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Tuberculosis in the Tintswalo district of the Northern Province

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SECTION 4

THE INTERVIEW STUDY

This section will describe a series of interviews performed, both on individual patients at different stages of their treatment, and on groups of patients and community members. The chapters of the section are:

18 Interviews on individual patients

19 Group Interviews

CHAPTER 18

INTERVIEWS ON INDIVIDUAL PATIENTS

This chapter describes the series of interviews which were conducted on all patients on treatment for tuberculosis, and includes:

Objectives

Methods

Results

Discussions and implications for management of tuberculosis in this district.

18.1 Objectives

i) To determine from each patient on treatment their knowledge, beliefs, attitudes and actions relating to tuberculosis, as well as a number of selected socio-economic variables about the patients and their households.

ii) To measure any associations between these variables and treatment outcomes

18.2 Methods

Population:

The study population for the interviews was all patients with tuberculosis who lived in the Tintswalo district, who were registered at Tintswalo in the period 1st July 1994 to 31st December 1995, as well as those patients admitted in January 1996, who were due to complete treatment during July 1996. The population was not sampled.

Measurement:

A series of interviews were conducted by trained field researchers at three points during treatment:

i) As close to the day of discharge from hospital as possible. Those not admitted were interviewed before they left hospital.

ii) After 2 months of treatment, either at the hospital or a clinic when the patients attended for review, or at home.

iii) At the end of treatment when the patients attended Tintswalo hospital for their final discharge from treatment.

Each interview used a set of structured questions designed for this study. A copy of each is attached as Appendices C5, C6 and C7. The mothers or minders of patients under the age of 15 years were interviewed.

The first interview (5 pages long) had questions about:

Demographic characteristics of patients and their households

Previous tuberculosis

First actions when sick

Knowledge about treatment (patients were asked the duration of their treatment and the number of doses of pills per day. If both were correctly stated, knowledge was categorised as correct)

Beliefs about cause

Anticipated problems with treatment

The second (2 pages long) asked about the process of treatment:

Time to reach supporter and costs

Means of transport to clinic or hospital & problems experienced

Satisfaction with treatment

Services consulted since discharge

The third (3 pages long) reviewed the process of treatment:

For clinic attenders (intervention group):

time to reach, mode of transport, cost, waiting time, problems experienced, preferences about treatment place

Hospital attenders (control group and those nearest the hospital):

time to reach, mode of transport, cost, waiting time, problems experienced, preferences about treatment place

General comments

[This third interview was only administered from the 1st of January 1995.]

Pilot study:

An interview study of 100 patients admitted during 1994 was completed during early 1994, and acted as a pilot for this study. Members of the local community and the hospital staff reviewed the questions, and modifications were made according to their suggestions. The initial English version was translated into Tsonga, the language of the majority of residents, then back into English by another translator. Any changes in meaning were corrected, and discussed further with interviewers. A number of patients who did not form the study population were interviewed to test the understanding of the questions, and the time needed for each interview.

Conduct of the interviews:

The two field workers shared responsibility for the interviews, one usually conducting the

first and third interviews, the other the second. They were trained through extensive discussions and practice. The nurse manager and the author monitored the process regularly by observing random interviews to ensure a sensitive approach, completeness, and correct documentation. Interviews were conducted in the language of choice of each patient - most in Tsonga and some in Sotho. The author reviewed all interview forms and coded answers, and once a month discussed all interviews conducted during the preceding four weeks, to clarify obscure answers, any problem issues, and ensure that patients whose interviews were incomplete or missing were traced to complete these.

Confidentiality, and the right to refuse or to stop at any point during interviews without prejudice to treatment was explained to every patient, and was ensured by the researchers.

Limitations:

Interviews were achieved only with considerable organisation and management of time and resources.

