who had been in jail for assault and murder, etc. and many were also drug abusers and gangsters. Revealing information of this nature, could endanger the lives of informants, in which instance I could have been identified as a police informant or “spy”. Not only would my entire research project and that of team members, be jeopardised, but it would also put my own life at risk. Here the seriousness and unconditional importance of the maintenance of anonymity became quite evident. Therefore, I employed the use of pseudonyms in case studies when referring to situations involving specific informants.

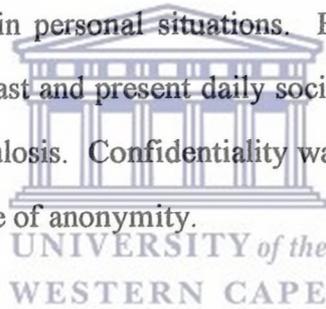


3.4.4 Confidentiality

One of the main aims of this study was to bring to the fore “life as lived in Uitsig and Ravensmead with tuberculosis”. On the basis of this, I informed my informants that although I would protect their identity, I would be telling tales as they had occurred in my presence. Informants then, on the basis of this had the opportunity to accept or decline to be part of my research study.

My interviews with both patients and clinic staff proved that those patients who had alcoholic tendencies were treated appallingly by certain staff members. Where people were at risk of being identified through the disclosure of specific situations and events, I did not make use of their stories as they had occurred.

Fortunately, because all the informants I had interviewed were the patients of the clinical team with whom I worked, I was not overly concerned with them not maintaining confidentiality of information as these clinicians were bound by doctor-patient confidentiality as stated within the Hippocratic Oath (Friedlan; 1994). My condition for giving them access to my notes though, was that the details thereof would not be made available to the nursing staff who could use it to the detriment of patients in that they might become biased to their attitudes to patients and patient care. Furthermore, team members were not given access to extremely personal information that informants had asked me to specifically keep totally confidential between them and myself. In these instances I had an ethical duty to even provide clinician team members with pseudonyms for these patients when referring to certain personal situations. However, they were only really interested in patients' past and present daily social contact patterns for its bearing on the spread of tuberculosis. Confidentiality was therefore maintained indirectly through the maintenance of anonymity.



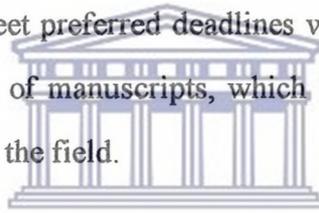
3.5 WORKING IN A MULTIDISCIPLINARY TEAM

The research team who funded my study, comprised of medical doctors, biochemists, microbiologists, immunologists, geneticists, geographers, nursing sisters, a sociologist and two medical anthropology students - myself and a fellow student.

As student, I started being employed as research worker with responsibilities for interviewing patients whose mycobacterium tuberculosis organisms had been IS6110 strain typed by a biochemistry team member. According to the results of his biochemical analyses with IS6110 strain typing, certain of the patients in the list had probably had contact with each other where they transmitted the disease to

one another. It was thus my job as social scientist with social interviewing skills, to conduct anthropological interviews in order to determine whether any patients in the list had in fact had contact of any nature with each other without revealing the names of any of the other patients. This involvement led to the decision to use data from this research for purposes of my own studies. Luckily, quite a few of the persons I had to interview for the biochemist team member were patients I had intended to interview for my research. I was thus simultaneously completing a full-time degree, as well as being employed full-time as a team member.

There has been limited interdisciplinary work of the kind that is presently being pursued. Therefore, initial interrelationships between myself (regarding the nature of my work) and fellow biomedical team members were very tense. I was sometimes unable to meet preferred deadlines with information necessary for the preparation and writing of manuscripts, which lead to the feeling that I was not efficient in my duties in the field.



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Being female, young, “coloured” and a student, I had a tough time advocating my worth as a competent anthropological researcher. I used the fact that these biomedical researchers were “white” middle class, middle-aged professionals to my absolute advantage. I “scared” them into respecting my abilities as a social scientist. I pointed out to them that their work was confined to the laboratories where they carried out their experiments with mycobacterium. Here they knew patients only by laboratory numbers; numbers to which I had given faces. Whereas the growth of bacteria could be predicted quite accurately, “extracting” information from informants could take between ten minutes to ten visits. This was something I felt they did not understand unless they were actually present in the field. And knowing that they would not go into the field, I brought the field to them in the regular report-back meetings we had. Reporting on experiences of

witnessing family conflicts, having to go into, and making decisions to drink with patients in shebeens in order to build up rapport, and the intensely intimate and personal experiences that informants had shared with me, brought my work into greater perspective for them. I watched with great satisfaction as many of them sat in awe as I explained what doing fieldwork actually entailed. The nerve and persistence needed in going to people as many as eight times before they agreed to be interviewed, being offered a urine-soiled unmade bed to sit on when conducting an interview, being forced to acquire a taste for alcohol that one did not refuse for fear of offending respondents, having to be a counsellor, taxi, and most importantly, having to be a much needed friend to people who were often in despair because of their impoverished living conditions.. Although I gained respect, most importantly, I brought into perspective that informants are far more than just variables or laboratory numbers in a research project, they were the research. Without informant perceptions and experiences of illness, there would be nothing to research. The very sputum from which researchers have drawn so much knowledge and information to further their academic careers, is a bodily fluid which informants could have refused to supply them with.

My experiences in a multidisciplinary team, has made this research project more relevant. Just like the differences that existed between us concerning fieldwork, prior to my field reports, so too, by bringing to the fore the differences that exist in biomedical and actual patient perceptions and experiences of contact in the communities, researchers would be in a better position to eradicate tuberculosis with the direct help of patients themselves. By patients understanding what kind of contact transmits tuberculosis, they would be able to avoid it and decrease their susceptibility for transmission. So too, by doctors being aware of what type of contact and where this contact occurs in the communities, they may begin to understand why tuberculosis control and eradication strategies have not been completely effective.

I managed to maintain ethical neutrality and objectivity in the fact that I was not trying in these meetings to indicate whose research methods was right and whose wrong. I was merely trying to highlight the differences that exist between the two in doing research. I also constantly emphasised that the one aim of our research endeavours was to assist with the eradication of the tuberculosis epidemic in Uitsig and Ravensmead. Therefore, we had to take a team approach in so doing, where we had to respect the methods (no matter how different from our own) of each others work because we were all working towards the eradication of tuberculosis in these communities and had to compliment each other in the process.

In conclusion, in his opening address to the Third Annual Public Health Forum in London, Sykes (in Porter and McAdam, 1994) called on a partnership, an amalgamation of resources and the sharing of knowledge in the fight against tuberculosis. It was only after many months of presentations that I was finally fully accepted as a proper team member and came to realise the effectiveness and indispensable value of the dissemination and sharing of knowledge in the eradication of tuberculosis.

CHAPTER FOUR

REPORT

4.1 SOCIO-ECONOMIC CONDITIONS IN UITSIG AND RAVENSMEAD

4.1.1 “The Little Old Lady”

Today I found the true meaning of appreciation..... appreciation for life..... and I got a glimpse of life as lived in Uitsig....

The house looked as though it had not been occupied for many years. All, except two of the windows were broken, with no form of covering to prevent rain, wind and sand from seeping through the openings. There was not a single curtain or piece of cloth covering any of the broken window structures.

I entered around the back where a frail old lady, crooked with age, was sitting outside the muddy entrance to the back door on a drum to absorb the warmth and light of the sun which was absent in the house behind which she was seated. Frolicking beside her was her dirty-faced granddaughter and the opposite neighbours' little girl.

