

COMPLIANCE IN TB CHEMOTHERAPY
STUDY OF PATIENTS AT GEORGE HEALTH CENTRE IN LUSAKA

by

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**A dissertation submitted to the University of Zambia in partial fulfilment of the
requirement for the degree of Master in Public Health**

School of Medicine
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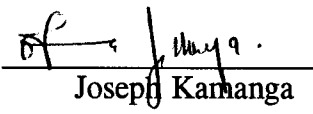
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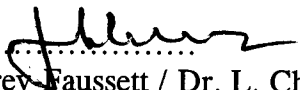
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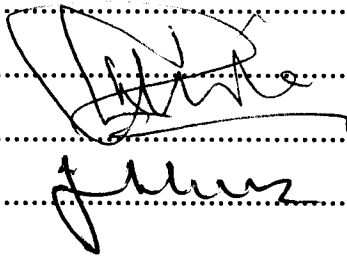
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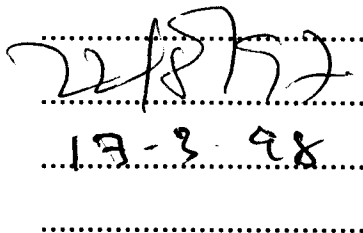
APPROVAL

This dissertation of **Mr. Joseph Kamanga** is approved as fulfilling the requirements for the award of the degree of Master of Public Health by the University of Zambia.

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ABSTRACT:

Tuberculosis has emerged as the most serious infectious disease in terms of morbidity and mortality in Sub-saharan Africa. The disease can be prevented from spreading and those who get infected can be cured if they are diagnosed and treatment is commenced early and taken for a sufficient length of time. To improve compliance and cure Direct Observed Therapy Short course (DOTS) chemotherapy has been introduced. But despite efforts to improve compliance as many as 35% patients on a 1995 Lusaka Tb cohort were reported as defaulters. This study aimed at exploring reasons for this non adherence.

OBJECTIVE:

This study was carried out to determine reasons for lack of adherence to tuberculosis chemotherapy among patients attending George Health Centre in Lusaka.

METHODOLOGY:

General observation of the functioning of the TB clinic was done. All patients on DOTS missing for more than one day in the intensive and more than a week in the continuation phase from the daily morbidity records kept at the Health Centre during the period of february and november 1996 were eligible to participate and were followed to their homes. Those followed were administered with a semi-structured questionnaire and were invited to participate in a Focus Group Discussion (FGD).

RESULTS:

The incidence rate of TB in 1996 was 47 per 10000 population. 215 (33%) of TB patients met definition of non adherent from the morbidity records, 21 (9.8%) of these were true defaulters. 18% had died, 35.8% had shifted residence, 20% gave incorrect address, 10.7% were wrongly labelled as non adherents while 5.6% could not be reached. Among respondents there is a belief in two types of Tb known as the new and the old type. The new type is perceived as being AIDS related and is referred to as bone Tb. Survivors of treatment are viewed as having suffered from old Tb. Respondents felt DOTS was like a punishment because they were required to walk daily for treatment as a result some sent their children to collect drugs for them on a daily basis. Long waiting time is a problem and there is a general lack of counselling on duration and importance of compliance to regimen while the stage of disease impaired some patients from attending and there is stigma attached to AIDS and TB which prevents some patients from attending. The study also established that among women there is a belief not to engage in sexual intercourse while on treatment and are therefore scared of being divorced as a result some did not tell their spouses that they were on Tb treatment and some simply stopped once they felt better. High rental charges and being unemployed made some patient change residence frequently.

Conclusion:

Poor record keeping and high mortality rates contribute to high rate of defaulters being reported. DOTS is generally not being practised as prescribed. Establishment of Tb Health posts and extending operating hours at Health centres would decongest the patient load and improve service.

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May God bless you all and now take time to read salient problems of TB as regards to compliance.

This dissertation is dedicated with deep feelings to my wife Febby as a pillar towards my achievement and to my sons; Chinguwa, Mafananiso, Wezi and my daughter Mwanjiwa Milika for their great comfort and encouragement.

EXECUTIVE SUMMARY

Statement of the Problem

Tuberculosis is a global emergency. Its relationship with Human Immune-deficiency Virus (HIV) has changed the epidemiological pattern with the peak of the disease being mainly in the reproductive and productive age group.

Tuberculosis can be controlled, prevented and cured. This is because the source of infection is usually a person who is ill, secreting the bacilli, who can be identified and get treated to eliminate foci of infection.

To improve compliance to anti-tuberculosis chemotherapy, the World Health Organisation (WHO) has introduced some measures, among these is the introduction of a short course chemotherapy guidelines and the Directly Observed Therapy (DOT). Despite these measures, a Lusaka TB cohort in the first quarter of 1995 reported up to 35 per cent of patients as defaulters of treatment. Tracing defaulters is one of the key activities in the TB control program.

There is therefore a need to establish reasons why some patients on tuberculosis therapy do not adhere to the prescribed regimen.

Objectives

To determine reasons for lack of adherence to tuberculosis treatment among TB patients attending George Health Centre in Lusaka Urban.

Methodology

- o General observation of the functioning of the TB clinic during normal working hours was done .
- o Records of all TB patients in the years 1995-96 for George Health Centre were reviewed both at UTH and George Health Centre.
- o All patients at George Health Centre in the period of February to November 1996 whose record cards were not ticked for more than a day as having reported for DOT and those missing for over a week on continuation therapy after the monthly review date, were defined as defaulters.
- o All defaulters were followed to their homes. A semi-structured questionnaire was administered to all defaulters except for two. These two and the last eight defaulters were invited to participate in Focus Group Discussions (FGDs)
- o Nine FGDs were held stratified according to sex, for those early in treatment; those who were still compliant near the end of treatment; members of Neighbourhood Health Watch committees; defaulters and one combined for members of staff.

Results

The incidence rate of Tuberculosis under George Health Centre in 1996 rose to 47 from the 37 per 10,000 population in 1995. Between February and November 1996 there were 809 TB patients on the register. 215 (33 %) of TB patients during this period were eligible for follow-up as non-adherents. 21 (9.8%) patients met the definition of non-adherent/defaulters, 18 per cent had died, 35.8 per cent had shifted from the area, 20 per cent gave a false address, 10.7 per cent were wrongly labelled as defaulters while 5.6 per cent could not be reached due to distance.

Common Health Problems

In all the nine FGDs and semi-structured questionnaires, Tuberculosis ranked first or second among the top 6 common diseases perceived. It alternated with Malaria and diarrhoea diseases. Other health problems mentioned included cholera, scabies, measles and sexually transmitted diseases.

Nomenclature

TB is commonly known as TB in most of the local languages. '*Chifuba chantanda bwanga*' (cough that is spread but not cured once you get it and patients thin away) seems to be the perception of TB that does not get cured and kills.

Beliefs on Types and Cause of TB

Two types of TB are recognised: The new TB sometimes referred to as Bone-type and the old type (Cough-out). The new type is felt to be associated (or even =) to HIV/AIDS kills but the old is curable. Among the causes of TB mentioned are breathing contaminated air, drinking '*kachasu*' illicit alcohol, sexual intercourse with a woman who aborted and eating beef infected with 'foot and mouth' disease. Health seeking behaviour follow causal factors; patients with "new TB" are likely to go to traditional healers, once they do not improve from medicines given at the clinic. Those who survive treatment and get cured assume themselves to be suffering from old TB and therefore do not consider themselves to have HIV.

Some Factors Identified as Determinants of Non-Compliance

Health Service Factors

o Directly Observed Therapy (DOT)

Patients felt daily walking to and from health centre was like a 'punishment.' The common complaint was burning of the feet. The incentive of adhering to therapy seemed to diminish once the patient felt better. Observation in the clinic showed that some patients did not swallow their drugs whilst in the clinic but only collected them on daily basis. There is a fear of contracting another type of TB through sharing the same cup and therefore patients avoid using the clinic cups. Urine tests are not done

to monitor the taking of drugs. DOT in its present form needs to be re-evaluated and implemented in accordance with prevailing circumstances. A Week's supply of drugs and weekly reviews could be an alternative.

o Waiting Time

During the monthly review, patients wait for a long-time. "We TB patients are not seen as human beings" "*bationa monga si ndife bantu*". "They concentrate on children first." Some gave a history of having collapsed due to hunger while others returned home without being reviewed after becoming impatient. There is need to review how patients are attended to and one possible way is to have permanent staff reviewing patients on daily basis. This could decongest the clinic tremendously and create a good provider - patient interaction and confidence in the health services.

o Health Education/Counselling

The component of health education and sustained counselling is generally lacking. One female patient took ATT drugs for one day only. Health education is crucial in case holding beginning at time of admission to therapy and should be followed by sustained counselling. Only 26 percent of "defaulters" knew how long their treatment should have lasted.

Disease Related Factors

o Sickness and Side Effects

Some patient stop taking prescribed treatment because they became too weak to walk especially if there is no 'wheel barrow' and somebody to carry them to clinic. Others said they were afraid to get drug reactions and that drugs made them feel hungry. They then decided to stop when they just felt better. The duration of TB chemotherapy was also a factor as they got tired of taking medicines.

Social Cultural and Economic Factors

o HIV and Stigma of Tuberculosis

Stigma attached to HIV and related tuberculosis prevented some patients from being seen around the TB clinic '*ama wanu*' (bad omen) as they would suspect that you are suffering from incurable disease, '*ubulwele wa ntanda bwanga.*' Patients sometimes, to avoid being followed and for others genuinely not knowing home addresses, gave an incorrect address. The issue of HIV and Tuberculosis can be addressed through proper sustained counselling giving factual information. Reduction in delay time and provision of privacy would ensure a more user friendly service.

o Traditional Beliefs

Among women there is a belief that once on ATT you are not expected to have sexual intercourse '*kujingula*.' Women are afraid of being divorced, hence they are forced to stop taking the drugs and in some cases hide from their husbands. There is a need for providers of health services to take cognizance of cultural factors acting as barriers and address them through counselling, education of couples, families and community.

o Change of Address

High rental charges and unemployment makes people very mobile in high density areas. They may move to homes within the neighbourhood or out of the health centre catchment area without notifying the clinic staff. There is need for a proper referral mechanism so that monitoring of patients is continued.

Suggestions

Suggestions from participants on how TB can be controlled and defaulting reduced were:

- . Accelerated health education and counselling
- . Use of peer educators such as former TB patients
- . Involvement of family members in administering and collection of drugs
- . Prompt attendance to patients
- . Establishment of health posts in the compound, nearer to patients in order to reduce the distances covered
- . Provision of adequate supply of drugs for at least a week and more cups to be available at the clinic
- . There should be permanent TB nurses on the TB desk.
- . Re-introduction of TB isolation hospitals as used to be the case with Kafue Gorge and Kabwe TB hospital.

Recommendations

Based on the findings of this study the following hypotheses have been generated and need to be tested as recommendations.

1. De-motivated staff results in poor patients' knowledge of signs, causes and consequences of TB which leads to a high default rate among TB patients.

De-motivated staff are less likely to counsel and encourage patients, leading to a high default rate.

Study needed: Randomised intervention study

2. The level of compliance to TB chemotherapy is determined by the level of disability.

Study needed: Cohort study measuring disability level at entry and on follow-up

3. Involvement of peer educators and family members can reduce non-adherence.

Study needed: Intervention study, Randomised controlled trial

4. Provision of adequate supply of drugs reduces rate of non-compliance.

Study needed: Observation cohort

5. Distances and costs determines rate of defaulting.

Study needed: Observation of cohort

6. Availability of staff would reduce waiting time, congestion and thus improve defaulting.

Study needed: Observation of cohort

7. Adequate take home supply of drugs followed by sustained counselling would improve compliance.

Study needed: Randomised intervention study

8. Establishment of TB health posts can improve quality of patients care.

Study needed: Intervention prospective study

9. A TB clinic operating a 24 hour service would have less defaulters.

Study needed: Randomised intervention study

10. Alcohol in take is a factor in the defaulter rate.

Study needed: Observational of cohort

TABLE OF CONTENTS

	PAGE
CHAPTER ONE	
1.0 STATEMENT OF THE PROBLEM	1
Literature Review	2
Conceptual Frame Work	4
Explanation of Terms	5
CHAPTER TWO	
2.0 OBJECTIVES	7
CHAPTER THREE	
3.0 STUDY POPULATION AND TUBERCULOSIS (TB) SERVICE	9
CHAPTER FOUR	
4.0 METHODOLOGY	13
CHAPTER FIVE	
5.0 APPROACH TO DATA ANALYSIS AND RESULTS	18
CHAPTER SIX	
6.0 DISCUSSION	41
CHAPTER SEVEN	
7.0 CONCLUSIONS AND RECOMMENDATIONS	42
ANNEXA 1: CONSENT LETTER	52
ANNEXA 2: CONSENT FORM	53
ANNEXA 3: FGD NEW TUBERCULOSIS PATIENTS	54
ANNEXA 4: FGD WITH NON-ADHERENTS AND COMPLIES	55
ANNEXA 5: HEALTH CENTRE STAFF AND MEMBERS OF HEALTH NEIGHBOURHOOD COMMITTEES	56
ANNEXA 6: NON-ADHERENT QUESTIONNAIRE	57
REFERENCES	61

LIST OF TABLES

TABLE 1	-	MONTHLY INCIDENCE OF TUBERCULOSIS IN 1995 AND 1996 AT GEORGE HEALTH CENTRE
TABLE 2	-	MONTHLY PREVALENCE OF PATIENTS WHO SHOULD BE ON ATT AT GEORGE HEALTH CENTRE
TABLE 3	-	RESEARCH QUESTIONS, METHODS AND INFORMANTS
TABLE 4	-	PROFILE OF PATIENTS RECORDED AS DEFAULTERS
TABLE 5	-	RESPONSES TO SEMI-STRUCTURED QUESTIONNAIRE
TABLE 6	-	FACTORS IDENTIFIED, HYPOTHESIS GENERATED AND STUDIED RECOMMENDED
TABLE 7	-	MAP FOR LUSAKA URBAN HEALTH CENTRES
MATRIX 1	-	NEW TUBERCULOSIS PATIENTS
MATRIX 2	-	COMPLIES
MATRIX 3	-	NON-ADHERENTS (DEFAULTERS)
MATRIX 4	-	NEIGHBOURHOOD HEALTH COMMITTEE
MATRIX 5	-	MEMBERS OF STAFF

CHAPTER ONE

1.0 STATEMENT OF THE PROBLEM

Tuberculosis has resurfaced as a global emergency. Estimates for the next 5 years indicate that by the year 2,000 there will be 15 million new cases of tuberculosis in sub-saharan Africa, (Mwinga, 1995). In Zambia the registered case load trend for both pulmonary and non pulmonary tuberculosis more than doubled between 1982 and 1994, from 14,353 reported cases to 36,000, (BHS MOH 1982-92, MT 1995). The average increase of the total number of new cases from 1992 to 1994 was about 20% per year. No further increase was observed in 1995, (Bosman, 1996).