* For more than a year, only one vehicle was available to the research team. This was needed by the research nurse for daily visits to clinics as well as for follow-up visits to non-adherent patients. It became necessary to organise a second car.
* The field workers required in-service training, monitoring and support in the planning of interviews. Not all interviews took place according to the planned timing; patients were sometimes discharged without the interviewers' knowledge.
* Travelling in the district was a time-consuming, energy sapping process, not always with successful outcomes. The homes of many patients were visited many times. Unsuccessful attempts were discussed in detail, and plans made for each person,

depending on the likelihood, as stated by family or neighbours, of the patient's return. A data sheet was used for these searching visits for patients not found for interviews. (Appendix C8) After a maximum of five visits without success, the patient was usually considered "lost". If patients' families said they were out of the district (usually working or seeking work), they were categorised as such, but only after attempting to find them at home at weekends or whenever they were expected by the families. Some patients died before interviews took place.

Repeatability:

A random sample of patients were scheduled to have one of their interviews repeated at a subsequent date by one of the interviewers, not necessarily the same as the original interviewer. There were 39 such repeats planned (5% of all 778 interviews), 12 for the first interview (4% of 303), 15 for the second (5% of 286) and 12 for the third (6%). If the individual selected was not available after 2 visits to their homes, that individual was replaced by another randomly selected patient. The purpose of the re-interviews was to see if answers to the same questions at different times were comparable, and thus to assess validity of answers. BMDP statistical software (University Press of California, 1988) was used to calculate percentage agreements and, for continuous variables, Wilcoxon correlation coefficients.

Analysis:

Results of the interviews were entered into the EpiInfo 6 programme and analysed. Descriptive univariate, then bivariate analysis was performed, the latter studying associations between certain variables using chi square tests. Multivariate analysis, using

the Stata programme modelled a number of dependent variables against treatment outcomes.

18.3 Results

Results are presented under the following headings:

Response rate
Place of interviews
Demographic and personal characteristics
Health service first attended
Knowledge about treatment
Beliefs about cause
Anticipated problems
Supporter visits - time and cost
Transport to clinic or hospital
Satisfaction with treatment
Services consulted since discharge
Clinic attenders: access issues and preferences
Hospital attenders: access issues and preferences
General comments
Repeat interview results
Analysis of treatment outcome associations

18.3.1 Response rate:

There were 327 patients eligible to be interviewed three times during the course of their treatment, but the 99 registered in 1994 were eligible for two interviews only as the questionnaire was not designed by the time this subgroup completed treatment . The number of each of the interviews completed, the numbers not done, and the reasons for the failure are shown in table 49.

TABLE 49: NUMBERS OF PATIENTS INTERVIEWED AND REASONS FOR THOSE NOT DONE

	Interview 1	Interview 2	Interview 3
Interviews done	303 (93% of 327)	286 (87% of 327)	189 (58% of 327 OR 83% of 228)
Interviews not done	24	41	138
Reasons for no interview			
died	10	13	15
outside the district	5	14	14
unknown	7	11	18
refused	2	2	2
unfit for interview		1	
excluded*	-		99

* excluded were 99 patients registered during 1994, who were not interviewed because the third interview form was not yet ready

The number of patients who had 3,2 and 1 interview, and for those who had 1 or 2, and which interview(s) were done is shown in table 50.

TABLE 50: NUMBERS OF EACH CATEGORY OF INTERVIEW DONE

INTERVIEW	All 3	Two	One	None	Total
1		102	16		303
2		100	1		286
3		4			189
Total	185 (56%)	103 (31%)	17 (5%)	22 (7%)	327 (100%)

Just over half the patients had all three interviews.

Twenty two patients were not interviewed at all. Eight of these patients died before any interviews could be done, two refused, five had moved out of the district, and seven could not be found.