Upon explaining to her why I was there, the little old lady introduced herself to me as Miena Waal¹³ and invited me into her house where there was an unmade bed on which we could sit for the interview as there was no other place to sit, or anything to sit on in the courtyard. Immediately though, upon entering, I knew

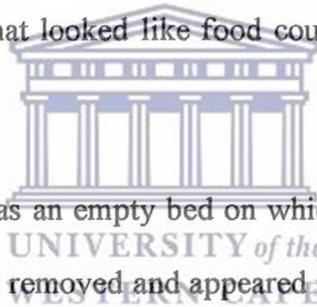
¹³

A pseudonym.

that this was not going to be an interview of any sort, but a lesson in life. A lesson I would be taught by a little old lady I had never before met or seen in my life. A little old lady whose face I would never be able to forget.....

A strong sense of appreciation began filling my veins, spreading to my whole being. I would never again see life with the same perspective as before.

In what was supposedly the kitchen, was no piece furniture except a cupboard whose doors were broken off exposing nothing but the bareness thereof. I assumed that this was the kitchen because although there was no tap and basin therein, or in any other room for that matter, the kitchen was normally the room where the back door was found. There was no table, other cupboards, or any other form of objects that looked like food could be cooked or stored therein in this “kitchen”.



In the bedroom there was an empty bed on which we sat and a hi-fi system from which the plug had been removed and appeared not to be in working order. In the dark room Miena opened the front door which was kept closed by an old car battery to allow for enough sunlight to penetrate the room so that we could see each other's faces. At once I could feel the stuffy stale smell of soiled clothes and urine leave the room for a moment as the breeze came in through the opened door. But even the uncovered broken windows kept the odour inside. The black burnt walls resembled those in all the other rooms; exposed to regular “galley”¹⁴ fires - obviously for warmth during the cold winter days and nights. By the dirty clothes

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This is a fire made in a large drum around which people sit for the warmth from the fire.

and rubbish alike that were strewn on the floors, it was clear that they had not seen a broom quite often, or actually, not at all. I had even wiped my feet quite vigorously on the piece of cement flooring that served as the back stoep so that I would not walk the mud into the house, but the little old lady did not seem to mind at all as she walked placidly into the kitchen to lead the way to the bedroom where we would talk.

The other two “supposed” bedrooms were completely empty. Only a few clay bricks stacked on each other, for which I saw no purpose, were visible. However, they were obviously a substitute for some piece of furniture Miena’s family did not have - chairs perhaps? Everything was lifeless. The only feature that resembled any form of life in this little house, was the sweet little old lady.... The little old lady who brought life to the house that had looked liked it had been a deserted building that had become the long-time hideout for vandals.

For someone who could not sleep if the kitchen had not been tidied spotlessly or even stand the sight of a pair of dirty socks lying out of the basket, I could not seem to find the untidiness in this house where garbage was lying all over the floors. I did not mind having to sit on the urine stained mattress of an unmade bed, because I had in an instant become content with life, and finally figured that I had been sent to that community for a much greater reason than completing a degree, which suddenly was insignificant to the person that I would become at the end of my visits to Uitsig and Ravensmead.....

The above narrative is meant to provide a clear idea of the seriously impoverished socio-economic conditions under which most tuberculotic patients that I had interviewed in Uitsig and Ravensmead live. It also aims to put into perspective

the real meaning of “poor socio-economic conditions” used throughout this paper. It describes these “poor social socio-economic conditions” and explicates on their wider implications for tuberculosis patients in relation to their daily living, relations, contacts and interactions with the community and the biomedical domain who controls the management of tuberculosis in the communities. There were two aspects of poor socio-economic conditions that I explored specifically, which are discussed below.

4.1.2. Overcrowding

As I only interviewed homes where there were two or more cases of tuberculosis, I could not juxtapose the population density of the homes where there were cases of tuberculosis with that of homes where there were no cases. Although I mentioned previously that in a few instances I found as many as 25 people to live on a single plot, the study did not find crowding to be a significant factor in terms of the number of persons actually living in the dwelling where the patients themselves live.

As utilised by the Department of National Health and Population Development, indices of crowding were based on Batson’s (1994) household density ratio. According to his computations, a household member > 10 years of age, constitutes one equivalent person (EP) and those < 10 years of age, each constitutes half an equivalent person. Each sleeping room per household should not sleep more than 2,5 equivalent persons. Any number of equivalent persons over 2,5 per sleeping room is indicative of crowding (Coetzee et al, 1988).

From the above, the average number of equivalent persons per sleeping room for all the households I interviewed with a tuberculosis patient was 2,7 equivalent

persons per sleeping room. This indicates that there are in fact not overly crowded conditions in these homes.

A very important factor that did seem to have an important impact on transmission was alcohol (ab)use, the discussion of which follows below.

4.1.3. Alcohol Consumption

Alcohol consumption usually occurs at the local neighbourhood bars called shebeens. In Ravensmead alone there are approximately 84 shebeens where alcohol is sold at a low cost - much cheaper than at the wholesalers or established pubs. The contact patterns that occur at these shebeens are of a very close nature. By close, is meant that patrons sit on each other's laps, dance closely together (blues) etc.¹⁵. Because the music is so loud, when people speak to each other they often come into extremely close contact viz. talking directly in the others face, so close that the person talking actually spits in the others face as they talk¹⁶. Consequently, a total of 85% of all the patients in the study drank regularly in social groups. I ascertained that most of those informants who worked received a weekly wage, either from their permanent jobs, but mostly because they had temporary positions in neighbouring factories. This way they would have money every Friday evening.

An example of these regular social gatherings: I arrived at Joe's place flat at approximately 9:30 one Saturday morning. The person who came to the door said that he would go and call him, but vehemently insisted that I wait at the door for

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"Blues" music is slow music, usually love songs. Dancing to blues music requires that people actually embrace each other and dance closely together.

¹⁶ This has actually personally happened to me on a few occasions in the shebeen.

him. He came to the door and after explaining who I was and what I was doing there, Joe invited me into the lounge. Because I could see that he had company, I suggested that I come back on another day. He insisted though that I stay and interview him, even in front of his friends saying: "Hulle almal weet ek het TB gehad" (They all know that I had TB). Although I conducted the interview, I kept the personal questions for another visit. Anyway, every couple of minutes after I had asked a few questions, he would excuse himself to go into one of the bedrooms from which a huge cloud of smoke was visible. Along with this cloud of smoke came the strong smell of cannabis. As the lounge filled with his friends who came from this bedroom, so too they would go back to the bedroom every ten minutes. Joe admitted that they were smoking "dagga" (cannabis). He asked if I did not mind, they could not help it because it was a habit they had learned in jail.

He told me that they would have gatherings of this nature every Saturday or when there was money. He said that there was always money though.

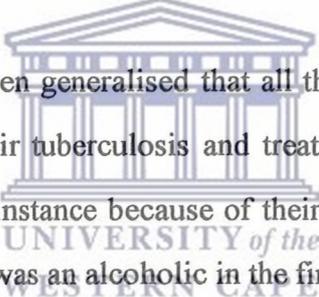
His wife entered with groceries while I was there. Although she did not look too pleased with all the men in her lounge, she did not appear to be angry either. Joe said that she did not mind as long as he gave here money for food.

For Joe, these gatherings was a manner in which they could "Koel af" (Cool off) from a long week.