The relationship of tuberculosis with HIV, the virus that causes AIDS has introduced serious difficulties in relation to case finding, treatment and follow up due to a dramatic increase in the number of cases and stigma attached to AIDS. The peak for both tuberculosis and HIV is among the productive age groups; men 25-34 years and women 14-24 years. Of the patients with confirmed tuberculosis 49-57% are already infected by HIV, (Elliot, 1992).

Tuberculosis can be controlled and eventually eliminated in the World. This is because the source of the infection is nearly exclusively a person who is sick with the disease and thus can be identified. The rate of spread of infection can be reduced quickly if the infectious cases are identified and effectively treated. Reduction in the number of sources of infection will inevitably improve the epidemiological situation, (TGLIC, 1994). The tools required to carry out the tasks exist and can be applied efficiently.

To improve compliance, the World Health Organization (WHO) has introduced short course chemotherapy guidelines but despite this up to 35% per cent of a cohort on tuberculosis therapy in Lusaka urban absconded in the first quarter of 1995, (Bosman, 1996). It is also most likely that some of those recorded as defaulters will have died. Defaulter tracing is one of the key activities in the TB control program whose task is to ensure that tuberculosis ceases to be a major public health problem in Zambia with a reduction in consequences of the diseases on the individual.

To enhance tuberculosis control activities now there is need to establish the reasons why some patients on tuberculosis therapy do not adhere to prescribed treatment.

1.1 Literature Review

In countries with a high prevalence, where the annual risk of infection is 1% or more, 30-70% of the adult population is already infected with tuberculosis bacilli at some point in their lives, (Tan, 1995). Any facility which provides for the treatment of tuberculosis must have a good mechanism to detect treatment defaulter and take immediate remedial action, (Masuyama et al, 1993), only then can we maintain a high standard of control of the disease and prevent the emergence of drug-resistant organisms. Specific health centres for TB patients subjected to intense staff supervision were more likely than those at General Health centres receiving routine supervision to complete treatment. The effect of the intervention on bacteriological conversion (cure) rate was also favourable (Jin et al, 1993)

A study in 130 cases of pulmonary tuberculosis in foreigners residing in Japan found defaulter rate was high at 40.8%, (Ibid). The reason for defaulting was broken down into; discontinuation on his own 68%, repatriation 15% and side effects 19%. In this study the average time of default was 3.2 months after the start of treatment. To reduce on default and irregular drug taking once they feel better another approach has been to shorten duration of treatment. In China a project on directly observed short course chemotherapy by a highly motivated staff had a defaulter rate of 1.6% in their cohort of new smear positive TB cases, (Stott, 1982).

DOT has now successfully been implemented in a variety of settings and found to be associated with substantial improvements in rates of adherence and drug resistance (Alwood, 1994). Results of chemotherapy programs in Malawi, Mozambique and Tanzania had defaulter rates of 2.2%, 11.3% and 9.9% for short course chemotherapy. For standard therapy, the rate of absconding was 24.2% for Mozambique and 15.7% for Tanzania, (Murray, 1996). Long hours of waiting at the public clinic, failure to explain the objectives and actions to the people being served and persuade them to cooperate fully in what is being done, has been highlighted as some of the reasons for failure to control tuberculosis, (Bignall, 1982).

Failure to complete tuberculosis treatment leads to a high relapse rate, prolonged patients' illness, drug resistance, increased likelihood of spreading the infection and adding to the cost due to re-treatment, (Murray et al 1990). For a cost effective tuberculosis treatment, during the intensive phase of treatment (2 months when every dose is supervised) if more than one dose is missed action should be taken. In the continuation phase of treatment (6 months) if a patient fails to attend on the date in a month action again is essential (Crofton et al, 1992). Economic reasons and fear of losing a job has been cited as some of the important reasons why patients may not return to the clinic for their drugs, (ibid).

The high incidence of adverse reactions to thiacetazone has reduced patients' willingness to take the drug. Patients therefore need to be clearly informed of the course of treatment they will be expected to follow and this is often not effectively done. Patients are likely to comply if treatment is perceived as effective and none toxic, (Elliot, 1992).

Simple measures such as reminder letters sent to defaulters were found to be efficacious even in illiterate patients (Paramasivan, 1993). They have also consistently been found useful in reducing broken appointments in variety of settings (Macharia, 1992).

If treatment is to be accessible it must be as near as possible to the patient's home with the minimum possible transport cost to the patient. Drugs must be reliably delivered to the treatment Centre, the waiting time for patients must be as short as possible and staff at the centre must be helpful and approachable. Shortening drug regimens is one of the keys to improving compliance, (Porter, 1992). A random survey in Nigeria to establish reasons for treatment failures among patients with asthma found that in mild disease compliance was worse. The severity of the condition was a sure incentive to comply with treatment. Intellectual level or occupation, age and sex did not explain the fluctuations in compliance, (Khella, 1988). Housing conditions were a major problem, when living with a large family in cramped premises.

TB has a devastating effect on a poor community's socioeconomic fabric. Poverty, over crowding, ignorance and severely limited financial and organizational resources with which to execute effective therapeutic and prevention programs are the main causes of high rates of disease, (Murray et al, 1991).

As a result of stigma attached to TB, employees risk losing their jobs and housing if it becomes known that they have TB. The stigma and stress may be worse for women, (Crofton et al, 1992). In some cultures, having TB may make it difficult to find a husband or may result in divorce. Links between HIV and TB increase stigma. According to Smith, (1993) and the International News - Letter on AIDS, (issue 31, 1996), the 10 most important reasons that may contribute to failure in completing treatment are; poverty, distance, lack of awareness, contradictory advice, social problems, side effects, unavailable drugs, powerlessness, feeling better and unsympathetic staff.

Encouraging people to seek and complete TB treatment is essential for successful TB care and control. Understanding local beliefs, community education and health worker training all play important roles. Beliefs about TB and causes are important influences on peoples' behaviour. Ensuring drug compliance is vital for treatment success. Non compliance is the chief cause of relapse (Harries, 1995) and drug resistance, (Pozniak, 1993), directly observed therapy (DOT) is probably the most effective way to ensure drug compliance.

Health education is a vital tool in reducing poor treatment compliance, (Tiwari, 1992) patients who report for care must be motivated at the first out patient department (OPD), at the time of diagnosis, at drug collection and when reporting for reviews. Family members, relatives and friends should also be motivated at the health institution and at home so that they can keep a watch on the treatment.

Health education given to mothers at 3 monthly intervals, improved compliance with chemoprophylaxis in tuberculin positive children (Sanmarti, 1993). Health education by a nurse in the patient's home was most effective followed by health education by a nurse via the telephone and health education by a doctor at the clinic.

In a report to the Zambia National AIDS/TB program, in Eastern province, of the 463 patients enrolled on short TB chemotherapy 9% of cases died, 9% defaulted and 11% were transferred. In Lusaka of the 462 cases enrolled on short course chemotherapy 5% died, 35% defaulted and 4% transferred (Bosman, 1996).

Supervised, intermittent outpatient therapy has been used within the control program in South India, but has met with limited successes probably because defaulters were not actually traced, (Datta et al, 1993). If patients are too sick to walk they will not attend and if they are able to walk they will not attend clinics which are only open during working hours, (Fox, 1993). Thus a variety of methods of delivery of therapy must be considered with the patients' convenience in mind.

In Wangas, Kenya, success without defaulting among patients on leprosy therapy in one clinic was achieved by holding the clinic without fail and demonstrating personal concern for the well being of the patient, (Huikeshoven, et al, 1978). The control field worker did not always appear at his clinic and when he did his behaviour towards patients was abrupt and authoritarian. Defaulters from the clinics and even patients who continued to attend had grudges against the man. He did not seriously attempt to give health education or to motivate patients to ingest medicine punctually, (ibid).

A retrospective study in Montreal chest hospital found the most important cause of failure of anti-tuberculosis therapy the result of the patient not taking the drug as prescribed. Compliance was higher among those initially hospitalized, those assessed to have better understanding, those prescribed for a duration of 6 to 9 rather than 12 months of therapy and those who returned to follow up within 4 weeks of initiation of therapy, (Menzies, et al, 1993). Compliance could be improved by enhancing patient understanding, closer follow-up and shorter therapy, particularly for those at lower risk of reactivation.

Using anthropological and sociological methods, researchers found that patients weigh costs and benefits of taking particular medications as they perceive them within the context and constraints of their every day lives and needs. More than four fifths of all the patients with suspected inflammatory arthropathy expressed dislike at having to take drugs at all, (Donovan, Blake, 1992). Almost every patient said they would like more information about the drugs they were taking and any others that might be suitable. Fear of side effects was cited by nearly two thirds as primary reason for failure to comply, (ibid).

Among the multitude of barriers to compliance, lack of accessibility, lack of information and indirect costs of treatment (Van Der Werf, et al, 1990) play a key role. Attention to all these factors might improve the care of TB patients, by ensuring structural and functional optimisation of TB control programmes, and by giving directions for effective educational and health promotion programmes (Liefoghe, R., et al, 1995).

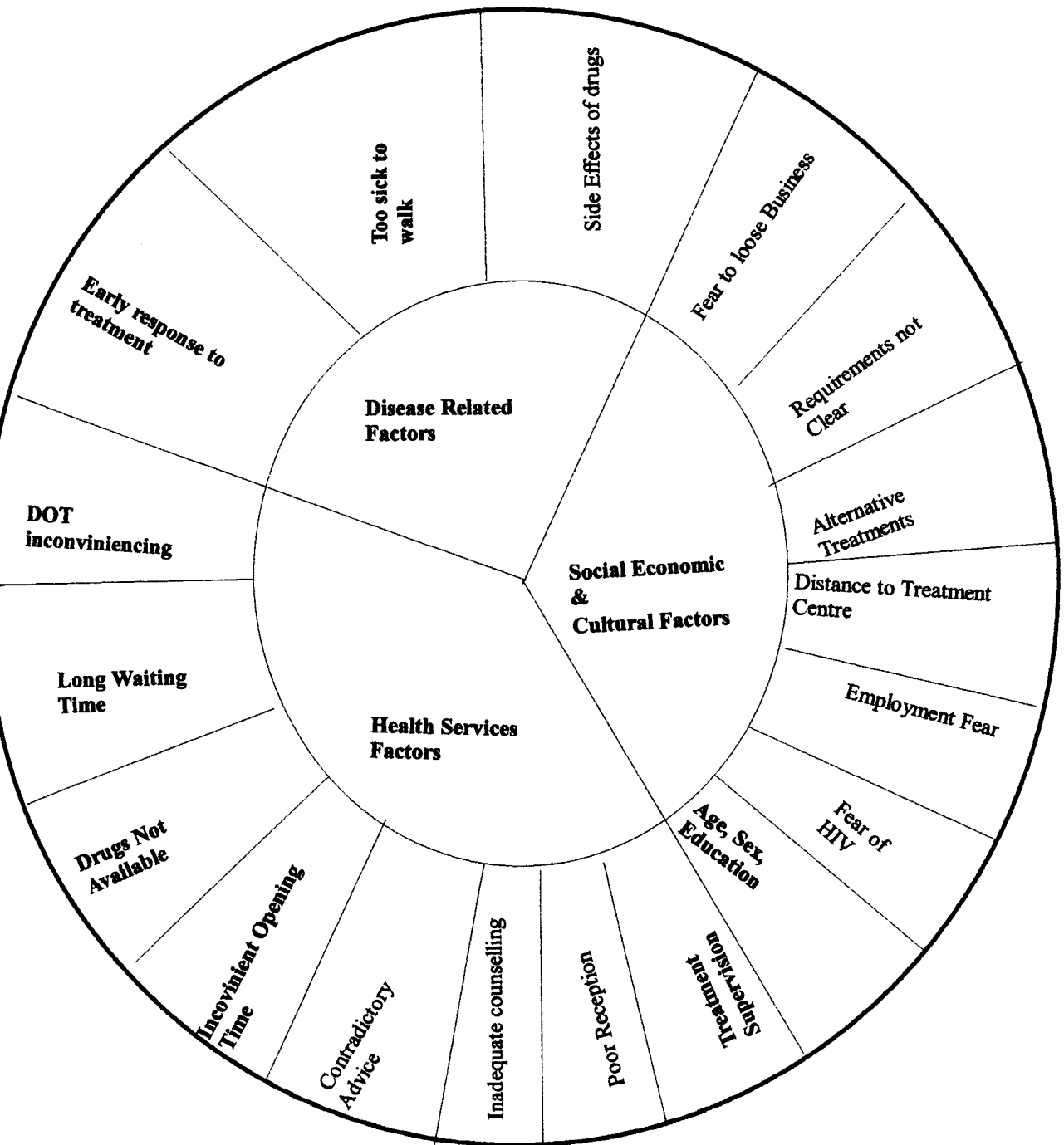
1.2 Conceptual Frame Work

The conceptual frame work is based on several sociological, anthropological factors and surveys tackling the problems of TB. Tuberculosis is curable with current treatment but many stop taking the treatment. Service, disease and socioeconomic and cultural factors may contribute to non adherence to treatment even when effective treatment is available. These factors are highlighted in a pie chart on the next page.