Possible bias due to non-respondents:

In order to assess any differences between those interviewed and those who were not, a comparison was done between those who had three interviews and those who had none, and between those who ha no or one interview, and those who had two or three. Variables compared were age, sex, the distance from homes to hospital, and treatment outcomes. Table A21 with these results is in the appendix. There were no differences in age categories, sexes, nor in distances from home to hospital for these groups. However those who had two or three interviews were more likely to have successful outcomes than those who only had one or two. ($X^2=120.5$; df1; $p=0.00000$). Those who had one or no interviews were more likely to have died. The latter is obvious since those patients who died during treatment would not have had three interviews. The greater likelihood of interrupting treatment for those not interviewed, or who did not complete at least two interviews may have introduced some bias into results. There was the possibility that interruptors had different beliefs, levels of knowledge, and experienced more problems with treatment. However 25 of the 35 interrupters (71%) had the first interview, with information on knowledge, beliefs and socio-economic data.

18.3.2 Place of interviews:

Of the 303 first interviews, 233 (77%) took place as scheduled at Tintswalo or Mapulaneng hospitals. The remaining 70 were mostly done at patients' homes (66 patients), with only four at a clinic. About half the second interviews (150 of 286, or 52%) were done at patients' homes, 118 (41%) at Tintswalo hospital at the time of a patient visit, 15 (5%) at a clinic and 3 (1%) at the patient's place of work. Half (96 of 189 or 51%) of the third interviews took place at Tintswalo hospital as scheduled. Most of the rest (89 or 47%) were done at the patients' homes. Two interviews were done at work, and 2 at a clinic. Interviews taking place later than scheduled were not expected to influence answers to questions. It used more research time to visit patients at home if they had been missed before discharge or at a hospital visit.

18.3.3 Demographic characteristics of patients:

Educational status:

The highest school standard obtained by the 303 patients is shown in table 51.

TABLE 51: EDUCATIONAL STATUS OF PATIENTS

Highest schooling attained	n	%
Less than 4 years formal education	133	44
Primary (std 2-5)	83	27
Secondary (std 6-10)	87	29
(std 9 and 10)	(37)	(12)
Total	303	100

Forty four percent had no formal education, 29% had at least some secondary schooling, 37 of whom (12% of all) had achieved standard 9 or 10. Five, all teachers, had some tertiary education. Eleven people mentioned some form of post-school course, 4 of these were trade certificates.

The relationship between age and education was explored in the data in table 52.

TABLE 52: RELATIONSHIP BETWEEN AGE AND EDUCATIONAL STATUS

Age Groups (in years)	HIGHEST EDUCATION ACHIEVED			
	Less than 4 years formal	Primary	Secondary	Total
Under 15	18 (51%)	6 (17%)	11 (31%)	35 (100%) (12%)
15-29	10 (16%)	14 (23%)	38 (61%)	62 (100%) (20%)
30-59	76 (45%)	59 (35%)	35 (21%)	170 (100%) (56%)
60+	29 (81%)	4 (11%)	3 (8%)	36 (100%) (12%)
Total	133 (44%)	83 (27%)	87 (29%)	303 (100%)

The educational status measured for patients under 15 years of age was that of their mothers, who were interviewed. This age group was excluded when those under 30 and under 60 were compared with all others. Significantly more patients under 30 had completed more than 4 years of schooling ($X^2=23.5$; df1; $p=0.0000$), and had completed some secondary education ($X^2=42.9$; df1; $p=0.0000$).

There was no association between sex and education. ($X^2=0.01$; df1; $p=0.93$) (Appendix A).

Occupation:

Two hundred and eleven patients, 78% of those aged 15 years or more, said they had worked for money outside their own homes at some time. Almost one quarter (23%) had worked for up to 5 years, another quarter (26%) for 6 to 10 years, and the rest for more than 10 years. The nature of the work is shown in table 53.

TABLE 53: TYPE OF WORK OF INTERVIEWEES

Type of work	n	% within sub-group	% of total
MANUAL			
miner	27	18	
manual labour	105	69	
domestic/gardener	21	14	
Total	**153**	**101 ***	73
SEMI-SKILLED			
driver	10	33	
clerk	4	13	
salesperson	8	27	
security	8	27	
Total	**30**	**100**	14
SKILLED			
tradesman	15	54	
machine- operator	8	29	
professional	5	18	
Total	**28**	**101 ***	13
TOTAL	211		100

* percents rounded

The results of educational status and type of work are shown in table 54.