Thus, speaking to my informants, alcohol consumption is basically a way of life in their communities. This utterances are in accordance with Wilson and Ramphele (1989) who contends of a Karoo community, that: "Plain poverty and adverse social circumstances have a lot to do with this high incidence of alcoholism, for alcohol has a numbing and care-diminishing effect which makes life more tolerable for those who have to struggle daily for the bare necessities of living"

(Wilson and Ramphela, 1989:160). In other words, whatever methods patients find that can take their mind off their dire circumstances, they use to their full advantage.

Firstly, the clinic staff does not comprehend this notion as explanation of the excessive use of alcohol in the Uitsig and Ravensmead communities. They simply hold the patients accountable for their drunken states in which they constantly find themselves. However, patients inform me that by moralising, they simply resist the care given by the clinic more. According to them: "Ek gaan na die kliniek toe om my pille te kry, nie om die susters se aanhoudende geraas met my nie, hulle is amper soos was vroue". (I go to the clinic to get my tablets, not to listen to the constant scolding of the sisters, they are almost like washer women."

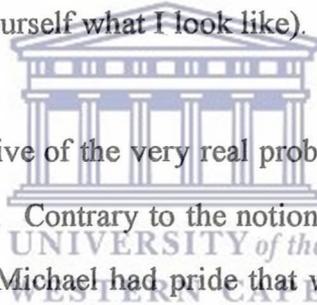


These staff members often generalised that all these tuberculosis patients did not want to be cured of their tuberculosis and treated them as though they became tuberculous in the first instance because of their alcoholic tendencies, failing to explore why the person was an alcoholic in the first instance. I therefore informed informants that I wanted to disclose information where people would be able to tell their own story about their embodied experience of being tuberculous and the drive behind alcoholism. I wanted to extract the feelings, perceptions and experiences of having tuberculosis in a community with epidemic proportions. This was something that most clinic staff were not really interested in, but due to the fact that informants wanted their tales to be told, I had an obligation to these informants to "tell" their stories, in terms of Wilson's notion that: "in such cases doing so becomes part of the field worker's obligations to the community" (Wilson, in Devereux and Hoddinott, 1993:34).

I also ascertained from preliminary clinic visits that nurses often scolded and spoke harshly of informants who failed to take their medication. These nurses attributed non-compliance to patients' abuse of alcohol and drugs. However, I noted that they simultaneously failed to determine or were not interested in why patients abused these substances. For example, if a patient were an alcoholic before he/she developed active tuberculosis, being on tuberculosis medication will not deter such a person from continuing to consume alcohol, as it is an addictive substance. Freidman et al.(1987) note that among alcoholics and drug addicts, there is a high prevalence of tuberculosis, but, according to Comstock and Comstock "Alcoholism and drug addiction are also associated with tuberculosis, although it is not clear whether these diseases increase susceptibility to tuberculosis, or whether conditions conducive to substance abuse are similar to those leading to tuberculosis" (Comstock and Comstock, in Reichman and Hershfield, 1993:40). In view of this one should consider that intervention for the alcohol problem may assist with the compliance of tuberculosis treatment. This does not imply that it is expected that the nurses be social workers, but that they should take a more phenomenological perspective to tuberculosis patient care. I therefore wanted to "expose" the kind of lifestyle that makes one susceptible to developing active tuberculosis. To illustrate this, Michael's feelings of being unemployed, tuberculous and alcoholic utter the sentiments of someone who had no control over his lifestyle as an alcoholic.

He explains: " 'n man is mos ok trots. Ek het 'n goeie werk gehad en kon vir my family sorg. Ek het nie eintlik gedrink nie, net weekends om van die week se harde werk af te koel. Toe het hulle mense by die werk afgedank en ek was een van hulle. Dit was net 'n afdraan van daar af want ek was heeldag by die huis. En met so veel tyd op my hande het ek ook meer tyd gehad met my vriende. Ons het meer dikwels by die shebeen 'n draai gaan maak. Later aan was ons a groepie wat

minstens vier keer 'n week saam gedrink het, ja sommer uit dieselfde bottel. Ek het pyp begin rook ook - alles om net van my probleme te vergeet. Sodat ek nie hoef te gedink het nie aan hoe ek nie meer vir my family sou kon sorg nie. Toe kry ek TB, en na dit, kyk maar self hoe lyk ek nou.” (A man is proud. I had a good job and could provide for my family. I did not actually drink, just weekends to relax after the week's hard work. Then they were retrenching people at work, and I was one of them. It just went downhill from there because I was at home the whole day. And with so much time on my hands I also had more time with my friends. We made a turn at the shebeen more often. Later there was a group of us who drank together at least four times per week, yes, out of the same bottle. I started smoking pipe¹⁷ - all to just forget about my problems. So that I would not have to think about how I could no longer provide for my family. Then I got TB, and after that, see for yourself what I look like).



This narrative is indicative of the very real problems that face people who live in Uitsig and Ravensmead. Contrary to the notions of many medical staff that they do not have any pride, Michael had pride that was taken from him when he lost his job and could no longer provide for his family. There are no recreational facilities in these communities therefore in the midst of stress, one has no other outlet than alcohol that is readily available at the nearly one hundred shebeens in these areas.

Referring to the research findings of the Carnegie Inquiry, Wilson and Ramphele (1989) note that boredom breeds in communities where there is nothing to do. This boredom then gives rise to despair that: “eats away at the soul and overwhelms individuals with a sense of utter hopelessness” Wilson and

¹⁷

Dagga.

Ramphele, 1989:160. They note that these are the feelings that lie behind alcoholism and violence.

As noted previously, as well as having contact within the community, like Michael has, tuberculosis patients also have contact with the biomedical domain on a daily basis for the taking of their medication. This contact is referred to as biomedical contact.

4.2 BIOMEDICAL CONTACT

Although DOTs system has been implemented, allowing for patients to receive their medication from trained tuberculosis care-giver community workers, many patients still receive their medication from the clinic where, if they discontinue use, are severely reprimanded. Following are some of the reasons patients cease with medication before the stipulated six-month period.

4.2.1 Side-effects¹⁸ of Anti-tuberculosis Therapy

Side-effects are one of the main reasons why patients have not always complied with tuberculosis therapy. The other reason being the treatment they experience at the hands of biomedical care-givers. As one of my respondents have informed me in response to my questions about their experiences of biomedical care: “Ek sê nie hierdie goed om die kliniek swak te maak nie. Ek sê net wat met my gebeur het” (I do not say these things to make the clinics out to be bad, I am merely telling you what happened to me). Similarly, I do not note their experiences in order to discredit the clinic staff or biomedical care, it is meant to give a picture

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Among the side-effects of anti-tuberculosis therapy are drowsiness, headache, mental confusion, muscular weakness, acute psychosis, anxiety, depression, optic neuritis, impaired hearing (Gibbon and Swanepoel, 1991)

of things as they happened between some clinic staff and the patients. One respondent's case serves as illustration:

Never in her life had she ever had a problem with her hearing. Then suddenly, her hearing became seriously impaired. Shortly thereafter she began experiencing episodes of nausea which she reasoned could not be due to a pregnancy because “Ek was dan nou net siek¹⁹” (I was just sick shortly). All she was casually told at the clinic was that her symptoms were just side-effects of the anti-tuberculosis therapy she was currently taking.

Matthew had ceased to continue with his tuberculosis medication and was subsequently diagnosed as being multidrug-resistant.