1.3 Explanation of Terms

1. Tuberculosis in this study implies notified pulmonary or extra pulmonary tuberculosis. It was beyond the scope of this study to examine the criteria by which patients are diagnosed and notified with TB, although it is appreciated that in the era of HIV both under- and over-diagnosis occur quite frequently.
2. A Non adherent is one who fails to take or to attend clinic to take the prescribed medicine for one day or more days in the intensive phase or for one month or more in the continuation phase.
3. A Health neighbour hood committee is responsible for a geographical zone and the people living in. The committee report to the health centre about the needs and problems in their zones.

**FACTORS DETERMINING LACK OF ADHERENCE
TO PULMONARY TUBERCULOSIS
TREATMENT**



CHAPTER TWO

2.0 OBJECTIVES

2.1 General Objective

To determine the reasons for lack of adherence to Tuberculosis treatment among patients attending George Health Centre who have been diagnosed and notified to have tuberculosis.

2.2 Specific Objectives

1. To explore whether the health service given to patients with tuberculosis are a contributing factor to lack of adherence to treatment.
2. To find out whether the seriousness of the disease and response to treatment is associated with lack of adherence.
3. To assess if social, cultural and economic factors encourage defaulting.

This was mainly a qualitative study using focus group discussion and responding to a semi-structured questionnaire, but not testing any hypothesis.

According to the World Health Manual of group interview techniques, "people live in communities and form ideas and attitudes in relation to other people around them. Focus group discussion interview techniques allow you to assess opinion and beliefs in a more natural setting than the individual interview provides. Opinions expressed in a group interview setting can be more accurate than those expressed in surveys and participants have the opportunity to react to the opinions of others. This point of view helps you to learn how people feel about an issue and how their feelings may affect their behaviour" (1987).

2.3 Research Statements

This study therefore expected to explore information on the following research statements:

- 2.3.1 Patients do not adhere to tuberculosis regimens because systematic advice and counselling is not provided
- 2.3.2 Patients do not adhere to treatment because operation hours of a health institution are not convenient
- 2.3.3 Those recorded as defaulters will actually have died, been too sick to attend or left the residential house?

2.3.4 The level of education determines the level of adherence

2.3.5 Job insecurity contributes to defaulting

2.3.6 There are alternative medicines being taken by those who default

2.3.7 Directly Observed Therapy (DOT) has improved compliance.

This information will be used to:

2.4 Generate hypotheses for further testing.

CHAPTER THREE

3.0 STUDY POPULATION AND TUBERCULOSIS (TB) SERVICE

3.1 Study Site

To understand and determine underlying reasons behind failure to adhere to tuberculosis regimen, George Health Centre was conveniently chosen. It has the second highest Tuberculosis workload at over 10 per cent of recorded cases in Lusaka, (Bosman, 1996). The centre is also one of the few centres in the city currently doing sputum examinations. The population profile and other indices of social economic and housing conditions are fairly homogeneous.

3.2 George Health Centre

George Health Centre has a catchment population of about 338,278 (1995 estimates) from nine main compounds, namely, George itself which contributes 51 per cent, others are Lilanda-West and Lilanda Site and Service, Desai, Soweto, Paradise, Lusaka West Farms, and Ballastone Park.

3.3 Staffing

The Centre has currently seventy members of staff. The members include six registered nurses, thirty-five enrolled nurses and three clinical officers. One of the clinical officers was on sick leave receiving anti-tuberculosis therapy in the Intensive Phase. One of the two remaining clinical officers, is the TB and Leprosy control officer but he also attends to general cases. The average month workload in 1996 was about 6,568 patients visits.

3.4 Tuberculosis Control Activities

Patients with tuberculosis do not have a permanent room in which they are seen. They are either seen in the bay inside the clinic or at the space on the entrance to the clinic opposite the antenatal clinic or in the demonstration room. The latter has permanent seats and a running water tap and a sink.

There is no permanent nurse attached to the TB clinic. Any of the enrolled general nurses is assigned on a daily basis. Most of them have attended a TB management course. Where the nurse scheduled to be at a 'TB desk' as it is called, fails to report, the sister-in-charge has to find a substitute and in such cases the patients may receive treatment quite late.

There is a laboratory technician doing TB sputum examinations and those found with Acid Alcohol Fast Bacilli (AAFB) are commenced on treatment immediately. In 1996, 72 (23 per

cent) of the 313 sputum specimen examined at George laboratory were found with AAFB. The majority of patients on TB register are, however, referrals from University Teaching Hospital.

3.5 Tuberculosis Clinic

The incidence of TB in 1996 under George Health Centre catchment was 47 per 10,000 population, leading to an expected prevalence of >339 patients on therapy at any one time. There are approximately 100 patients on daily Directly Observed Therapy (DOT) with up to 2 new cases daily being added to the register each working day, Table 1 and 2.

All patients notified have an identity card which they carry. On the identity card there is a number which accesses them to a treatment card left in the clinic. The card has a calendar and is supposed to be marked each time drugs are taken or supplied.

During the study period, it was quite common to see nurses write numbers of patients on cards with the hope of pulling them later and having them marked, which at times they did not do. The result of this is that even those who attended the clinic and got the drugs were not marked and appeared as being absent.

Water is not always available at the TB desk (if the clinic is being conducted) outside the demonstration room. When water is available in the container or from the tap, it is not uncommon to hear patients grumble about the use of same cups and this is clearly demonstrated by several patients who come with their own cups. When the nurse is not alert some patients pretend to drink their medicines but actually drank water only, and put their medicines in the pocket. It is very common to see children or spouses being sent to collect drugs on patient's behalf. Some patients are brought on wheel barrows, whilst others can be seen carried on the back or on an improvised stretcher.

3.6 Monthly Review

All patients are expected to be reviewed by the TB control officer once a month. Two review dates falling on Wednesday or the third and fourth week of the month are used. These dates are set by the District TB Control Officer in the office of the Director of Public Health.

The estimated monthly number who should be on ATT at George Health Centre is between 450-600 patients (Table 2) in both Intensive and Continuation Phase based on monthly incidence in the year 1996, but just over 50 per cent of these are reviewed. On a review date patients report as early as 6:00 hours with some sending their children as an advanced party with a card, so that it can be deposited in front. The clinic may go on up to late afternoon (long slow queue).

During the Study period, some patients were seen returning to their homes after waiting for a long time and only came the following day to collect their drugs. As a result of not being reviewed some patients have continued being on an Intensive Phase of treatment well after two months of daily collecting ATT from nurses.

Table 1: Monthly Incidence of Tuberculosis in 1995 and 1996 at George Health Centre.

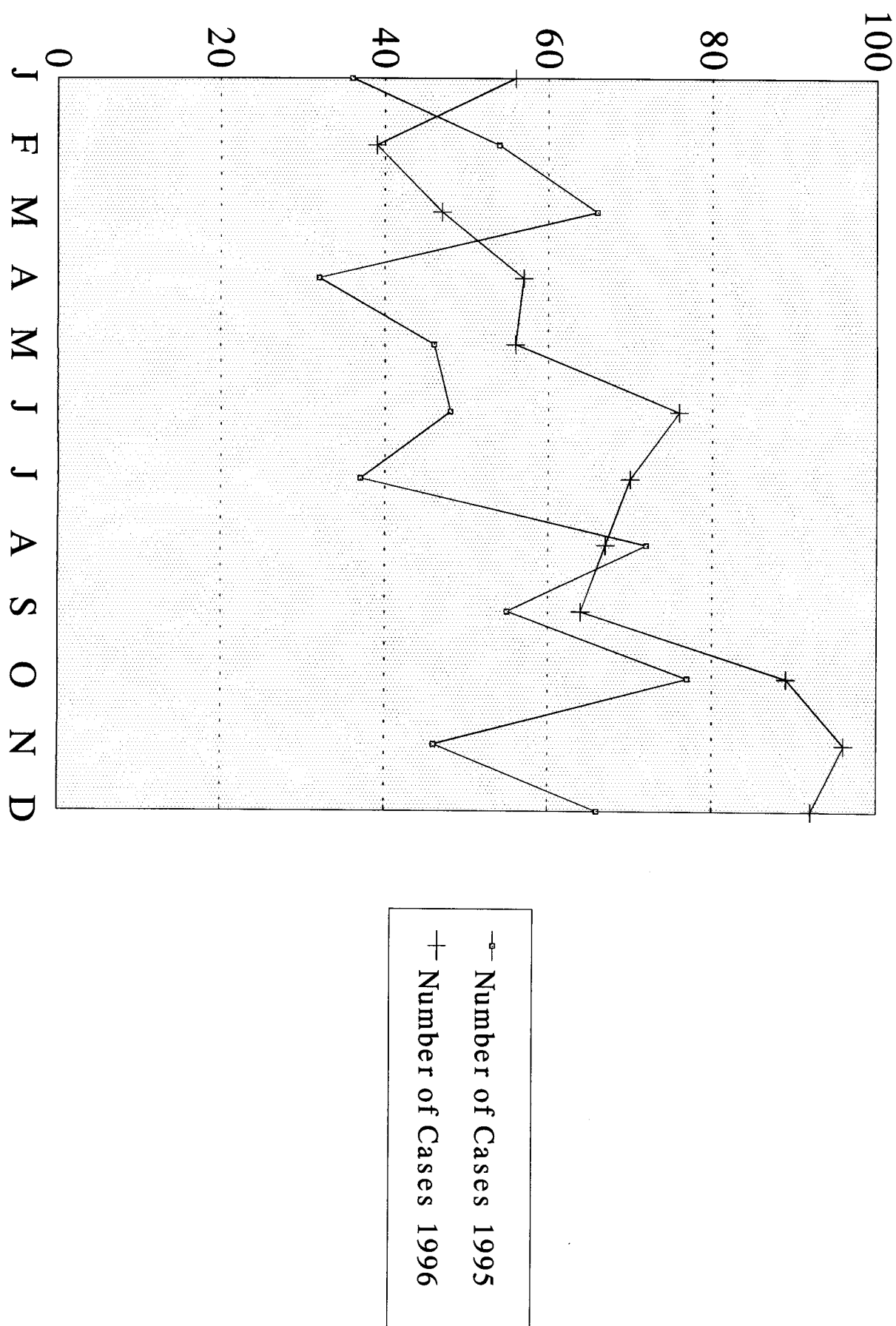
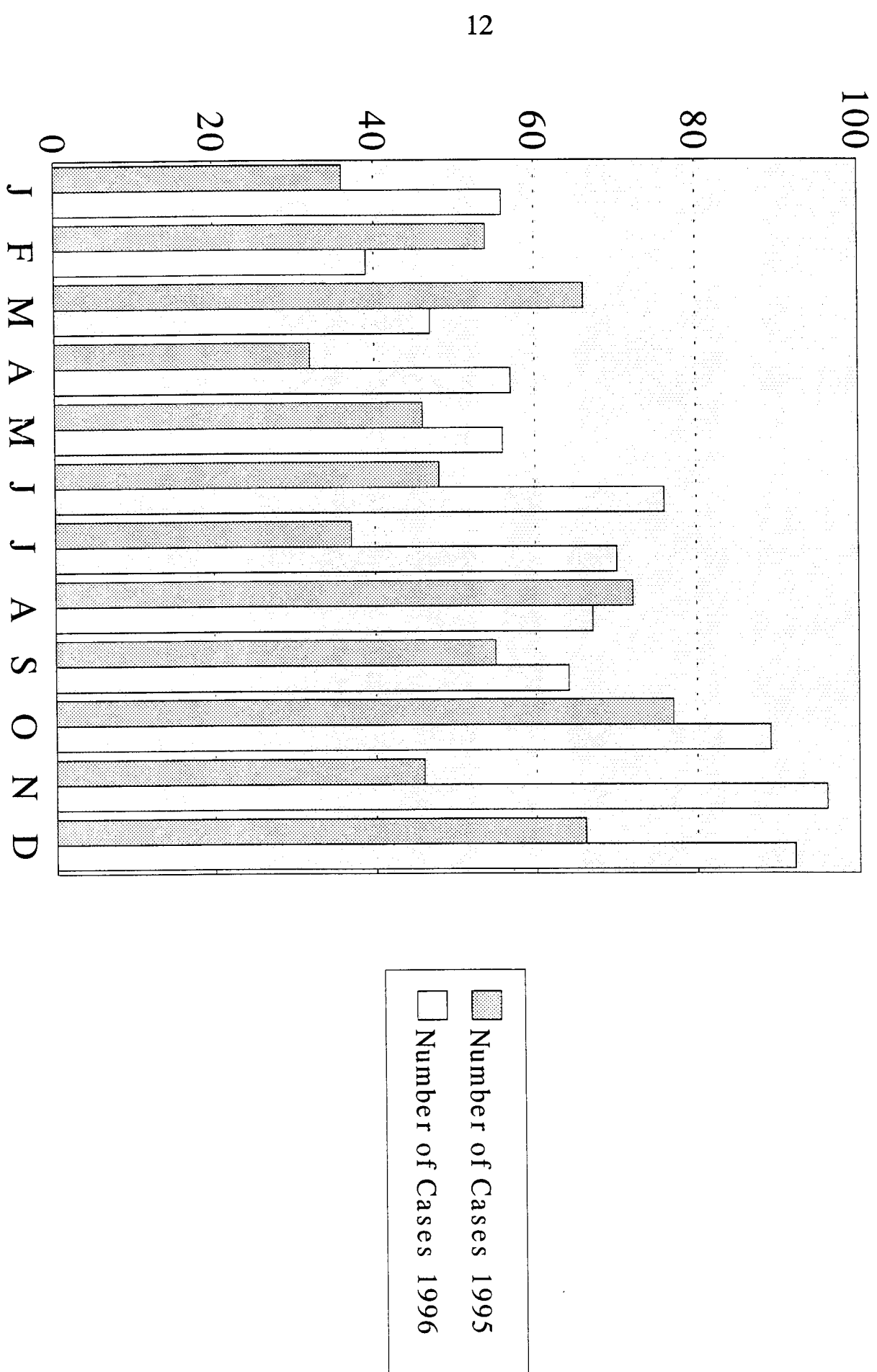


Table 2: Monthly prevalence of Tuberculosis in 1995 and 1996 at George Health Centre



CHAPTER FOUR

4.0 METHODOLOGY

4.1 Steps Taken in the Implementation of the Study

4.1.1 Step 1: Permission to Proceed

In accordance with the governing regulations on research involving human subjects, approval was obtained from the Research Ethics Committee of the University of Zambia. Permission to conduct the Study at George Health Centre was also obtained from the District Director of Health.