TABLE 54: EDUCATIONAL STATUS AND WORK

EDUCATION	TYPE OF WORK				
	Unemployed	Manual	Semi-skilled	Skilled	Total
Informal	36 (27%)	76 (57%)	9 (7%)	12 (9%)	133 (100%)
Primary	14 (17%)	55 (66%)	7 (8%)	7 (8%)	83 (100%)
Secondary	42 (48%)	22 (25%)	14 (16%)	9 (10%)	87 (100%)
Total	92 (30%)	153 (51%)	30 (10%)	28 (9%)	303 (100%)

Significantly more of those with some level of secondary education were unemployed ($X^2=18.4$; df1; p=0.0000), and, if they were working, were engaged in semi-skilled or skilled occupations. ($X^2=15.9$; df1; p=0.0000)

Household information:

The total number of people living in the households of the 303 patients interviewed was 1870. The mode per household was 5, and the range 1-17. In 230 homes (76% of all) there was at least one young person under 15 years of age (mode 1, range 1-9), and there was a child under 5 years of age in 126 of the homes, 42% of all (mode 1, range 1-3). There were one or two old-age pensioners in 86 homes (28% of the total) (one in 61 homes and two in 25), and one or two disability pensioners in 16 homes (5% of all) (one in 15 homes, and two in one).

In 179 homes, 59% of all, there was at least one person earning money (mode 1, range 1-4). In 124 homes, 41%, there was said to be noone earning. Total monthly income (which included pensions) per household as estimated by the interviewees were nil in 64 households (21%), R100-480 in 64 (21%), R500-1970 in 146 (48%) and more than R2000 in 29 homes (10%).

18.3.4 Previous and family tuberculosis:

Thirty five patients (12% of all) admitted to a previous episode of tuberculosis, two thirds of which had been during the six years preceding the interview. Most, 29 or 83%, had been treated in Bushbuckridge at Tintswalo or Mapulaneng hospital. Twenty of the 35 (57%) said the duration of their treatment had been 6 months; the rest were either less (8) or more (6) or uncertain (1).

Ninety one patients (30%) said a family member was either currently on treatment for tuberculosis (24 patients) or had been in the past (67 patients).

18.3.5 Service first attended:

Patients were asked where they went first when sick with their current (tuberculosis) illness. Results are shown in table 55. In response to this open question, one quarter (77 patients) said they had first attended a traditional or faith healer. When specifically asked if they had ever attended traditional or faith healers, 117 (39%) said they had.

TABLE 55: FIRST PLACE ATTENDED FOR CURRENT ILLNESS

Place	n	%
Tintswalo hospital	106	35
Other hospital	30	10
Total hospital	**136**	**45**
Clinic	64	21
Private dr	25	8
Total allopathic health service	**225**	**74**
Traditional/faith healer	77	26
TOTAL	302 *	100

* 1 patient of the 303 did not answer this question

Associations with place first consulted:

Patients over the age of 15 years were more likely to attend traditional healers ($X^2=8.13$; df1; $p=0.004$), those under 15 were more likely to be taken to the hospital.($X^2=11.76$; df1; $p=0.0006$). Females and manual workers were more likely to go to a clinic. ($X^2=14.5$; df1; $p=0.03$ and $X^2=4.8$; df1; $p=0.02$ respectively) Manual workers were less likely to go to private practitioners ($X^2=7.1$; df1; $p=0.007$).

Those patients who lived more than 9 kilometres from the hospital were more likely to have gone first to a traditional healer than those who lived closer ($X^2=14.5$; df1; $p=0.034$), while those who lived within 9 kilometres were more likely to have first attended the hospital ($X^2=17.5$; df1; $p=0.00002$).