Besides common childhood illnesses like chicken pox, measles and mumps and cold or influenza, Matthew had never been ill one day in his life. Then three years ago he was diagnosed as having tuberculosis, signalling the start of a downhill battle for him. An athlete at school and active in sport after school too, he was reduced to an inactive recluse. As his wife explained to me: “ Ons was baie gelukkig. Sels toe hy gediagnos was met TB. Hy het nie ‘n probleem daarmee gehad nie en het sy pille gevat want hy wou gou weer beter geword het. Maar toe begin die groot probleme. Hy het goed begin vergeet, onnodig geskêl en geskree, en hy was net nie meer hom self nie. Hy het mal geword.” (We were very happy. Even when he was diagnosed with TB. He did not have a problem with it and took his medication because he wanted to get well soon. But then the big problems began. He began to forget things, scolded and screamed unnecessarily, and was just not himself anymore. He became mad). Upon visiting the clinic, the

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This is slang for having one's menstrual period.

reply was that it was simply a side-effect of the tuberculosis drugs. For Matthew and his family though, *just* a side-effect was no minor problem as the clinic had explained, it was a crisis situation and the only alternative was to discontinue the use of his medication.

Although Sarah had not experienced any side-effects of the medication and completed her six-months of treatment, being tuberculous, had in itself been a side-effect. She found herself becoming compulsive in her demeanour with other individuals. She did not want people to talk too closely with her or shake her hand. Resultantly, she never went out anymore to avoid being in contact with anyone but her family members who she knew were “safe²⁰”, for fear of becoming diseased with tuberculosis again.

“Julle is gelukkig julle is nie susters van die kliniek nie, anders sou ek vir julle van die bleddy trappe afgegooi het.” (You are lucky you are not sisters from the Clinic, or else I would have thrown you from the darn stairs”.) This was the welcome we received at a visit myself and fellow student received when we visited the home of a family of whom four members had had tuberculosis. We were quite lucky we had mentioned that we were students because the lady who said this had indeed looked like she was ready to throw us down the stair case of the flat in which she lived.

Upon questioning, we determined that Della’s bitterness stemmed from the fact that she had suffered quite severe symptoms of the anti-tuberculosis therapy. She had suffered from symptoms of deafness, to being institutionalised for dementia.

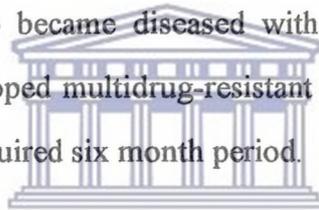
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She knew all her family members did not have the disease because when she was diagnosed, they also went for sputum tests to determine whether they were also diseased. Therefore they were “safe” - to her. She did not know this of other people though.

Moreover, she had even attempted to take her own life. Her hostility towards the clinic though stemmed from the fact that they were extremely unsympathetic to her situation. She informed us that she was even accused of being pretentious of her symptoms and side-effects.

I had mentioned in a round about manner to a few of the clinic staff the hostility of one of the patients I had interviewed that day. To my disgust they replied: “Ai, sy is een van daai MDR pasiënte, hulle is almal so moeilik”. (Ai, she is one of those MDR²¹ patients, they are all so difficult).

Surprisingly this was a common reaction of the nursing staff to the people who had multidrug-resistant tuberculosis. Evidently most of the patients whom I interviewed who had multidrug-resistance were not infected by a multidrug-resistant person and so became diseased with multidrug-resistant tuberculosis. They had in fact developed multidrug-resistant tuberculosis because of cessating treatment before the required six month period.



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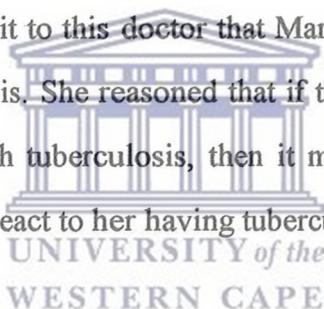
Della's brother also had tuberculosis. He had qualified in one of the biomedical sciences, but since he was diagnosed with tuberculosis his life went down-hill. He had admitted to not completing his medication. But he informed me that it was not because he was being deliberately difficult. Even though he considered having been infected from one of the many sputum specimens with which he worked, he maintained that: “Skoon, geleerde mense kry nie tuberculose nie. Hoe het ek dit dan gekry.” (Clean, educated people do not get tuberculosis. How did I then get it). He had not come to terms with having tuberculosis and supposedly being a disease of the uneducated and unsanitary, he began to question his worth and thought that he was not living a virtuous life. The last straw for him came

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Multidrug-resistant

when the nursing staff came around to his place of employment to give him the medication that he had stopped taking. He could not handle people knowing that he had tuberculosis. He quit his job and has not had (according to him) a good job since. He blamed the nurses for having come around to his place of employment.

Like Della's brother, Mariam interestingly told me that she had not suffered any side-effects of the anti-tuberculosis therapy, but had indeed suffered a side-effect of the contact she had with the tuberculosis doctor just when she had come to terms with the fact that she had tuberculosis, Mariam went to see the clinic doctor who obviously treated her like she was a leper. The doctor stayed behind the desk and treated her as though she/he just wanted Mariam to leave the consultation room as soon as possible. She said the doctor did not even want to touch her. And it was only after her visit to this doctor that Mariam began to develop a complex about having tuberculosis. She reasoned that if that was the manner that a doctor reacted to someone with tuberculosis, then it must really be a dreaded disease. And how would others react to her having tuberculosis.



Many of my informants quoted the side-effects such as those mentioned above as being the reason they stopped with their therapy. Others have noted their unsatisfactory interactions with clinic personnel as their reason for discontinuing with medication. Many informed me that they actually contemplated not continuing with therapy because of these interactions. They were determined not to give the nurses the satisfaction of "getting to them". However, they seemed much more emotionally strong to be able to persevere the unkind behaviour of the nursing staff.

At this point the principles underlying the biomedical paradigm came to the fore quite evidently - their failure to comprehend the mind-body holism at play in the

illness experience. They fail to realise that tuberculosis is a psychological as well as physical disease. These narratives are evidence that tuberculosis in these communities is treated and controlled by biomedicine as a purely physical, physiological disease, free of any psychological or emotional feelings. However, studies on embodiment and the phenomenology of illness experience have become increasingly important ways of investigating the relation of meaning and experience as intersubjective phenomenon (Good, 1994). As opposed to the biomedical perception of the body as object of knowledge, in this tradition the body is perceived as the subject of knowledge, experience and meaning as preceding representation.

Authors like Turner (1984), Scheper-Hughes and Lock (1987), strictly oppose the empiricist Cartesian view of the body, and have adopted a phenomenological perspective whereby humans are seen to respond actively to an external society and actively create their own meanings and their own society through interaction with each other. For example, Scheper-Hughes and Lock (1987) purport that the body is simultaneously a physical and a symbolic artefact, as both naturally and culturally produced. In other words, we possess mindful bodies with embodied knowledge.

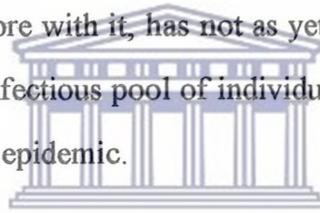
In support of the mindful body phenomenon, Maus (quoted in Turner, 1984) rejects the customary dichotomies of subject/object in favour of unity of mental and physical experience. Turner (1984) contends that while the body is an object with specific physiological characteristics and therefore subject to natural processes of ageing and death, it is never just a physical object. In conjunction, Scheper-Hughes and Lock (1987) purport that illness is not just an isolated event, nor an unlucky brush with nature. Illness is in fact a form of communication, a language of the organs through which nature, society and culture speak

simultaneously. The body should thus be viewed as the proximate terrain where social truths and contradictions are played out. Therefore studies of the body and illness should be carried out phenomenologically as a means of investigating the relationship between meaning and experience as intersubjective phenomenon. Because the medical sphere was a set of dominant rules and guidelines imposed on people to ensure their well-being, bodies were thus placed under biomedical control. Therefore in accordance, tuberculosis can never be viewed as a solely physiological disease because by being non-compliant patients are acting out their resistance to the kind of treatment received by biomedical care-givers. The biomedical care-givers have to realise and acknowledge the subjective, embodiment in which the disease is played out. Failing this, biomedicine maintains its perspective of tuberculosis as being exclusively a disease while losing sight of patients embodied experience of their illness. Therefore in view of this phenomenon, I propose that the biomedical paradigm active in the treatment of tuberculosis, become educated on the holism that exists between mind and body and treat tuberculosis with this interrelation in mind. Not only will patients feel that they are in control of their disease, but by the renewed approach of doctors and nurses to tuberculosis care, there might be an increase in compliance (at least from patients who have had unsatisfactory experiences with the biomedical domain, like those above).