4.2 General Observation of functioning at Clinic

During normal working hours, the investigator was present in the clinic and recorded observations concerning the patient/clinic interaction.

4.2.1 Step 2: Selection of Participants for FGD and Semi-Structured Questionnaire

4.2.2 a) Retrospective Review of Records at the University Teaching Hospital (UTH)

All records of Tuberculosis patients notified at the University Teaching Hospital and referred to George Health Centre for drug supply and monitoring were obtained from computerised data of all TB patients notified by University Teaching Hospital. In the period 1995-96 this data was kept by the Zambian AIDS Related Tuberculosis (ZAMBART) project in the Department of Medicine.

4.2.3 b) Retrospective Review of TB Records at George Clinic

All TB records in the years 1995-96 were reviewed. These records include all patients diagnosed, commenced on treatment and referred for follow up at George Health Centre. They also included all sputum positive diagnosed and commenced on Anti-Tuberculosis Therapy (ATT) at George Health Centre.

4.2.4 c) Using the Zambia National Tuberculosis Treatment Cards

All patients whose cards were not ticked for more than one day in Intensive Phase or for one week or more in the Continuation Phase as having come to take their drugs were recorded as non-adherents and were eligible for inclusion. Those who resumed after defaulting were also included.

Initially patients in the period of April to October 1996 formed up the study sample. This was, however, later extended back to February, 1996 in order to have a sufficient sample.

The names of patients, card numbers, addresses, date when treatment was commenced and first default date were obtained.

4.2.5 d) Using Two Male Research Assistants Familiar with the Compounds

All homes of allegedly non-adherents were visited. Permission to administer a detailed semi-structured questionnaire was obtained from those found at home. The last five men and five women were invited to participate in an all male and all female focus group discussion. Two of the participants, one male and one female, were not given a detailed semi-structured questionnaire but had a demographic part of the questionnaire.

Invitation letters were left at the homes of those who were not present to visit the clinic and see the researcher at the TB desk. The questionnaire was then administered.

4.3 Step 3: Focus Group Discussion (FGD)

4.3.1 Description of Research Tool

Nine out of eleven planned FGDs were done as the main method to explore information needed to understand factors underlining lack of adherence to tuberculosis therapy.

In order to facilitate discussion and have a greater contribution considering the difficulties and practicability of getting enough subjects, FGD's consisting of 5-11 people were held. Only two FGDs out of the planned four for non-adherents were not done, partly due to insufficient subjects, secondly it became clear that no new information was to be obtained.

To afford more open discussion and avoid gender differences in expressing opinions of what has been referred to as the "peacock effect" (Axelrod and Myril, 1975) where men out-speak women, separate FGDs for men and women were held. The FGD took 45 minutes to 1½ hours.

4.3.2 The first and second FGD, for men and women respectively, were held for newly diagnosed TB patients who had taken treatment for less than a week. This aimed at exploring understanding of their health problem, information given and illness concept.

4.3.3 The third and fourth FGD were held for men and women who had almost completed treatment. These are survivors of the disease and the aim was to illicit their views on

health services, disease related and social economic factors as determinants of defaulting.

- 4.3.4 The fifth and sixth FGD were held for members of neighbourhood health committee whose function is to be 'watch dogs' of health in the community. They deal with issues of sanitation and health reforms. The discussion aimed at identifying patterns and trends in health seeking behaviour and the perceptions of the community about defaulting.
- 4.3.5 The seventh and eighth FGD of male and female respectively, were held for non-adherents. These were a mixture of early and late non adherents. The definition used was that of defaulting for a day or more in Intensive Phase and a week or more in Continuation Phase. Factors based on service delivery, disease and social factors based on personal experience were explored.
- 4.3.6 The ninth and last FGD was held with 10 members of staff and one of the two research assistants. The staff included the sister-in-charge, the two clinical officers and six of the nurses involved in dispensing drugs to TB patients.

4.4 Step 4: Semi-Structured Questionnaire

A semi-structured questionnaire was administered by the researcher to 17 of the 19 participants.

TABLE 3: RESEARCH QUESTIONS, METHODS AND INFORMANTS

RESEARCH QUESTIONS	METHOD	INSTRUMENT	INFORMANT
Do patients not adhere to Tuberculosis regimen because systematic advice and counselling is not provided?	- Interview - FGD	- Questionnaire - Tape-recording - Notice	- Adherents - Non-adherents
Do patients not adhere to treatment because operation hours of a health institution are not convenient?	- Interview - FGD	- Questionnaire - Tape-recording - Notice	- Adherents - Defaulters - Neighbourhood Health Committee - Staff
Are those recorded as defaulters will actually have died, been too sick to attend or left the catchment area?	- Records - Interviews	- Health Centre records	- Family members - Landlords - Neighbours - Neighbourhood Health Committee members
Does level of education determine the level of adherence?	- Interview	- Questionnaire	- Responses analysis - Staff
Does job in security contribute to defaulting?	- Interview - FGD	- Questionnaire	- Adherents - Non-adherents
Are there alternative medicine being taken by those who default?	- Interview - FGD	- Questionnaire - Tape-recording - Notice	- Adherents - Non-adherents - Neighbourhood Health Committee - Staff
Has Directly Observed Therapy (DOT) improved compliance?	- Interview - FGD - Participant observation	- Questionnaire - Tape-recording - Notice	- Adherents - Non adherents - Staff

4.5 Limitations to the Study

The limitations in this study can broadly be divided into three:

- i) The limitations that relate to the instruments/tools used
- ii) The limitations that are related to the subject under study
- iii) The limitations that relate to study site

4.5.1 a) Limitations that Relate to the Instrument Used

There has been some arguments about the use of qualitative methods like focus group discussion as the only instrument or tool to be used in trying to answer some research questions. One argument against use of FGD as the main tool has been due to the fact that they are usually done in a natural setting and therefore have less control on different variables and data to be generated. In this Study all the FGDs were held in a common room of the Maternal Child Health Clinic (MCH) of the Health Centre. This was seen as the only suitable place in the clinic building.

FGDs are mainly used to supplement quantitative research and therefore are a better method for exploring understanding. Rather than to infer or test hypotheses, they generate a possible range of questions.

This Study therefore did not test any single hypothesis but aimed at providing insights into the tuberculosis problem as regards non-adherence to treatment.

4.5.2 b) Limitations Relating to Subjects Under Study

The increase in incidence of tuberculosis has largely been attributed to HIV. This is probably a result of endogenous reactivation of dormant tuberculosis in infected patients and also due to susceptibility by those immune-suppressed.

The result of this study has shown high morbidity and mortality among patients. The disabilities caused by the disease leads to a general fear and increase stigma already attached to the disease. This can be seen through high mobility and false addresses given by the patients.

Difficulties in diagnosis of TB especially with underlining HIV may lead to under or over diagnosis. Thus patients, who do not in reality have TB may still be on treatment and may not respond. This may affect their adherence.

4.5.3 c) Limitations that relate to the Study and Population

George Health Centre was conveniently selected. Findings from this Study based on the population which is homogeneous and of low social economic status cannot be generalised to the whole population of Zambia nor even of Lusaka.

CHAPTER FIVE

5.0 APPROACH TO DATA ANALYSIS AND RESULTS

The approach to data analysis and presentation of results was based on the methodology and instrument used. The following steps were followed:

5.1 Analysis

5.1.1 a) Establishing Non-Adherents

All followed non-adherents were grouped into defaulters who had not resumed treatment at time of the Study, defaulters who had resumed, those who had died, those who shifted residence from the one on the card, those who gave false addresses, those wrongly labelled as defaulters and those not visited.

5.1.2 b) Focus Group Discussion (FGD)

Notes were taken by the note-taker and the researcher. The discussion was tape-recorded (Permission was obtained from participants).

Notes and tapes were analyzed later in the evening by the researcher. Recurring themes as related to research questions were noted. The tapes were replayed for clarity of the information. Matrices were then developed based on the category of responses.

5.1.3 c) Semi-Structured Questionnaire

Nineteen of the twenty-one non-adherents responded to a questionnaire. The questionnaires were coded, entered and analyzed using EPI 6 Info computer package.

5.2 Results of Non-Adherent Follow-Up

There were 809 new cases of tuberculosis patients in 1996 under George Clinic, affecting people over 5 years. The population above 5 years was about 173,534. This therefore gives annual incidence of the disease of approximately 47 per 10,000 persons.

The Study covered period of February to November 1996. During this period 661 new cases were entered as new cases, 215 (33 per cent) were identified as possible defaulters and were therefore followed. Table 4 gives a summary of the patient recorded as defaulters or non-adherents. The actual non-adherent rate was nearly 10 per cent of which only five (2.3 per cent) had defaulted without resuming treatment. Eighteen per cent of those recorded as defaulters had actually died whilst seventy-seven (35.8 per cent) were reported to have shifted from the contact address, and therefore could not be interviewed. A further 20 per cent had given false or non-existent addresses and 5.6 per cent could not be visited due to logistics. Thus, 132 (61%) could not be classified as to whether they had defaulted, resumed, not defaulted or died.

TABLE 4: PROFILE OF PATIENTS RECORDED AS DEFAULTERS

SEX (NO)	DEFaulter NOT RESUMED	DEFaulter RESUMED	DIED	SHIFTED NO CONTACT ADDRESS	WRONG ADDRESS	NOT DEFAULTED	NOT VISITED
M 121	3	6	28	41	25	9	11
F 94	2	10	11	36	18	14	1
215	5 (2.3%)	16 (7.4%)	39 (18%)	77 (35.8%)	43 (20%)	23 (10.7%)	12 (5.6%)

At least $39 + 23 = 62$ (29%) should not have been recorded as defaulters. Therefore the true figure for defaulters in George Health Centre for the study period is <23 per cent rather than the 33 per cent, recorded in the routine statistics. WHO's new global targets (Kochi, 1991) suggest that 15% is the maximum acceptable default rate.

5.3 Results from FGD and Semi-Structured Questionnaire

The Study emerged with two sets of results, one of qualitative nature arising from nine Focus Group Discussions (FGDs) held and another of quantitative nature arising from nineteen Semi-Structured Questionnaires administered.

The process of validating the data was a continuous one throughout the Study. The FGD tapes had to be replayed to ensure accuracy of information. In order to give an overview of the data from Focus Group Discussions Matrices have been used.

MATRIX 1A: NEW TUBERCULOSIS PATIENTS

DEMOGRAPHIC DATA

AGE GROUP/SEX (NUMBER)	MARITAL STATUS	EDUCATIONAL LEVEL	OCCUPATION
23-37 Male = (6) Mean Age = 30	.Single = 2 .Married = 2 .Divorced = 2	.Primary = 2 .Junior Secondary = 1 .Senior Secondary = 3	.Control room attendant = 1 .Welder = 1 .Self employed = 1 .Unemployed = 3
18-43 Female = (11) Mean Age = 30	.Single = 7 .Married = 1 .Divorced = 1 .Widow = 2	.Primary = 10 .None = 1	.Business = 2 .Unemployed = 9

MATRIX 1B: HEALTH SEEKING BEHAVIOUR AND COMMON HEALTH PROBLEMS

AGE GROUP/SEX (NUMBER)	DURATION OF SYMPTOMS BEFORE COMMENCEMENT OF ATT	ORDER OF HEALTH SEEKING BEHAVIOUR PRIOR TO ATT	ORDER OF PERCEIVED HEALTH PROBLEMS
23-37 Male = (6)	.< 1 month = 1 .1 month-1 Yr = 4 .> 1 Year = 1	.Health centre = 3 .Private clinic = 2 .Traditional healers = 1	.Malaria .Tuberculosis .Cholera .Diarrhoea .Abdominal pains .Sores on the body .Herpes Zoster .Traumatic wounds
18-43 Female = (11)	.< 1 month = 3 .1 month-1 Year = 6 .> 1 Yr = 2	.Health centre = 7 .Traditional healer = 3 .Private clinic = 1	.Tuberculosis .Abdominal pains .Cholera .Headache

FGD: NEW TUBERCULOSIS PATIENTS

MATRIX 1C: CAUSAL BELIEFS, REASONS FOR HIGH TB RATES AND SUGGESTED CONTROL MEASURES

AGE GROUP/SEX (NUMBER)	BELIEFS ON TYPES AND CAUSE OF TB	REASONS GIVEN FOR HIGH TB RATES	SUGGESTED CONTROL MEASURES FOR TB
23-37 Male = (6)	.Two types -new kills -old does not kill .Airborne - breath in .Personal contact .Drinking 'kachasu' (illicit brew) destroys lungs .Sexual intercourse with women who aborted or miscarried .Eating beef infected with 'Foot and Mouth disease "denkete"	.Use of some cups, tins of "chibuku" and other utensils .Some patients stop taking TB drugs as soon as they feel better .Heavy alcohol intake .Congestion in the compound	.Health education in the community .Peer educators from among TB patients
18-43 Female = (11)	.Two different types -new kills, detected in saliva -old does not kill, not detected in saliva .Cause by HIV germ 'akashishi' .Contaminated razor blades .Coughing out and breathing in TB germ	.Using some cups when drinking .Shortage of some TB drugs .Fail to walk to health centre and get treatment	.Avoid sexual promiscuity .The clinic should have enough drugs