There was no difference in educational status between patients who first attended traditional or faith healers, and those who attended allopathic health services.

18.3.6 Knowledge about treatment:

Most respondents, 272 or 90%, had correct information about the frequency and duration of drugs. Of the 31 with incorrect replies, 13 had the dose correct but the duration incorrect, 10 the duration correct but said pills were to be taken more than once daily, and 8 had both incorrect. Those who had less than four years of schooling were less likely to be correct. ($X^2=5.5$; df1; $p=0.01$) There was no association between knowledge and age categories, sex, previous episodes of tuberculosis, nor with patients on treatment at Tintswalo hospital compared with those attending clinics.

18.3.7 Belief about the cause of tuberculosis:

The first question in this section was open and asked patients what they believed was the cause of their disease. Results are given in table 56.

TABLE 56: PATIENTS' BELIEFS ABOUT THE CAUSE OF TUBERCULOSIS: OPEN QUESTIONS

Belief	n	%
Unknown	91	30
Spread from others or inadequate past treatment	90	30
Dust or work on mines	50	17
Cigarettes and/or alcohol	34	11
Work exposure to chemicals/fumes	21	7
Cultural	17	6
Total	303	101 *

* percentages rounded

A list of possible answers was then offered. Affirmative answers were ranked as presented in table 57.

TABLE 57: BELIEFS ABOUT THE CAUSE OF TUBERCULOSIS: CLOSED QUESTION ANSWERS

Stated Cause	%
Spread	95
Mine work	95
Poor nutrition	89
Inadequate treatment	88
Contaminated food	86
Cigarette smoking	79
Alcohol use	74
STD	71
Disobeying traditional rules	63
Bewitchment	14

Stated beliefs from the open questions were divided into 4 categories: cause unknown, spread or inadequate treatment, environmental or personal habits (lifestyle), and traditionally ascribed causes. These categories were tested for associations with a number of other variables.

Belief in spread: Those who believed in the spread of disease from others were more likely to have secondary education (X^2=6.5; df1; p=0.01), have attended hospital first (X^2=6.99; df1; p=0.008), to be female (X^2=12.02; df1; ,p=0.0005), and young (under the age of 15 years) (X^2=17.3; df1; p=0.00003). [This meant that mothers of young children were more likely to take their children to hospital, since measured belief of children under 15 years was that of the mothers]

Traditional belief: Traditional beliefs in the cause of tuberculosis were more likely to be

associated with stated first attendance at traditional healers (X^2=19.12; df1; p=0.00001). They were not associated with educational status.

Belief in environmental and lifestyle causes: These were features of males (X^2=33.9; df1; p=0.0000), and of those with less than secondary education (X^2=110.4; df1; p=0.00000)

Unknown cause: Those who said they did not know the cause of tuberculosis were more likely to be female (X^2=9.6; df1; p=0.0019), and have less than secondary education (X^2=58.9; df1; p=0.0000). [Female sex and educational status were not themselves associated - Appendix A22]

Factors not associated with beliefs were knowledge about treatment, previous episodes of disease, HIV status, occupation, distance from patient's homes to hospital, and different treatment groups.

18.3.8 Anticipated problems with treatment:

Only 3% of patients (10 of 303) anticipated problems with their treatment, all citing lack of money or lack of transport. Five of these 10 were due to receive treatment at Tintswalo hospital, and four of those five lived within nine kilometres of it.

Eighteen patients (6% of 303) asked questions about their treatment. These were answered by the interviewers.

18.3.9 Supporter visits: time and costs

The presence or absence of a supporter for each patient was measured against educational status. Those patients who had had some level of formal education were more likely not to have a treatment supporter.(X^2=4.1; df1; p=0.04) Most respondents who had supporters (74% or 190 of 256) said it took up to 5 minutes to reach their supporters.

Fifty six (22%) said between 6 and 15 minutes, and 10 (4% of 256) more than 15 minutes. Only 4% took more than 15 minutes. For almost all (178 of 179 asked), there were no costs.