The attitudes of nurses to patients may be attributed to the fact that “real medicine does not in effect encompass the patient, but pathologies (Freund and McGuire, 1991). In other words, doctors are socialised into a purely dichotomised view of the body, failing to take heed of and treat the sociological components of the patient's illness .

This is even played out in the sentiments of nurses towards patients' dissatisfaction with the side-effects of anti-tuberculosis therapy. They contend that they do not know what the big deal is with patients quitting therapy because of the side-effects of anti-tuberculosis therapy. They do not realise the broader implications on the person's body and social world in which they live. They maintain that if they want to get well, they should just “grin and bear it”.

Furthermore, if the stigma attached to tuberculosis is being perpetuated in clinics, people will continue to “hide” their disease. By promoting feelings and actions that any one can get tuberculosis, irrespective of colour or creed, then more people might come to acknowledge the disease. This is especially important in view of the fact that the avenue of people actually having tuberculosis and suspecting it but not coming to the fore with it, has not as yet been explored. By being afraid, there could still be an infectious pool of individuals in the communities who could still be perpetuating the epidemic.



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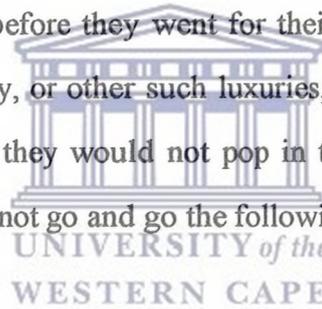
Shamiela's feelings are representative of this phenomenon:

“...Toe ek eers uitgevind het dat ek TB het was my reaksie: Nee fok, ek het ga TB nie. Ek wil liewe nie weet dat ek dit het nie.” (...When I first discovered that I had TB my reaction was: No, fuck, I don't have TB. I rather do not want to know if I do have it.” She explained to me that her reaction had been influenced by her memory of her friend's contact at the clinic. She noted that the manner in which the doctor examined and spoke to her friend was most upsetting to her. For her, if the doctor was afraid of getting it, then it must be a dreaded disease indeed - something she would not want to be diagnosed as having because the reaction of some people in the community was no different from the doctor's.

The negative contact patterns of biomedicine with some tuberculosis patients have even extended to prescribing patients' dress code.

4.2.2 Improper Dress Code

As you enter the Uitsig clinic, there is a big notice indicating that women should not wear curlers or pantihose on their hair when they come to the clinic. The notice goes on to note: "Kom laat ons trots wees op julle". (Come let us be proud of you). I asked patients about this notice and their feelings thereof. They asserted that it was very condescending as some of the nurses were much younger than they were, so who were they to tell them (the patients) that they wanted to be proud of them. Patients were actually reprimanded for not taking heed of this notice. Not wanting to be scolded at, they would skip their daily treatment if they had washed their hair before they went for their medication, because not having blowdryers or electricity, or other such luxuries, they had to sun-dry their hair. If their hair was not dry, they would not pop in to the clinic for their medication, they would instead just not go and go the following day when their hair was dry.



On a couple of occasions I conversed with some nursing staff about patients in general. The conversation yielded that patients had no pride in themselves. They said that they did not know why, if patients knew that they were coming to the clinic to see the doctor or nurse, they did not dress themselves neatly or have a bath at least. They based this on the notion that when going to the doctor, people have the habit of dressing in their newer underwear and "church clothes". What they failed to realise was that this generalisation could not be extended to impoverished communities like Uitsig and Ravensmead where the clothes that some people wear are the only clothes that they have or the other clothes that they do have do not look any better than the ones that they have on at that time.

In accordance with the moralising of patients and unkind behaviour suffered at the hands of the biomedical care-givers, Tagliacozza (1993) notes the perceptions of patients of nurses. Quoted are patient views that they should possess a friendly and kind personality, have an interest in their patients, be eager to the needs of their patients and dedicated to their patients. The results of this study indicated that personality traits ranked far above that of the nurses' actual knowledge and technical skills.

4.3 PERCEPTIONS OF CONTACT

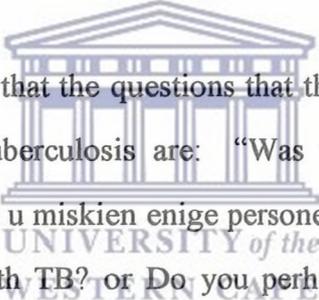
If asked if a patient had contact of any nature with a specific person, the patient would sometimes think a bit and reply that they had not. On further investigation and prying, it would be determined that the patient had in fact had contact with that person. What they define as contact though, is actually knowing the person very well; in other words, being good friends who often drink together either at their homes or in the shebeen; or someone who they would meet with regularly. Important in their perception of contact though, is friendship. This is a pertinent factor because even though if he/she were a regular patron of a specific shebeen and would often drink in the same group as another patron, but they had not in fact built up a friendship, they would perceive this as: "Nee, ons het nie eintlik kontak met mekaar nie." (No, we do not actually have contact with each other). This would imply that the person might in fact have the same kind of relations that he/she would have with one of their friends²², but would not perceive it as contact and so, might have infected the person or have been infected from the person. However, this persons' name would not be given to the tuberculosis care-givers because they did not perceive these people as contacts. If however, the care-

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My respondents have noted that although there is a problem of gangsterism in the communities, there is nevertheless a large sense of comraderie among community members.

givers and patients had the same idea of what contact was, they might have been assisted with the contact-tracing procedure which could narrow the field of the infectious pool. For the biomedical paradigm, on the other hand, contact was described in accordance with those described in the literature²³.

Contact merely meant that the person had to come into contact with a diseased individual. They classify contact like Chapman and Dyerly (1964:49), from sleeping together to “transient, irregular, but not close”. However, what is close? What they do not understand though, is that when they question patients on their contact patterns, they do not realise that the patients answer will depend on who and what they (the patients) think contacts are because the nurses do not ask for specific types of contact.



Nurses explained to me that the questions that they would ask patients who have been diagnosed with tuberculosis are: “Was u miskien in kontak met enige persoon met TB? of ken u miskien enige persone met TB?” (Were you perhaps in contact with anyone with TB? or Do you perhaps know of anyone with TB?). They would then go on to record the names of all the family members of the patients living in their household. In this manner they assume that all other people living in the patients' household are in fact family of the patients. When nurses asked whom patients had contact with, the contacts that they provided were those people whom the nurses had asked lived in the same household as the patients. This brings us to the notion of what a household actually is, which has consequently become debatable as possible sites of transmission.

The differences concerning the perceptions of households are in effect complicated by the fact that doctors, nurses and other biomedical persons have

²³ Refer to chapter 2.

been following the definitions of households as they are conceived of in literature over many years. They have never stopped to consider what a household is for community members either.