MATRIX 2A: ADHERENTS (COMPLIES)**DEMOGRAPHIC DATA**

AGE GROUP/SEX (NUMBER)	MARITAL STATUS	EDUCATIONAL LEVEL	OCCUPATION
18-56 Male =(6) Mean Age =33	.Single =2 .Married =4	.Primary =4 .Junior Secondary =2	.Businessman =2 .Security guard =1 .Unemployed = 3
19-31 Female = (11) Mean Age = 26	.Single = 1 .Married = 7 .Divorced = 2 .Widow = 1	.Primary = 7 .Junior Secondary = 4	.Business woman = 4 .Unemployed = 7

MATRIX 2B: KNOWLEDGE AND ILLNESS HISTORY PROBLEMS

AGE GROUP/SEX (NUMBER)	KNOWLEDGE OF DISEASE	DURATION OF SYMPTOMS BEFORE SEEKING MEDICAL ATTENTION	AVERAGE LENGTH ON TREATMENT
18-56 Male =(6)	.Yes =6 .No =0	.<1 Year =0 .1 month-1 Yrs =0 .>1 Year =6	.>6 months =3 .>7 months =2 .>8 months =1
19-31 Female =(11)	.Yes =11 .No =0	.<1 month =2 .1 month-1 Yr =8 .>1 year =11	.>6 months =4 .>7 months =3 .>8 months =1

FGD: ADHERENTS (COMPLIES)

MATRIX 2C: HEALTH SEEKING BEHAVIOUR, FREQUENCY OF DRUG TAKING AND BELIEFS ON HIGH TB INCREASE

AGE GROUP/SEX (NUMBER)	ORDER OF HEALTH SEEKING BEHAVIOUR PRIOR TO ATT	FREQUENCY OF TAKING ATT	REASONS GIVEN FOR HIGH TB RATES
18-56 Male =(6)	.Traditional healer =4 .Heath Centre =2	.Daily =6	.Fertiliser and chemicals applied to crops and food
19-31 Female =(11)	.Health Centre =5 .Traditional healer =5 .Private clinic= 1	.Daily =11	.Closure of Kafue Gorge and Kabwe TB hospitals resulting in TB patients spreading disease in the community . Bible prophecy of increasing epidemics to come

FGD: ADHERENTS (COMPLIES)**MATRIX 2D: CAUSAL BELIEFS, TYPES OF TB AND SOME SOCIAL FACTORS CONTRIBUTING TO DEFAULTING**

AGE GROUP/SEX (NUMBER)	TYPES OF TB AS PERCEIVED IN THE COMMUNITY	COMMON BELIEFS ON TRANSMISSION AS PERCEIVED BY ADHERENTS	SOCIAL FACTORS CONTRIBUTING TO DEFAULTING
18-56 Male = (6)	.Two types -Bone TB -Sputum TB .Bone TB is AIDS related and kills .Sputum TB does not kill. Patients get well	.Smoking burns lungs .Heavy drinking (wine and "kachasu") burns lungs .Food eaten after fertiliser and other chemicals applied	.Transport .Residence change .Job security .Too much alcohol in-take .AIDS label - stigma
19-31 Female =(11)	.Two types -with a cough -without a cough .With a cough has malaria symptoms .Without a cough has swollen abdomen symptoms	.Sharing cups, plates, spoons .Sharing room without enough fresh air .Eating contaminated meat .On over loaded buses 'muchintubwingi' .Hereditary	.Fear to be associated with AIDS .Compound influence .Alcohol .Distance .Some employers refuse to give permission

FGD: ADHERENTS (COMPLIES)

MATRIX 2E:

EXPRESSING HEALTH SERVICE RELATED, DISEASE RELATED
FACTORS AND SUGGESTIONS TO REDUCE DEFAULTING

AGE GROUP/SEX (NUMBER)	HEALTH SERVICE RELATED FACTORS	DISEASE RELATED FACTORS	SUGGESTIONS TO REDUCE DEFAULTING
18-56 Male = (6)	.Long waiting time . Congestion	.Feel better .Stigma - bad omen 'Ma one' assume you have AIDS	.Former TB patients be used as peer educator .Involvement of family in the care .More staff .Improve on time .Daily Observed Therapy (DOT)
19-31 Female = (11)	.Long waiting time .Relatives refused to collect drugs on behalf of very sick patients .Shortage of some drugs .Treatment take long (duration)	.Feeling better .Some medicines are bitter .Side effects of drugs - hunger and dizziness	.Begin clinic early .Relatives be allowed to collect drugs .DOT should continue because some patients do not take drugs at home

MATRIX 3A:

NON-ADHERENTS (DEFAULTERS)
DEMOGRAPHIC DATA

AGE GROUP/SEX (NUMBER)	MARITAL STATUS	EDUCATIONAL LEVEL	OCCUPATION
30-44 Male =(5) Mean Age = 35	.Single = 2 .Married = 3	.Primary = 4 .Junior Secondary = 1	.Business = 2 .Unemployed = 3
16-66 Female = (5) Mean Age = 34	.Single = 1 .Married = 1 .Divorced = 1 .Widow = 2	.Primary = 3 .None = 2	.Unemployed = 5

MATRIX 3B:

KNOWLEDGE AND ILLNESS HISTORY

AGE GROUP/SEX (NUMBER)	KNOWLEDGE OF DISEASE	DURATION OF SYMPTOMS BEFORE SEEKING MEDICAL ATTENTION	AVERAGE LENGTH ON TREATMENT
30-44 Male = (5)	.Yes = 5 .No = 0	.<1 month = 0 .1 month-1 Yr = 0 .>1 Year = 0	.Mean = 70 days .Range = 54-99 days
16-66 Female = (5)	.Yes = 5 .No = 0	.<1 month = 1 .1 month-1 Yr = 4 .>1 year = 0	.Means = 46 days .Range = 19-56 days

FGD: NON-ADHERENTS (DEFAULTERS)

MATRIX 3C: HEALTH SEEKING BEHAVIOUR, FREQUENCY OF DRUG TAKING AND BELIEFS ON HIGH TB INCREASE

AGE GROUP/SEX (NUMBER)	ORDER OF HEALTH SEEKING BEHAVIOUR PRIOR TO ATT	FREQUENCY OF TAKING ATT	REASONS GIVEN FOR HIGH TB RATES
30-44 Male = (5)	.Traditional healer = 3 .Heath Centre = 1 .Private clinic = 1	.Daily = 2 .Daily some = 1 .Sometimes = 2	Don't know, women affected more
16-66 Female = (5)	.Traditional healer = 4 .Health Centre = 1	.Daily = 5	.Adding salt to relish by women who have aborted /miscarried .TB patients not kept in hospital .Using same cups

FGD: NON-ADHERENTS (DEFAULTERS)**MATRIX 3D: CAUSAL BELIEFS, TYPES OF TB AND SOME SOCIAL FACTORS CONTRIBUTING TO DEFAULTING**

AGE GROUP/SEX (NUMBER)	TYPES OF TB AS PERCEIVED IN THE COMMUNITY	COMMON BELIEFS IN TRANSMISSION AS PERCEIVED BY NON- ADHERENTS	SOCIAL ECONOMICAL FACTORS CONTRIBUTING TO DEFAULTING
30-44 Male = (5)	.Two types - new; of the bones and fluid, you finish like AIDS patient - old presents with a cough	.Using same cups	.Transport money .Change of residence .Family problems .Funerals .Distance .Using same cups
16-66 Female = (5)	.Two types - new is of unknown origin - old results from sleeping with a woman who aborted	.That the present TB is AIDS .Old TB - sleeping with women who have aborted or eating food prepared by her .new type - unknown origin	.Fear to be divorced because sex is not allowed whilst on treatment 'kujingula' .Funerals .Travels .Using same cups

FGD: NON-ADHERENTS (DEFAULTERS)

MATRIX 3E: EXPRESSING HEALTHSERVICE RELATED, DISEASE RELATED FACTORS AND SUGGESTIONS TO REDUCE DEFAULTING

AGE GROUP/SEX (NUMBER)	HEALTH SERVICE FACTORS	DISEASE RELATED FACTORS	SUGGESTIONS TO REDUCE DEFAULTING
30-44 Male = (5)	.Long waiting time .Favouritism among staff .Some drugs not available .Some nurses are rude .Pay attention to children. TB patients not seen as human beings <i>'bationa monga si ndife bantu'</i>	.Some patients are too weak to walk daily .DOT make you 'drunk' or have blackouts if medicines are taken late. .TB drugs makes you hungry .Feels much better	.Enough supply of medicine .Establishment of Health posts in the compound .Medicine should be given very early in the morning .There should be enough cups .Relatives be allowed to collect drugs
16-66 Female = (5)	.Long waiting time .Instructions on taking medication, duration and side effects not told .Distance . 'Pills' (medicine) shortage .Nurses do not mark when medicines are given	.Duration of treatment 'tired of drinking medicines' .Feeling better .Vomiting in early stage	.Families should be involved .Only those on wheel chair should drink medicine at home

MATRIX 4A: NEIGHBOURHOOD HEALTH COMMITTEE (NHC)

DEMOGRAPHIC DATA

AGE GROUP/SEX (NUMBER)	MARITAL STATUS	EDUCATIONAL LEVEL	OCCUPATION
32-57 Male =(5) Mean Age =41	.Married = 4 .Divorced = 1	.Primary = 3 .Junior Secondary =1 .Senior Secondary =1	.Trader = 2 .Bricklayer = 1 .Unemployed = 2
27-59 Female = (9) Mean Age = 34	.Single = 1 .Married = 6 .Widow = 2	.Primary = 4 .Senior Secondary = 3 .None = 2	.Unemployed = 9

FGD: NEIGHBOURHOOD HEALTH COMMITTEE (NHC)**MATRIX 4B: COMMON HEALTH PROBLEMS, REASONS FOR INCREASE IN TUBERCULOSIS, BELIEFS ABOUT CAUSE AND CARE OPTIONS**

AGE GROUP/SEX (NUMBER)	COMMON HEALTH PROBLEMS IN THE COMMUNITY AS PERCEIVED BY MALE NHC	BELIEFS IN THE COMPOUNDS ABOUT TYPES AND CAUSE OF TB	CARE OPTIONS FOR PATIENTS AS PERCEIVED BY MNHC
32-57 Male = (5)	.Diarrhoea .TB .Malaria .Scabies .Swollen legs .Sore eyes .Dysentery .Yellow fever (Jaundice) .Cholera .Meningitis	.Two types of TB - new type - result of traditional value loss. This is AIDS related - old type is hereditary	.According to symptoms .Private clinics .Health centre after private fails .Traditional healers if suspect witch-craft '<i>masenga</i>' or '<i>masalamusi</i>'
27-59 Female = (9)	.Cholera/diarrhoea .TB .Malaria .Measles .Vomiting .Eye problems .STDs .Paralysis .Bleeding	.Two types of tuberculosis -TB of bones, this is sexually acquired and not cured -TB of sputum, this is airborne and curable .TB is caused by sleeping with a woman who has aborted .TB is caused by eating beef from an animal suffering from foot and mouth disease '<i>denkete</i>'	.Health centre first .Private clinic if they fail, they refer patients to the hospital .Traditional healers -cut the '<i>Uvula</i>' -use '<i>shalankuku</i>, <i>kabuula</i> or <i>muchinga pula</i>'

FGD: NEIGHBOURHOOD HEALTH COMMITTEE

MATRIX 4C: EXPRESSING REASONS FOR INCREASE IN INCIDENCE, REASONS FOR NON-ADHERENCE, PROBLEMS TB PATIENTS EXPERIENCE AND SUGGESTIONS IN IMPROVING COMPLIANCE

AGE GROUP/SEX (NUMBER)	REASONS ADVANCED FOR INCREASE IN INCIDENCE OF TUBERCULOSIS	PERCEIVED REASONS FOR NON-ADHERENCE TO TREATMENT	SUGGESTIONS FOR IMPROVING COMPLIANCE
32-57 Male = (5)	.Careless disposal of sputum and spitting .Not following treatment instructions .Lack of health education .Patients not isolated .Sharing cups .Eating beef not examined .Loss of traditional value	.Difficulties in walking .Long waiting time .Staff attitude .Hunger after medication	.Creation of sub clinic .Dispensing of drugs should begin early .Health education
27-55 Female = (9)	.Careless spitting, sputum, urinating .TB patients not isolated .Sharing some utensils .Not completing course and take medicine regularly	.Feel better .Avoid getting hungry .Long waiting time .Staff attitude .Stigma-Associated with AIDS .Lack of counselling .Deaths .Difficult in walking to clinic	.Health education .Provision of food .Night duty staff should begin giving treatment before they knock off .Decentralise treatment to compounds .Permanent TB staff (nurses) .Involvement of neighbourhood committee in monitoring and health education .Re-introduce TB isolation hospitals

MATRIX 5A: MEMBERS OF STAFF AT GEORGE HEALTH CENTRE: AGE, RANK AND DURATION IN SERVICE

DEMOGRAPHIC DATA

AGE GROUP/SEX (NUMBER)	WORK STATUS (RANK)	DURATION IN SERVICE (MEAN)	DURATION IN SERVICE AT GEORGE HEALTH CENTRE (MEAN)
26-47 (39) Male = 3 Female = 5	.Registered nurse/ sister-in-charge = 1 .Clinical officers = 2 .Zambia Enrolled Nurses = 4 .Research Assistants = 1	.2-30 (18 years)	.2 weeks - 14 years (5 years)