18.3.10 Transport to clinic or hospital and problems experienced:

More than half of the 286 (180 or 63%) asked about transport to clinic or hospital (180 or 63%) used taxis or buses, 100 (35%) walked, and 6 (2%) used a car. Forty one (14%) experienced problems, 31 of these were lack of money, 9 said the place was too far to walk, and 1 said transport was not available.

18.3.11 Satisfaction with treatment:

All but 3 of 286 patient said they were satisfied with the treatment given at the clinic or hospital. Problems mentioned were staff (2) or excessive waiting time (1).

18.3.12 Services consulted since discharge:

Fifty five of 286 patients (19%) said they had consulted one of the following since their discharge from hospital, while still on treatment: traditional healer (25), faith healers (11), a private doctor (9), another hospital or clinic (10).

18.3.13 Clinic and hospital attenders: Access issues and preferences

Time to reach clinics or hospitals, modes of transport, direct cost, waiting times, problems experienced and the preferred place for follow-up treatment appear in table 58.

TABLE 58: CLINIC AND HOSPITAL ATTENDERS: VARIABLES

Variable	Categories	CLINIC ATTENDERS n=75		HOSPITAL ATTENDERS n=114 *	
		n	%	n	%
Time to reach	Up to 15 minutes	28	37	23	20
	15-30 mins	29	39	40	36
	More than 30 mins	18	24	50	44
Mode of transport	Walk	39	52	33	29
	Taxi	31	41	76	67
	Other	5	7	5	4
Cost	Nil	39	52	33	29
	R1-R2.5	26	35	22	19
	R3-10	10	13	56	50
	More than R10			2	2
Waiting time	Less than 30 mins	53	71	11	10
	30-60 mins	17	23	21	19
	More than 60 mins	5	7	81	72
Problems experienced	Yes	8	11	31	27
	No	67	89	83	73
Preferred place for treatment	Clinic	70	93	48	52
	Hospital	5	7	45	48

* some questions were answered by 113 patients, and preferences by only 93

Three quarters of clinic attenders had taken 30 minutes or less to reach the clinic, while 44% of hospital attenders had taken more than 30 minutes. Half the clinic patients walked, most of the other half had to pay less than R3 for transport. Seventy percent of hospital patients used some form of transport, half of them paid more than R3. The hospital waiting times were longer - 72% of patients spent more than one hour waiting. More of the hospital patients expressed problems.

Preferred place for treatment:

Of the 189 patients interviewed at the end of their treatment, 168 gave a preference for where they would like to have their tuberculosis treatment. One hundred and eighteen (70%) preferred a clinic, 116 (98% of the 118) because it was more convenient, 2 because they said the treatment was better there. Fifty (30%) preferred the hospital, 27 (54% of the 50) because it was closer, 23 because they believed the treatment was better. (Several specifically mentioned the presence of a doctor, or of X-rays at the hospital.)

Of the 75 respondents who were actually attending clinics for their treatment, 70 (93%) said that was the place they preferred, for reasons of easy access (68 patients) or better treatment (two). The other five preferred the hospital either because it was closer (1) or that they felt the treatment was better (four).

Forty six of the 93 respondents attending the hospital were "control clinic" patients (who lived in villages where the clinics did not provide tuberculosis follow-up treatment). Preference for clinic treatment was stated by 37 of those 46 (80%), all of whom said this would be more convenient. The remaining nine preferred the hospital because they believed treatment was better (six), there was a doctor there (two), or they worked there (one).

The other 47 were in the hospital group for whom Tintswalo hospital was the closest health facility). Most of these (36 of 77%) did prefer the hospital, but 11 (23%) said they would rather attend a clinic, if this were closer.

18.3.14 General comments:

Patients were asked what they would tell a friend or neighbour about their experiences with tuberculosis and its treatment, if that person was diagnosed with tuberculosis. Nearly all (183 of 187 that replied) had a positive message, that treatment was important. Of the remaining four, two said the treatment made them hungry, one that there were problems getting the treatment, and one that treatment was difficult at first, but became easier.