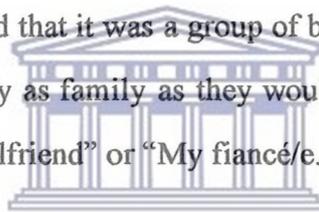
As noted by Lomnitz (1977:99), a household is “a social group of all individuals who share the same residence and who also share the same entrance or access to a residential unit” . However, patients perceived households as being: ”Ons familie”. (Our family). Lomnitz’s definition does not encompass anything about the household being family members, just a social group of individuals. Others have defined households as being the physical house in which the diseased individual lives. The household members would thus be those living in that house. In Uitsig and Ravensmead though, the occupants of a specific house are not always family; there are often many different backyard shacks whose occupants sometimes do not even know the occupants of the brick house in front or of the other backyard shacks on the same erf. Due to the bad socio-economic situation, the owner of the brick house in the front part of the erf, usually acts as a landlord who rents his “land” to other occupants so that his own income may be supplemented. This is a reciprocal relationship as the tenants cannot afford a house of their own and so have to make do with cheap housing viz. a shack in someone's backyard. And the landlord needs his earnings to be supplemented or sometimes he does not work and the money that he makes from renting out his land has to feed his family. and pay his own rent.

According to the findings of this study, although the sharing of a household with someone with active tuberculosis is a risk factor for the transmission of tuberculosis (Coetzee et al, 1988), it is however not a great risk factor. In accordance with Coetzee et al’s assertion, within epidemic communities such as Uitsig and Ravensmead with very low socio-economic conditions, each household

should have at least two cases of tuberculosis of the same strain. I have however, found the contrary. There is a great variation of strains within households, indicating that tuberculosis is also being spread some place outside of the households, within the community.

Medical dogma would indicate that those people with identical strains should have been in contact with one another. Logically one would expect that these people would all be living in the same household. The converse would also be thought to apply, where it would be expected that two persons who both have tuberculosis and live in the same household, would have the same strain of mycobacterium tuberculosis. I have found that this is not always the situation.

Moreover, questioning a few nurses and doctors, asking them what their idea of a family was, they replied that it was a group of blood relatives. Even common law marriages do not qualify as family as they would say: “No, he/she is not family, they are still my boy/girlfriend” or “My fiancé/e.”



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A vast difference in ideas came to the fore when I spoke to informants. They perceived family to be anyone they have had regular contact with for a considerable period of time i.e. approximately ten years, and common law spouses were referred to as husbands and wives. It was thus just accepted that once people who have children together and lived together and looked after each other, they were what the biomedical group referred to as blood relatives. Informants' ideas of family are in tune with the sociologist Murdock's (1991) definition of a family, being a social group of people who share a residence, and material resources where two of the people have sexual relations wherein they produce offspring.” Note that he does not propose that they be blood relatives. However, when patients are questioned as to their family relations or household

members, it is taken for granted that these relations will include only blood relatives.

In other words, had there been a consensus among biomedical domain and patients concerning the nature and cause of their illness, patients would be better equipped to provide information that could help the biomedical domain eradicate disease and aid them in the eradication of their illness. But, because both function within separate world views, they are not familiar with the others views and perceptions.

However, being trained within a sociological/ anthropological framework, social scientists have been able to identify and address such disparities and provide a foundation for the dissemination thereof so that health care will be for and with the patients and not about the patients. Therefore the implementation of a multidisciplinary team working within communities with epidemic proportions of diseases such as tuberculosis, is indispensable to the eradication of the disease because tuberculosis is a social disease and cannot be “mended” at biomedical level. Biomedicine but provides the necessary medication to aid in the optimal functioning of the physical body, which has been negatively affected by a social world.

4.4 MIND-BODY DUALISM

Biomedicine maintains a clear dichotomy between the mind and body whereby the body is viewed as a purely mechanical object free from and unrelated to the physical environment in which it is present. In this manner, disease would be viewed as a purely biological phenomenon. In other words, illness is reduced to a bodily function, viz. physical reductionism. From this it would follow that for

biomedicine an individual's social environment has absolutely no effect on their illness (Freund and McGuire, 1995).

Consequently this view of the body leads to the perception that body is a mechanical object whose breakdown is signalled by disease. Accordingly, like a mechanical object that can be “mended”, so too the body can be repaired when it breaks down. Again, there is a dichotomy because as with mechanical objects, if one part malfunctions, it can be repaired in isolation of the other parts. This notion gives rise to the phenomenon of the body as an object of biomedical control.

The word “control” seems quite ironic with reference to tuberculosis because the word is central to all tuberculosis intervention programmes e.g. the DOTs programme that states that effective *tuberculosis control* is compounded by case holding (Coetzee and Van Der Sandt, 1997); Grange and Festenstein’s human dimension to *tuberculosis control*; Collins’ Applied epidemiology and logic in *tuberculosis control* (1981); *Tuberculosis Control* Programmes in Developing Countries by Shears (1985); and many more. Sbarbaro (1996) even goes as far as to call the implementors of *tuberculosis control* programmes, “controllers”.

Tuberculosis is truly the patients' disease. However, they feel that the programmes that are implemented in the attempt to eradicate tuberculosis in their communities are being implemented from a higher power²⁴ onto lower beings²⁵. Patients however, want an active part in the eradication of their disease. They do not want to feel that they (their bodies) are empty, mechanical objects open to control and manipulation of the biomedical domain. Therefore, taking heed of patients

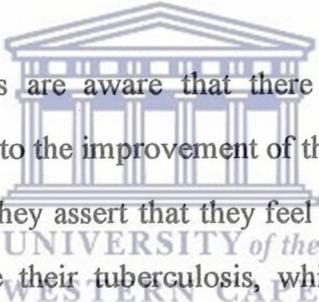
²⁴ i.e. Biomedicine.

²⁵ i.e. Patients.

perspectives on tuberculosis, has provided the groundwork for the incorporation and consequent importance of their views in tuberculosis eradication strategies to make for more effective programmes that may begin to see a downward slope in the present epidemic.

4.5 A TEAM APPROACH

Ellis (1993) uses a craniofacial team as a case study for his analyses of team functioning in health care. He maintains that through a teamwork approach the element of being patient centred acquires more meaning with regard to the kind of care given to a specific patient in the craniofacial clinic. He asserts that although team members retain autonomy in terms of their expertise, they do however function collectively in their goal of the healing of the patient.



I found that if patients are aware that there are a number of professionals functioning collectively to the improvement of their health, they are more willing to come to the clinic. They assert that they feel better knowing that there will be someone who will cure their tuberculosis, while there will simultaneously be someone to understand that having tuberculosis is much more than merely being infected with mycobacterium tuberculosis, it has other psycho-social consequences. This is precisely what Strauss and Ellis (1996) refer to in their notion that multidisciplinary teams, such as the craniofacial team, are a great advantage in that patients psycho-social as well as medical needs are addressed.

The problem with the team of which I was a part, was that professionals were not properly informed of the others' position as well as speciality. For example, my colleague and myself were introduced to other team members as anthropology students. However, prior to our introduction they were informed that we were social scientists. They gathered from this that we do the opposite of what they do.

They never *really* had an idea of the actual dynamics and complexities of the work of an anthropologist. They looked at what we have done, relative to what and how they performed their duties.

This is exemplary of what Ellis (1983) points out in his field notes of his team work:

“He said we spend too much time on discussing social and psychological aspects. Most of it was unnecessary to him. He said he did not want to know who went to bed with whom, and for what reason. All he needed to know is that they did so if it was relevant to the case.” (Ellis, 1993: 129).