FGD: MEMBERS OF STAFF AT GEORGE HEALTH CENTRE**MATRIX 5B: COMMON HEALTH PROBLEMS, PROBLEMS FACED BY PATIENTS, FACTORS CONTRIBUTING TO DEFAULTING AND SUGGESTIONS**

COMMON HEALTH PROBLEMS PRESENTED AT HEALTH CENTRE AS PERCEIVED BY STAFF	PROBLEMS FACED BY TB PATIENTS AS PERCEIVED BY STAFF	FACTORS CONTRIBUTING TO DEFAULTING AS PERCEIVED	SUGGESTIONS ON WHAT CAN BE DONE TO IMPROVE COMPLIANCE
.Tuberculosis .Malaria .Diarrhoea .Sexually Transmitted Disease .Headache .Measles	.Shortage of staff to serve them .Long waiting time .Inadequate supply of some TB drugs .Patients are reviewed on the days in a month set by Lusaka Urban District Management	.Health education and clear instructions not given .Side effects of some TB drugs .Congestion .DOTS inconvenience - distance .Staff attitude and patients preference .Stigma of TB and HIV .Deaths are not reported often .Poor UTH-George referral	.Improve staffing .two nurses needed daily to reduce delay daily .Health education and promotion beginning with UTH .Establishment of community based group to work with: -Health posts in the compound .Follow ups and close monitoring .Involvement of close relatives in care and giving of drugs .Provision of High Energy Protein Supplement (HEPS) .Liberalised review days .Drug availability maintenance

TABLE 5: RESPONSES TO SEMI-STRUCTURED QUESTIONNAIRE

DEMOGRAPHIC DATA

DEMOGRAPHIC	MALE	FEMALE	TOTAL
Sex	11	8	19
Average Age (Years)	32	31	
Range (Years)	20-46	19-50	
Marital Status			
1=Single	2	2	4
2=Married	7	3	10
3=Divorced	2	1	3
4=Widowed	-	2	2
Religion			
1=RomanCatholic	3	1	4
2=UCZ	1	1	2
3=Anglican	-	1	1
4=Others	4	3	7
5=None	3	2	5
Educational Level			
1=Primary	6	2	8
2=JuniorSecondary	1	2	3
3=SeniorSecondary	3	1	4
4=None	1	3	4
Occupation			
1=Unemployed	2	4	6
2=Trader	1	3	4
3=Skilled	2	1	3
4=Unskilled	5	-	5
5=Retrenched	1	-	1
Average Household Size (People)	4	6	
Who pays rent for house you live in?			
1=Self	10	-	10
2=Husband	1	3	4
3=Parents	-	3	3
4=Others	-	2	2

RESPONSES TO SEMI-STRUCTURED QUESTIONNAIRE**TABLE 5A: DISEASE RELATED FACTORS - DURATION ON TREATMENT BEFORE DEFAULTING IN DAYS**

	MALE (NO)	FEMALE (NO)	TOTAL
Mean duration in days before defaulting	73 (11)	64 (8)	19
Range duration in days before defaulting	16-124	1-180	
Resumed treatment after defaulting 1 = Yes 2 = No	9 2	6 2	15 4

TABLE 5B: REASONS FOR DEFAULTING

REASONS FOR DEFAULTING	MALE	FEMALE	TOTAL
Drugs not available	1	3	4
Side effects	3	1	4
Was not improving	1	2	3
Felt better	1	0	1
Work	1	0	1
Other reasons:	4	2	6
.not informed			
.nursing sick child			
.busy			
.was away			
.swollen legs			
.fear to get worse			

RESPONSES TO SEMI-STRUCTURED QUESTIONNAIRE**TABLE 5C: FACTORS RELATED TO HEALTH SERVICES**

	MALE	FEMALE	TOTAL
Long waiting time 1 = Yes 2 = No 3 = Sometimes	4 5 9	5 1 2	9 6 3
Average time taken during last visit in hours (range)	(1-6)	(1-6)	

TABLE 5D: HEALTH SERVICE FACTORS

	MALE	FEMALE	TOTAL
Were drugs prescribed available 1 = Yes 2 = No	8 3	6 2	14 5
Did you find operation time of the clinic suitable? 1 = Yes 2 = No 3 = Sometimes	7 3 1	7 1 0	14 4 1
Do you have suggestions regarding operation times of the clinic for TB patients? 1 = Yes 2 = No 3 = Noresponse	2 6 3	1 7 0	3 3 3
Were you told about your illness? 1 = Yes 2 = No 3 = Someextent	7 3 1	7 0 1	14 3 2
Were you informed clearly how treatment was to be given to you? 1 = Yes 2 = No 3 = Partially	4 6 1	1 6 1	5 12 2
For how long was your treatment to last? 1 = I don't know 2 = 8 months 3 = > 8 months 4 = < 8 months	6 4 0 1	7 1 0 0	13 5 0 1

RESPONSES TO SEMI-STRUCTURED QUESTIONNAIRE**TABLE 5E : HEALTH SERVICE FACTORS**

	MALE	FEMALE	TOTAL
How often were you to take your drugs? 1 = don't know 2 = daily 3 = other	3 7 1	2 6 0	5 3 1
How is the reception you receive at the clinic each time you visit? 1 = friendly 2 = hostile 3 = other	4 2 5	8 0 0	12 2 5
Are you asked whether you took the drugs the day before? 1 = Yes, always 2 = Yes, at times 3 = Never 4 = Not applicable	2 5 4 0	4 1 2 1	6 6 6 1
What is your opinion about you going daily (DOT) to the clinic to receive the drug? 1 = it is just fine 2 = not fine	2 9	1 7	3 16
What is your assessment of the services given to patients with tuberculosis at this clinic? 1 = fine 2 = much need to be done 3 = no comment	7 0 4	8 0 0	15 0 4
Why do people in your opinion stop taking prescribed TB drugs before they are told to do so? 1 = inconveniencing 1 = poor reception 2 = distance 3 = other	2 1 1 7	0 0 1 7	2 1 2 14
Do you think fear of HIV contribute to some people not willing to attend the clinic? 1 = yes 2 = no 3 = to some extent	2 5 4	1 4 3	3 9 7

RESPONSES TO SEMI-STRUCTURED QUESTIONNAIRE**TABLE 5F: FACTORS RELATED TO SOCIAL, ECONOMIC AND CULTURE**

	MALE	FEMALE	TOTAL
Could fear of HIV have contributed to your defaulting? 1 = Yes 2 = no 3 = to some extent	0 8 3	1 7 0	1 15 3
Do you think fear of losing employment affects attendance? 1 = yes 2 = no 3 = to some extent 4 = don't know	2 6 3 0	3 4 0 1	5 10 3 1
Does fear of losing business affect attendance? 1 = yes 2 = no 3 = sometimes	1 7 1	0 6 4	1 13 5
Do people with tuberculosis get medicine for TB in the compound? 1 = yes 2 = no 3 = I don't know	6 2 3	3 4 1	9 6 4
Have you ever taken any medication (traditional and modern) from the compound for the project problem? 1 = yes 2 = no	4 7	3 5	7 12
When you began treatment for TB were you given clear instructions by the staff? 1 = yes 2 = no 3 = to some extent	4 7 0	1 5 2	5 12 2
During the time you defaulted were you taking any traditional medicine? 1 = yes 2 = no 3 = sometimes	2 9 0	0 8 0	2 17 0
Does the distance from your home to the clinic affect your attendance? 1 = yes 2 = no 3 = to some extent	2 7 2	1 5 2	3 12 4

5.4 Some Suggestions from Participants (Semi-Structured Questionnaire)

In all the semi-structured questionnaire an open response was included, participants made recommendations in the form of suggestions. What follows are suggestions that were given and have been prioritised according to the most re-occurring theme.

- **Health Education**

Many participants called for improved health education beginning with University Teaching Hospital (UTH) up to the community. The message should cover the danger of promiscuity. They suggested that former TB patients be recruited to assist as peer educators and the involvement of Neighbourhood Health Committees.

- **Establishment of TB Health Post**

Participants suggested establishment of sub-clinics to work under supervision of health centres. Patients can collect their supplies or daily treatment at these nearest centres.

- **Family/Relative Involvement**

There were suggestions during some discussions that family members or relatives be involved in the care from beginning. These should be educated in administering of drugs and be allowed to collect drugs.

- **Directly Observed Therapy (DOT)**

They suggested that enough cups be made available and that very sick patients be given enough drugs to swallow at home. Though they said DOT improved compliance as some patients would not take drugs at home, they also suggested that they be supplied drugs at weekly intervals.

- **Operation Times of the Clinic**

The participants suggested that night duty staff begin dispensing TB drugs before knocking off. This will make patients who go early in the morning be attended to in good time.

They also suggested that there be permanent nurses attached to the TB desk and that drugs should be available always.

Participants also suggested that the review clinics be done on a daily basis to avoid congestion and time wasting.

CHAPTER SIX

6.0 DISCUSSION

6.1 Current Tuberculosis Treatment Policy

The World Health Organisation (WHO) and International Union Against Tuberculosis and Lung Disease (IUATLD) have issued recommendations on the treatment of tuberculosis in high HIV sero-prevalence countries, the category to which Zambia belongs. The Zambia National AIDS/STD/TB and Leprosy programme has already applied some of these recommendations.

Among these recommendations is the provision of Uninterrupted Supervised Chemotherapy, the reduction of health workers' workload and elimination of risks associated with parenteral therapy as well as prevention of adverse reaction especially those due to thiacetazone (TB manual, 1995).

The success of tuberculosis chemotherapy therefore depends on strict and rational application of cost effective guidelines such as:

1. Using correct drug dosages.
2. Ensuring that the initial phase of chemotherapy is given under daily supervision.
3. Ensuring regular patient attendance for the full duration of the continuation phase.
4. Tracing defaulters promptly.
5. Keeping accurate records of patient information and clinic attendance and
6. Ensuring that there is an adequate supply of drugs.

This Study explored factors that could explain reasons for non-adherence or defaulting on treatment. The factors identified from the literature and followed in analysis fall into three related categories. There are those factors related to service provision, those related to the nature of the disease itself and factors determined by the social cultural and economic environment.

6.2 Methodological Issues

Morgan (1988) in his book **Focus Group as a Qualitative Research** has stated that a Focus Group Discussion (FGD) avails a researcher to observe a large amount of interaction on a topic in a limited period of time. As a non-directional interview, open ended questions in a FGD allows individuals to respond without setting boundaries or providing checks, allows the subjects to comment, explain, share experiences and attitudes. However, Morgan (Ibid) observes that one of the hazards of this research method is that people want to tell how they wish things to be seen as opposed to how they are. The intent of FGD is to promote self disclosure among participants in order to generate themes which can be critical in hypothesis generation and in interventions.

6.3 Problems with Definition of a Defaulter

Different programmes have different definitions for a defaulters. Crofton, Horne and Miller (1992) defined a defaulter as a patient who has failed to attend for 2 or more months in spite of every effort to trace him/her. But, for a cost effective tuberculosis treatment, during the Intensive Phase of treatment when every dose is supervised, if more than one dose is missed, action should be taken (Ibid). In a continuation phase action should be taken if the patient fails to attend on a date for review in a month.

In Zambia a defaulter is one who fails to attend for 14 consecutive days during Intensive Phase or fails to attend for 2 months in the Continuation Phase. However, defaulter tracing is recommended as soon as the patient fails to attend 2 consecutive clinic days in the Initial Phase of treatment or 2 weeks in the Continuation Phase of treatment.

Given resource problems and the dearth of well conducted studies in Zambia on defaulters, the use of term "non-adherent" was applied to the subjects in this study during the process of selection and analysis. Non-adherent covers all those who missed more than a day of treatment in Intensive Phase and over a week in Continuation Phase after missing a monthly review.

6.4 Tracing of Non-Adherents

215 cases between February and November 1995 fitted the definition of non-adherent., This represented 33 per cent of new cases during that period. The finding is very close to defaulter rate of 35 per cent which has been reported in a Lusaka cohort, (Bosman, 1996). But again caution has to be exercised because this sample was not representative of Lusaka.

An attempt was made to follow all the 215 reported as non-adherents. The total sampling in the catchment area labelled an establishment of those reported as non-adherents. Table 4 gives a breakdown of those reported and findings.

Twenty-one (10 per cent) qualified as non-adherents or defaulters. This is almost in agreement with the 9 per cent in Eastern Province of Zambia study (Ibid). Only 2.3 per cent in our study had defaulted without resuming treatment.

However, the large number of those who had shifted residence without leaving a contact address (36 per cent), those who gave false addresses (20 per cent) and those who could not be visited (6 per cent) hampered analysis of the true situation. It is, however, plausible that some of those could have defaulted with or without resuming treatment, or could be added to the 18 per cent confirmed dead (twice as much as nine per cent reported in Bosman, 1996, analysis) or to the 11 per cent false recorded as defaulters.

There appears to be an absence of a system to know about those who are admitted to the hospital or transferred out. These may end up labelled as defaulters. During the study one patient had contracted cholera and was allegedly advised to stop anti-tuberculosis treatment

by health personnel.

The high mobility of patient has a negative effects in terms of case holding as some of those patients do not continue with treatment wherever they go. The transfer system for tuberculosis patient is not very clear on transfer and recording at the new centre.

The high mortality rates among patients is a reflection of treatment failure but much more a result of health service problems. Patients were diagnosed late and therefore delayed in commencement of treatment. They are a semi-illiterate and mostly unemployed population. TB has a devastating effect on a poor community's socio-economic factors. According to Murray et al (1991) poverty, over-crowding, ignorance and severely limited financial and organisation resources are the main causes of high statistics. The high rates of HIV among TB patients has compounded the situation. Over 70 per cent of TB patients are infected with HIV as well (Elliot, 1992).

6.5 Factors Identified as Contributing to Non-Adherence

6.5.1 Health Service Factors

In the focus group discussion and semi-structured questions issues bordering on the following emerged as contributors.

- a) Reporting system and review dates
- b) Directly Observed Therapy (DOT)
- c) Long waiting times
- d) Health education
- e) Reception and supervision

6.5.2 Reporting System and Review Dates

Failure to record or tick whenever a patient came to collect or swallow drugs was identified by both adherents and non-adherents including the staff. '*si ba tikinga*' is the expression used by participants in answering why there are so many patients who default from treatment and this was confirmed during follow-ups as some of the patients had just been to the clinic for re-supply of drugs but were given the drugs without recording. Some of these patients could be those who have friends at the clinic and would not like to be seen around. This has implications in terms of planning and resource allocation.

The other complaint among patients was that those diagnosed at the University Teaching Hospital maintained two review dates. At times these coincided and tended to be costly in terms of transport costs and time to and from the hospital.

Strengthening report system and ensuring that all patients receiving drugs are recorded would ensure sustained surveillance and proper audit of resources. The dual reviews by UTH and the clinic could be changed so that the former continues to provide only tertiary care in line with current health reforms of the Ministry of Health and reviews be left with health centres.

6.5.3 Directly Observed Therapy (DOT)

DOT was introduced by WHO to ensure drug compliance (Pozniak, 1993) Stott (1982) reported a project on directly observed short course chemotherapy by a highly motivated staff, reduced the rate of defaulting to 1.6 per cent. DOT is about swallowing drugs under supervision. Our observation during the study was that drugs were not swallowed as expected by all patients. Some patients only came daily to collect drugs which they carried home to swallow. Urine testing for the presence of drug metabolites is not done, therefore there is no knowing whether drugs are consumed or not. It was noticed after a tip, that some patients pretend to swallow drugs when actually they drunk only water.

During the study there were times when nurses engaged in arguments, trying to force patients to take the drug in their presence, but in most cases nurses appeared too busy counting drugs to notice patients not swallowing the drugs.

Participants complained that drugs caused them to feel hungry especially if taken late in the morning and others said they felt drunk. *'nikolewa monga namwa mowa'* Others thought the strength of the drugs were too much since they drunk a lot of tablets, *'ma gram yanali kupaka.'*

Findings on DOT suggest an urgent need for an evaluation. Patient feel daily walking to the clinic was like a 'punishment.' They complained of painful legs and feet. They were suspicious of getting another type of TB and other diseases *'ungatengeleko ma tenda yenangu'* by sharing the same cup. These views though not scientifically justifiable need to be considered especially that running water and cups are a problem at George Health Centre. There seem also to be no clear explanation as to reasons behind asking all patients to attend very early in the morning. Patients could be spaced during the day and possibly be given drugs in advance to take early morning at home, before coming for re-supply.

Menzies et al (1993) has noted that it was possible to have good results if patients are spaced in collection of drugs as long as they are accompanied by education, counselling, close follow-up and shorter therapy.

6.5.4 Waiting Time

For successful performance of a programme it is important that clinics open on time and are properly staffed. Bignall (1982) mentioned long hours of waiting at the public clinic as one of the reasons of failure to control tuberculosis. In all the FGDs including that of staff, long waiting times were given as one of the reasons. They found no problem with operational hours. The waiting time is worse during the review day when some patients came as early

as 6:00 hours and went back as late as 16:00 hours, the clinic started as late as 09:00 hours. Patients talked of personal experiences of "collapsing" due to hunger. Some patients lose patience and go back unattended but return for re-supply of drugs. The result of not being reviewed is that some patients have continued with Intensive Phase well after 2 months or in Continuation Phase well after 8 months.

Porter (1992) has advised that the waiting time for the patients be as short as possible and that staff at the centre be helpful and approachable. This calls on good time management and proper human resources allocation. Congestion on review dates and waiting time can be reduced if there was an open review mechanism. Patients could be reviewed on a daily basis or the review clinic held weekly by motivated, enthusiastic staff.

6.5.5 Health Education

Health education and counselling as emphasised by Tiwari (1996) is crucial for diseases like tuberculosis in reducing poor treatment compliance. This aspect of care was generally lacking during the Study. There appears to be in place a minimal counselling service and an absence of health education. Many patients in almost all FGD and in their questionnaire response talked of not knowing the duration of therapy. They were also not asked whether they took the drugs previous day or had problems with it whilst family members were not involved.

For an effective programme, case holding is important. According to Tiwari (Ibid), when patients report for care, they must be motivated at the out patient department, at the time of diagnosis, during drug collection and when reporting for reviews. Family members, relatives and friends should also be well motivated at health institutions and at home so that they can keep a watch on the treatment. The impression given by one of the nurses is that they see the aspect of health education and counselling as a one off affair which is supposed to be done at the University Teaching Hospital upon notification. Patients are concerned about their care and need sustained counselling and more information (Donovan, Blake, 1992).

6.5.6 Reception and Supervision

The prevalent feeling among patients was that generally they did not have problems with the staff at George Health Centre. They are just fine '*bali chabe bwino*.' Only very few were said to be rude and that they favoured some patients whom they supplied drugs for a long time. The nurses blamed rudeness on patients themselves as some patients do not want to attend daily and if she insists she is labelled as rude or being a bad nurse. The health centre is rarely visited by the district to monitor TB control activities and problems faced with TB care delivery.

Huikeshoven et al (1978) observed that in Wangas, Kenya, success without defaulting among patients on leprosy therapy was achieved by holding the clinic without fail and demonstrating personal concern for the well-being of the patient. Equity and concern for patients can

improve compliance.

6.6 Disease Related Factors

The following were issues determining rate of compliance generated from the study as they relate to the natural history of the disease and therapy.

1. Sickness
2. Side effect
3. Response to treatment

6.6.1 Sickness

In all FGDs and questionnaire responses it became apparent that some patients became too sick to walk. Some experienced severe burning of feet. Those who end up being admitted may not be counselled to continue with therapy at local clinic. During the study period some patients were ferried on a wheel barrow or carried on the back.

Poverty, poor nutrition and high HIV sero-prevalence are among determinants of poor prognosis of many diseases including tuberculosis. Many of the patients are diagnosed and commenced on treatment late, probably because of a poor index of suspicion and lack of diagnostic tools among health staff. They begin treatment when they are already too sick. The mechanism must be put in place for them to be cared at home and have medicine supplied in their homes or as nearly to their homes as possible. Khella (1988) has noted in a Nigeria study that the severity of illness was a sure incentive to comply with treatment. There is therefore a high probability of taking drugs at home by patients who are very sick.

6.6.2 Side Effects

News of drug reaction is common among people who are cautious of the high rate of adverse reactions of thiacetazone (Elliot, 1992). Tuberculosis treatment in the past has been characterised by side effects, fear of getting hungry in this community where food and its related diseases are common is another problem. Some of these effects can be avoided or improved on if permanent staff were in place and treatment given throughout the day. Patients would then come when they felt better or after eating.

6.6.3 Response to Treatment

The average duration on treatment before missing at least one day of treatment in this study was as early as 46 days (1.6 months). Some patients complained of simply getting tired of taking medicine.

Other studies have shown average defaulting time of 3.2 months (Masayuma et al, 1993). This is in the Continuation phase of therapy whilst in our study the average was very early

in continuation phase therapy. This runs a danger of disabilities and drug resistance. Both non-adherents and adherents mentioned that many of them missed once they felt better. According to the FGDs with staff at the centre, a long duration of treatment contributes to defaulting whilst the majority of patients did not know, for how long they were to take their treatment and hence the dangers of not completing the whole course. Continuous counselling of patients would therefore improve compliance. Shortening drug regimens could also be one of the keys to improving compliance.

6.7 Social Cultural and Economic Factors

Murray et al (1991) in their Paper "Cost Effectiveness of Chemotherapy for Pulmonary Tuberculosis in Three Sub-Saharan African Countries" have said that the effect of tuberculosis are more severe on a poor community's socio-economic fibre and that negotiation skills are said to increase with education.

6.7.1 HIV and Stigma of Tuberculosis

Elliot (1992) in a cohort study found rates of HIV among confirmed tuberculosis of 73 per cent, higher in extra-pulmonary TB. This study was done among people at higher risk of HIV. The majority of subjects were in the HIV peak age groups.

There is enough evidence to show that the association of TB with HIV has contributed to TB stigma. The participants talked of an association with an incurable disease '*ubulwele wa tanda bwanga*.' As a result of labels in the compound, many patients do not want to be seen around. They avoid attending the clinic because of HIV test fear. The male participants expressed having TB as '*ma wanu*' bad omens. Some said they did not even tell their wives, for fear of being suspected, as having had sexual intercourse with a woman who had aborted.

However, there are difficulties in diagnosing TB, some "TB patients" do not have TB but may still die from HIV.

6.7.2 Change of Residence

In order to avoid being seen around as 'TB' patient, some resort to change of residence. The members of the community in most cases know which home has a TB patient. Frequency in residence shifts is aggravated by land lords who increase rates at short notice. Patients who are usually out of employment without income and fail to afford rent, shift to a cheaper home.

6.7.3 Incorrect Address

Participants in the FGD revealed that some patients gave false addresses because they did not know their real addresses. In compound some homes did not even have numbers. We were also told that in the past there have been follow-ups of patients in the compound and those who knew about it or were told may be afraid of giving correct address to avoid being followed.

From observation, due to the poor literacy levels of most patients in this compound and because house numbers are not orderly arranged, many patients do not know their home numbers. Some patients on the first visit have been accompanied by friends or relatives who did not know the address but had to give one.

There is need for staff to continue reviewing addresses of patients and asking them to come with correct address on the next visit. Health Neighbourhood Committees arranged in zones could be used to ascertain addresses and patients can be registered under these zones.

6.7.4 Traditional Healers

In the FGDs of male and female adherents, the female neighbourhood committee and that of the staff mentioned that there is re-course to traditional medicine if witchcraft is suspect '*masenga*' or '*masalamusi*.' for those who do not improve whilst on treatment, the next option is traditional healers.

The feeling that one has been bewitched seem to give a greater comfort than that of suspecting HIV/AIDS. Though this was not a very prevalent belief it does influence adherence and health seeking behaviour.

6.7.5 Traditional Beliefs

Women defaulters mentioned fear of divorce as one reason that contributes to discontinuing with treatment. There is a traditional belief that while a woman is on TB treatment she should refrain from sexual intercourse and sleep on the floor. She should not share a bed with her husband '*kujingula*.'

Smith (1993) found that in some cultures having TB may make it difficult to find a husband and if married it may result in a divorce.

The diagnosis of tuberculosis has therefore social costs on women in communities highly dependent on men as bread-earners; another form of male chauvinism at play. A woman may therefore be forced to stop with medication as soon as she feels better, in order to resume her sexual role with her husband. In intervention studies cognizance of cultural traits is important. Counselling of couples by caring staff would alleviate these fears and strengthen marriage relations, which are crucial in this era of HIV epidemic.

CHAPTER 7

7.0 CONCLUSIONS AND RECOMMENDATIONS

Research Methodology

The total sampling of all reported defaulters (non-adherent) and use of a focus group discussion and a semi-structure questionnaire did generate information that gives some understanding into those who are reported as defaulters and determinants of such a group. It is therefore possible with this kind of information now to generate hypotheses that can be tested using quantitative methods.

Reported Defaulters

This study has established that the defaulter rates are not as high as has been recorded and reported. It has, however, found that mobility and mortality is high among the cohort of TB patients. It has also found, not conclusively that the majority of those recorded as defaulters have shifted residence and their outcome is unknown. Proper record keeping and monitoring can improve management and resource utilisation for patients with tuberculosis.

Directly Observed Therapy (DOT)

Though those who complete the course of anti-tuberculosis therapy are in favour of the system, evidence on the ground appears that what is being practised is not what is meant by DOT. There is need to evaluate it taking into consideration manpower requirement and problems that it causes on patients. Patients with HIV become too debilitated to attend daily. It is essential that local circumstances and what can be efficiently and effectively be done is considered. Studies are needed to compare case holding with different visit days.

Review Clinics

The congestion during the days of review does not give room for privacy and one to one counselling which is crucial in case holding. There is need to have patients spaced out during the month. There is also need to have drugs dispensed throughout the day and not just early in the morning. The relationship between the University Teaching Hospital (UTH) and George Clinic need reviewing so that the UTH remains only as a referral hospital, to avoid confusion arising from patients being reviewed at both centres.

Health Education and Counselling

Health education should aim at early attendance and clearing the misconception regarding tuberculosis as being incurable. This should be followed by sustained counselling so that drugs are taken regularly until the course is completed.

Establishment of Health Posts and Involvement of Laymen

The number of patients with tuberculosis is increasing so are the disabilities caused by the disease. The available structures are inadequate and distances patients covered is a problem. There is need therefore to create health posts, in line with reforms, to have drugs dispensed near homes of the patients. There are already Neighbourhood Watch Health Committees whose concept can be adapted and can be trained with close monitoring to help with care of patients. Former TB patients could also be used in health education and counselling activities.

Recommendations

Based on findings from this Study, the following recommendations are made. This study aimed at exploring information in order to generate hypotheses to be tested. The recommendations are therefore towards need for further studies involving a representative sample.

Possible Studies:

- Observational studies using the existing health system can be done. Contrasts between groups in outcome with variables such as distance, disability and alcohol consumption as being determinants of defaulting can be observed and analyzed using case control or cohort designed studies. Problem with these kind of studies could be the control of the various confounders.
- Randomised intervention studies can be done by randomising patients. Interventions such as health education, counselling and family involvement. Communities can also be randomised to for example peer educators versus health staff motivation. The problem is that while randomised studies are the strongest they are expensive and have more logistic problems.

Conclusion

This qualitative study has generated many interesting observations. The data area has a very rich source of information. Several further hypotheses that need to be tested have been generated.