A team work approach is indeed necessary and important in health care settings like Uitsig and Ravensmead because as a means of breaking the Cartesian legacy and phenomenological approach that exists between biomedicine and the social sciences. If both domains profess (as they do) that they function to heal²⁶ then they should work together in a team to do so, not to maintain autonomy in their respective professions, but to aid patients in the maintenance of own autonomy over their bodies.

²⁶ Be it illness or disease.

CHAPTER FIVE

CONCLUSION

5.1 SUMMARY OF FINDINGS

This study has set out to provide an illustration of the tuberculosis contact patterns that occurs within Uitsig and Ravensmead as possibly perpetuating tuberculosis transmission in the communities. These have included contact with the biomedical domain. If the contact patterns at this level is negative, it has proven to lead to patients not completing or taking their medication - perpetuating transmission.

Contact patterns at community level has included drinking together regularly in groups, either at neighbourhood bars or at friends' houses. The study has revealed that the kind of contact that occurs in these groups is of a physically close nature. Thus patients come into close proximity with each other; closeness which they would not ordinarily come into contact with at work for example.

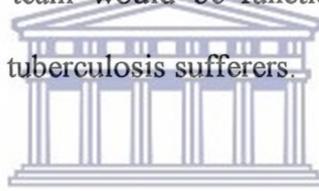
Furthermore, the importance of taking heed of patients' perceptions has been illustrated. Patients' perceptions have been found to be as important as that of biomedicine in trying to understand the present epidemic in Uitsig and Ravensmead.

By having illustrated the differing perceptions of contact, family and households that are held by the biomedical domain and patients, other researchers may be able to note that differing perceptions do exist and that they do impact on epidemics of this nature.

Nurses and other biomedical personnel should also be made aware of their attitudes towards patients and how this impacts on compliance. This point is especially important because nurses contend that sometimes they do not treat patients in the manner as noted above, intentionally, their work load just seems to get to them sometimes. However, nurses work load problems should not be made the patients problems or taken out on them in a negative manner.

5.2 RECOMMENDATIONS FOR FUTURE RESEARCH

It is recommended that multidisciplinary teams definitely be a part of other research of this nature. However, the team should spend some time before the actual implementation of the team, on work shops to discuss what team work really is, and how the team would be functioning to create better and more efficient patient care for tuberculosis sufferers.



Each group of tuberculosis patients should be assigned to a social scientist who should basically act as their mediator between themselves and the biomedical domain and who will provide the patient-centred care that patients demand.

Nurses and other biomedical people working with patients especially, should also be made aware of the disruptive effects of a mind-body dualistic perspective of tuberculosis, for patients.

In conclusion then, patients, biomedicine and the social sciences, should work together on modes of healing that are comprehensible to all three parties, and in so doing patients will receive care that they themselves have helped to implement. Doctors will have a satisfactory relationship with patients because they understand

the functioning of the others' worlds and will so have a satisfactory outcome to their health care delivery. And finally, social scientists would have bridged the gap in knowledge held by patients and within biomedicine, making way for the holism of mind and body.



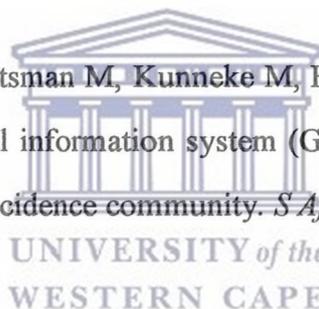
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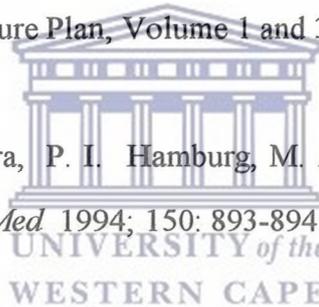
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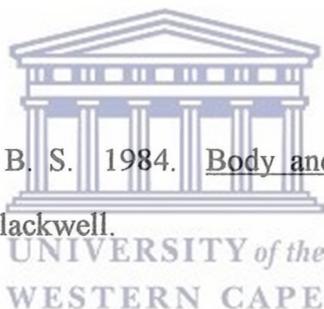
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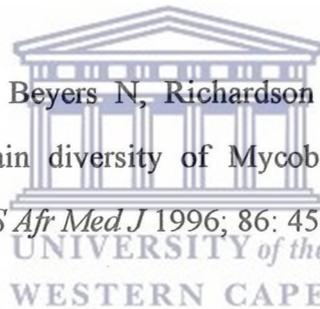
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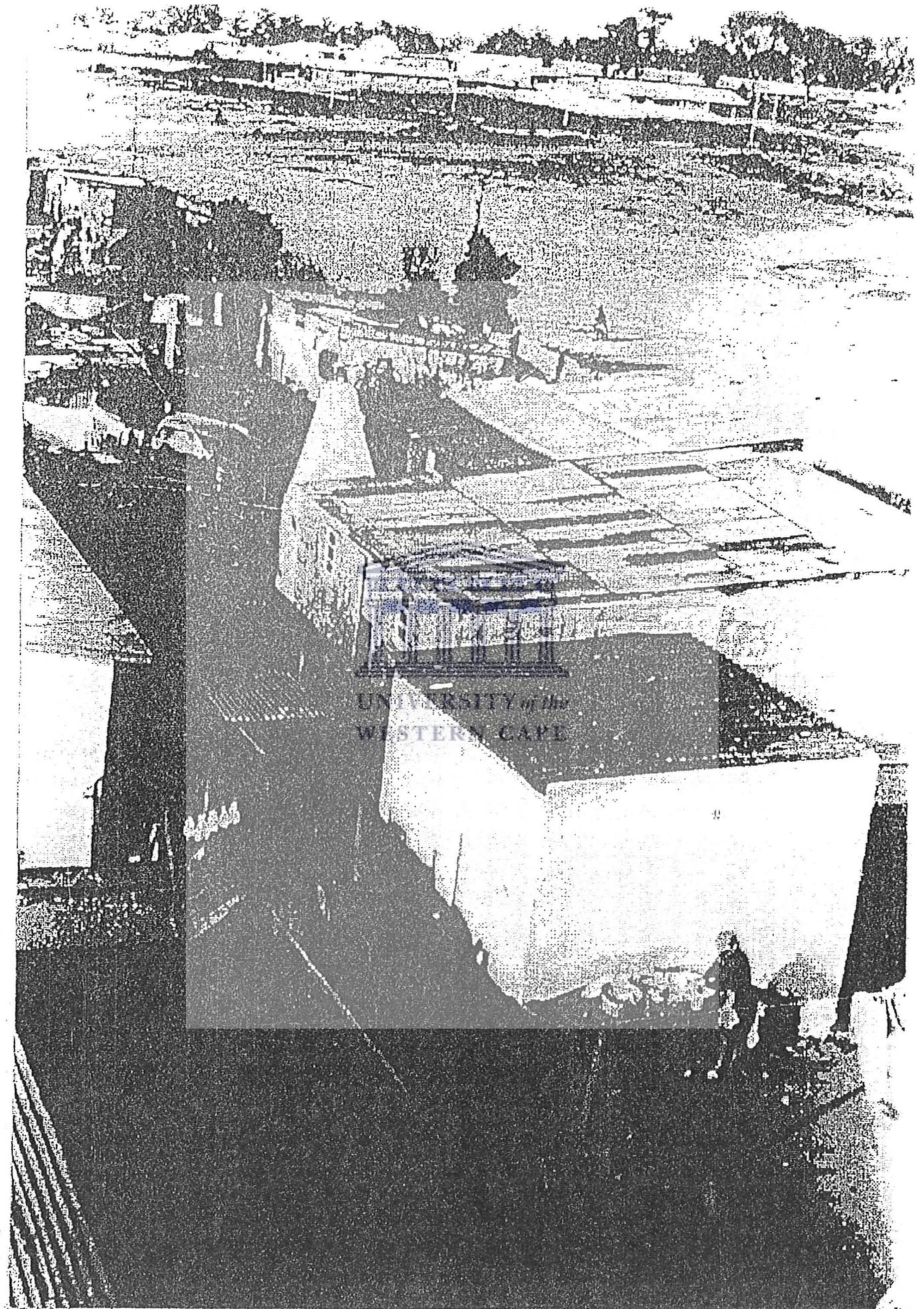
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APPENDIX I.II