However, the design of suitable quantitative studies to answer these questions is complicated by the difficulty in producing measurable indicators that truly reflect the issues raised. However, some of the ideas arising are readily suitable for quantitative studies and it is hoped that such studies can now be based on a firmer foundation.

The table below summarises factors identified, hypotheses generated and studies recommended.

FACTORS IDENTIFIED, HYPOTHESIS GENERATED AND STUDIES RECOMMENDED

FACTORS/VARIABLES IDENTIFIED	HYPOTHESIS GENERATED	QUANTITATIVE STUDY NEEDED	REMARKS
1. Patients stop taking medication once they feel better Patients are too sick to walk	The level of compliance to TB chemotherapy is determined by level of disability	Comparative study of adherents and non-adherents Cohort study measuring disability level at entry on follow-up	Need accurate diagnosis of TB Intervening variables: family support system
2. Use of peer educators Use of family members	Involvement of peer educators and family members can reduce non-adherence	Randomised case control study Intervention study e.g. (community) randomised controlled trial	Gender issues in peer selection Level of education and social economic status of the family
3. Drug supply	Provision of adequate supply of drugs reduces rate of non-compliance	Intervention prospective case control study Observation of cohort study	Ethical/political issues in supplying enough drugs to some areas only
4. Distance costs	Distance and costs determines rate of defaulting	Intervention study of two communities Observation of cohort	In high density areas difficulties in allocating services nearer
5. Waiting time, congestion, staff shortage	Availability of trained, motivated staff would reduce waiting time, congestion and defaulting.	Intervention study Patients/Clinic Observation cohort	Need human, material and money in training
6. Patients taking drugs home Hunger after taking drugs	Adequate take home supply of drugs followed by counselling would improve compliance	Prospective case control study Intervention study, Randomised (community) patients	Problems in monitoring drug taking
7. Nurses attitudes Health information Communication HIV/AIDS/TB stigma	De-motivated staff results in poor patients knowledge of signs, causes and consequences of TB which leads to a high defaulter rate among TB patients	Randomised community intervention	Difficulties in motivating and measurement of staff attitudes Social cultural factors on causes of TB
8. Health Posts	Establishment of TB health posts would improve quality of patients care	Intervention prospective study of comparable compounds	Monitoring of health posts and manpower headed
9. Clinic operating hours	A TB clinic operating a 24 hour service would have less defaulters	Randomised intervention study of clinics operating different times	More staff needed
10 Alcohol	Rate of alcohol in-take determines the defaulter rate	Case control/cohort Comparative study of adherents and non-adherents	Difficult to measure

ANNEXA 1

The University of zambia
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-- /---/1996

Dear Mr/Ms _____

CONSENT TO PARTICIPATE IN THE TUBERCULOSIS STUDY

As you might be aware tuberculosis is a big problem in Zambia and all over Africa. Good treatment is available to treat people completely but there have been some problems which have made some people not to take treatment as required.

As students from the University of Zambia interested in the health of people in the community we are carrying out a group discussion to find out problems and views regarding services offered to tuberculosis patients at George clinic.

You have been identified, having at one time attended George clinic to be one of the important persons who could participate in this discussion based on your own experiences.

If you are unable to attend, you may participate by answering a questionnaire which will take you not more than 30 minutes to answer.

The group discussion will not take more than one and half hours. There will be between 5-10 people of your sex only. The success and quality of our discussion will therefore be based on your cooperation and the rest of those invited. The information we shall obtain from you will be used to recommend best way of improving services. Refusal to participate in the research would not compromise treatment you might be receiving or will receive in future.

During the discussion soft drinks (cocacola/fanta) will be served free. At the end of the discussion you will be given some money as a honorarium to cover your expenses for attending.

You are there fore kindly asked to attend the group discussion on: Day _____ Date _____. To be held at

_____.

Remember you have been selected because we feel your suggestions can be beneficial to improving the services given to patients with tuberculosis. There will be no expert at the meeting and you will all be free to discuss and ask questions.

You will find us waiting for you 30 minutes before time to begin the discussion. If you are able to attend or accept to answer the questionnaire please sign the form attached.

ANNEXA 2

CONSENT TO PARTICIPATE IN THE STUDY ON TUBERCULOSIS

I have read/has been explained to me, the purpose of the study. The study aims at finding out the factors contributing to non-adherence to tuberculosis treatment among patients.

I have also been told that this will be a group discussion with people of my sex and that the information which will be obtained will be used to recommend ways of improving services offered to patients with tuberculosis.

I have also been informed that I have a choice to refuse to participate and my refusal to participate in the research would not compromise with treatment I am receiving or may be receiving in future.

I have therefore accepted to participate with the above understanding of the study.

Signed:
Client.

ANNEXA 3

Check-list 1

FOCUS GROUP DISCUSSION WITH NEW TUBERCULOSIS PATIENTS

Instruction to facilitator.

- .Introduction to the participants
- .Explanation of purpose to participants
- .Permission to use a recorder

QUESTIONS

1. What are the common health problems do you face in your compound?
2. Where do people first seek help when they are sick?
3. What do you know about tuberculosis?
4. What types of tuberculosis do people in the community know?
(probe)
 - What causes it (them)?
 - How is it treated (traditional and modern)?
 - How is it prevented?
 - How is it transmitted?
 - What are the vernacular names
 - Is the problem common?

ANNEXA 4

Check-list 2

FOCUS GROUP DISCUSSION - WITH NON ADHERENTS AND COMPLIES.

DEMOGRAPHIC DATA.

1. Sex
2. date of birth
3. Marital status:
 - a. Married
 - b. Single
 - c. Divorced
 - d. Widowed
4. Religion
5. Education qualification
6. Occupation
7. When diagnosed with TB
8. When last drugs taken
9. Frequency of taking TB drugs

FGD QUESTIONS.

1. Exploring service factors:
 - How are the services when one attends this health centre?
 - Are the services given to TB patients any different?
(probe differences)
 - Which factors contribute to patients not coming for treatment (probe for provider factors)
2. Disease related factors:
 - When you are ill where do you first go for treatment?
(probe for alternative therapy/traditional and other informal)
 - When treatment is commenced what makes patients decide whether to continue or stop treatment?
(explore illness, response, side effects)
3. Socioeconomic and cultural factors:
 - are there other reasons that might make patient stop taking treatment?
(explore traditional beliefs, practices etc)
4. What can be done for treatment to be complied?

ANNEXA 5

Check-list 3**HEALTH CENTRE STAFF & MEMBERS OF HEALTH NEIGHBOURHOOD COMMITTEE**

1. What are the common problems affecting people in this compound?
2. What are the health problems that people commonly present with at the health centre?
3. What problems TB patients experience in the compound and
4. What factors contribute to defaulting / non adherence?
 - disease factors?
 - service factors?
 - SEC factors?
5. What can be done to improve compliance ?
 - time?
 - place?
 - people?

14. Why did you stop taking the drug?
 1 =drugs not available 2 =side effects 3 =felt better
 4 =was not improving 5 =distance to clinic 6 =work
 e) others specify _____

15. What comments do you have regarding treatment you were receiving?

Health service factors

16. When you last attended clinic for your medication, did it take long to be attended to?
1 =yes 2 =no 3 =some extent

17. Approximately how long did you take from the time you arrived at the clinic to the time you returned home? _____

18. Where drugs prescribed for your problem available?
1 =yes, all 2 =yes, some 3 =no

19. Did you find operation time of the clinic suitable?
1 =yes 2 =no 3 =some extent

20. Do you have any suggestions regarding operation times of the clinic for tuberculosis patients?
1 =yes 2 =no

21. If yes what are your suggestions?

22. Where you told about your illness?

1 =yes 2 =no 3 =some extent

23. Where you informed clearly how treatment was to be given to you?
1 =yes 2 =no 3 =partially

24. For how long was your treatment to last? _____

25. How often where you to take your drugs?
1 =don't know 2 =daily 3 =other

26. How can you describe the reception you received at the clinic each time you visited?
1 =friendly 2 =hostile 3 =other

27. Each time you went to clinic did staff ask you whether you took the drugs the day before?
1 =yes, always 2 =yes, at times 3 =never

28. What is your opinion about you going daily to the clinic

to receive the drug?

1 = it is just fine 2 = not fine 3 = other

29. Please give reason for the above answer _____

30. What is your assessment on the services given to patients with tuberculosis at this clinic?

1 = fine 2 = much need to be done 3 = no comment

31. Please give reasons for the above answer _____

Social economical factors

32. Why do people in your opinion stop taking prescribed tuberculosis before they are told to do so?

1 = inconvenience 2 = poor reception 3 = distance 4 = other

please elaborate? _____

33. Do you think fear of HIV contribute to some people not willing to attend the clinic?

1 = yes 2 = no 3 = to some extent

Please elaborate further how? _____

34. Could this have contributed in your case?

1 = yes 2 = no 3 = some extent

35. Do you think fear of HIV contribute to some patient stopping going to the clinic to get their medication?

1 = yes 2 = no 3 = to some extent

Please explain why? _____

36. Do you think fear of loosing employment affect attendance

1 = yes 2 = no 3 = to some extent

please explain _____

37. Why did you stop taking your treatment?

38. Does fear of loosing business affect attendance?

1 = yes 2 = no 3 = i don't know 4 = some times

please explain _____

39. Do people with tuberculosis get medicine in the compound?

1 =yes 2 =no 3 =I don't know

please explain (what type) _____

40. Have you ever taken any medication (traditional and modern) from the compound for the present problem?

1 =yes 2 =no

which ones _____

41. When you began treatment for tuberculosis, were you given clear instructions by the staff?

1 =yes 2 =no 3 =to some extent

What were you told? _____

42. During the time you defaulted/not taking ATT at the clinic were you taking any traditional medicine?

1 =yes 2 =no 3 =sometimes

43. Did the distance from your home to the clinic affect your attendance?

1 =yes, definitely 2 =no 3 =to some extent

44. What can be done to improve patient care?

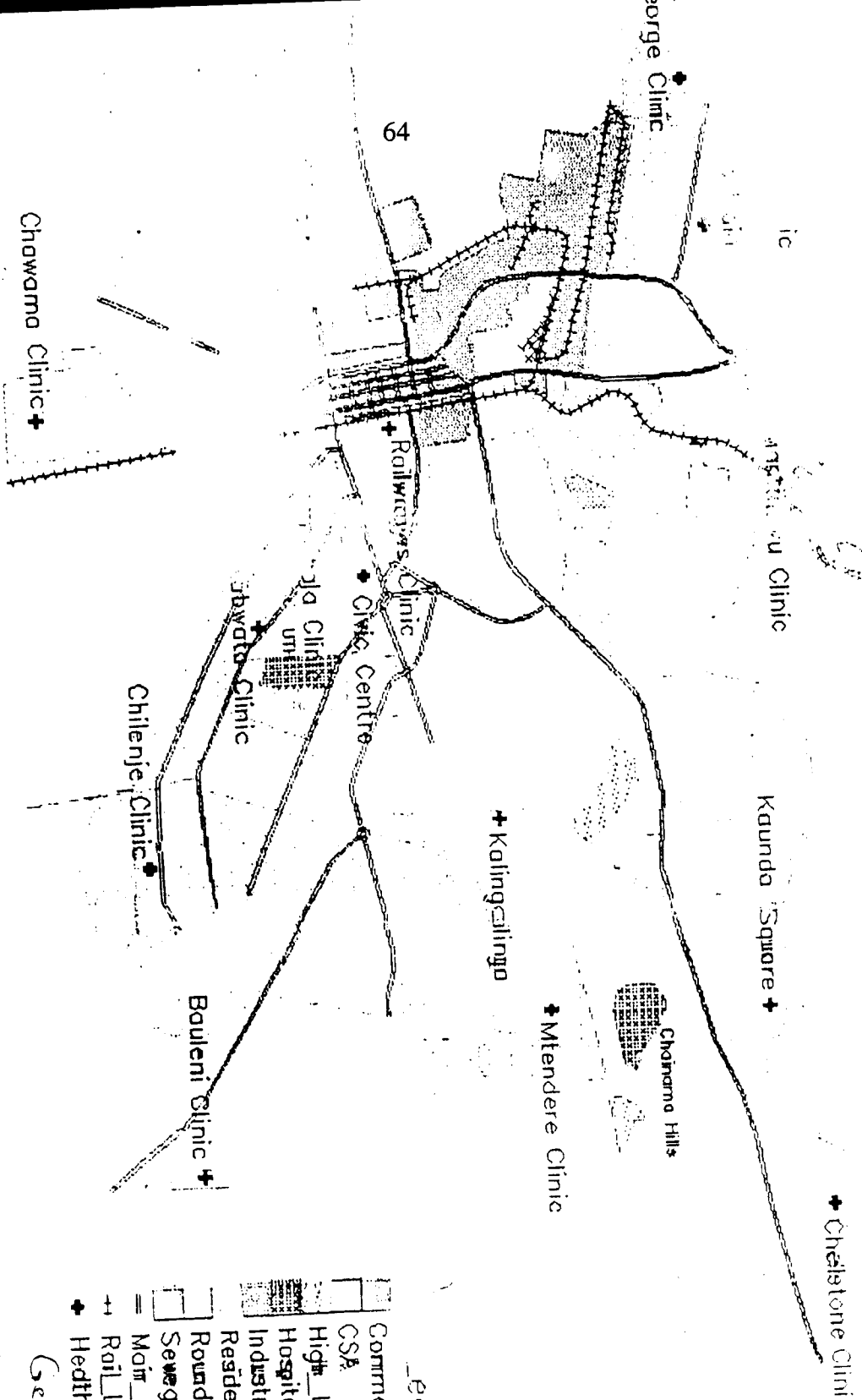
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Legend

- Commercial Area
- CSA
- High Learn Inst
- Hospital
- Industrial Area
- Resident Areas
- Round About
- Sewage Disposal
- Main Road
- Rail Line
- Health Centres
- George MC

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