**APPENDIX II: ERF'S WITH TWO OR MORE
CASES OF TUBERCULOSIS**

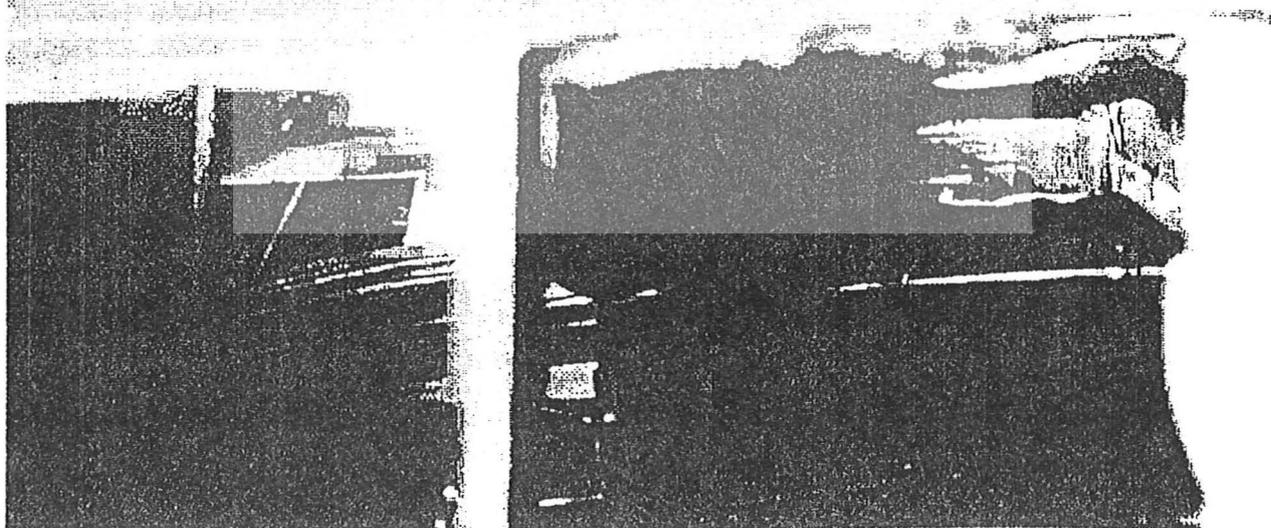
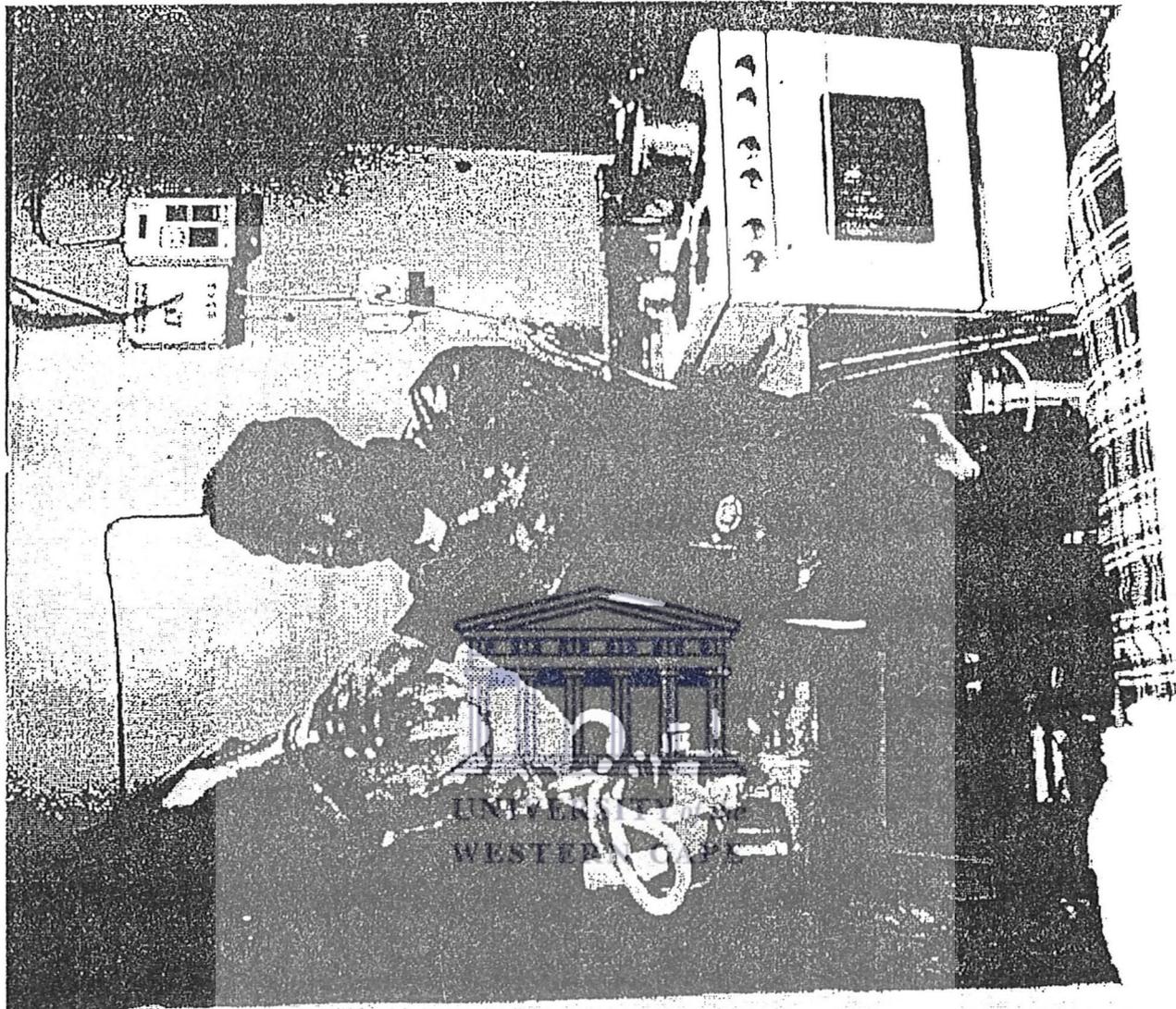




APPENDIX III: MINISTER EBRAHIM RASOOL, PARTICIPATING IN TUBERCULOSIS ERADICATION ACTIVITIES IN THE COMMUNITY



APPENDIX IV: CHILDREN WAITING FOR FOOD AT THE SOUP KITCHEN



APPENDIX V: THE HORSE THAT WALKS THROUGH THE KITCHEN



**APPENDIX VI: PARTICIPANT OBSERVATION - THE RESEARCHER
PLAYING WITH CHILDREN IN THE COMMUNITY**