Answers to a series of direct questions about the treatment were as follows: Twenty percent (38) said the pills caused side effects, 14% (26) that the nurses were not good, and 31% (58) that they did not feel that they were cured, as they still had symptoms. Four percent, in answer to a specific question, said they would recommend patients should attend a traditional healer. However, 11%, in response to an open question about where they would recommend someone should go if sick with tuberculosis, said they did not believe traditional healers could help this disease.

18.3.15 Results of repeat interviews:

The percentage agreement for each of the interview questions is tabled in Appendix 23. There was good agreement for questions other than those described here. The main group of questions with less than 75% agreement were statements of numbers of people in households, and times to reach and wait at facilities. The only other major discrepancies were in belief about cause (38% agreement), type of work (57%) and the means of

transport to hospital or clinic (55%). There were some differences in the general section about whether there were side effects of treatment, and whether the staff were kind (54% and 69% respectively)

18.3.16 Analysis of treatment outcome associations:

Bivariate analysis was used to examine associations between treatment outcomes and a number of the variables measured from the interviews. Outcomes were grouped as for the intervention study results in chapter 16. The full table of results is in Appendix 24. Significant associations with successful outcomes, p values less than 0.05 at 95% confidence level, were as follows: Age less than 30 years, female sex (only if deaths as an outcome are excluded), belief in spread or belief in causes other than lifestyle and environmental factors, being in the same home as the treatment supporter, and stating no problems with treatment.

Multivariate analysis:

The multivariate model used to identify predictors of successful treatment outcomes for patients who lived in the district, and who were interviewed, was described in chapter 16, page 216. The explanatory variables found to be significantly related to successful outcomes were having a treatment supporter, the belief that the disease was caused by spread from other people, presentation as a new rather than a re-treatment patient, and more than three years of formal education at school.

18.4 Discussion and implications for management of tuberculosis in this district

The series of interviews revealed much important information, and provided insights into

patients' experiences, attitudes towards tuberculosis, and their behaviours when sick. Health workers need to have this patient-centred view in order to provide health services to meet patients' needs, both social and cultural and logistic.

Interview studies can experience limitations in their ability to extract valid information. The interviewers in this study were remarkably sensitive and caring people, who did an enormous amount of travelling, and spent hundreds of hours talking to patients. The repeatability study found good agreement for most variables. It was not really surprising that stated numbers of people and times were inconsistent. For people with less formal education and without means of keeping time, exact numbers and time periods must have been unimportant in their lives. It is possible that household size changed over periods, for example at weekends, month ends and school holidays. Discrepancies in stated beliefs about cause of tuberculosis might have been because people really were confused and changed their minds, or because they had been exposed to health education during treatment (one hoped that was the case!). There were some variations in the means of transport patients said they used to reach health facilities. These would have depended on the availability of finances and transport facilities, and thus were not surprising differences identified in the repeat interviews.

There were certainly fewer interruptors than "completers" available for the interviews, but at least three quarters of the interruptors had interviews about their beliefs and early behaviours.

The study confirmed the **low socio-economic status** of patients. Of those who had ever worked, most were in the manual category. Half said their total monthly household income was less than R2000, with a mode of 5 people per household. Forty one percent of

households had no earners. This was comparable with the findings of the study quoted earlier from the same area in 1993, where the mean monthly household income was R520.[387] Nearly half of our patients had not completed four years of schooling. Lower educational status was associated with lack of knowledge about the cause of tuberculosis, or in belief that it was due to dust, smoking and drinking alcohol. On the other hand, better education was associated with knowledge that it was due to spread, which in turn was associated with hospital attendance when first sick.

It was salient to note that there were 1870 **household contacts** of the 303 patients with known disease, many of which contacts were young children.

The high proportion of patients who reported having had a **previous course of treatment** (12%) was similar to that in hospital records. Nearly a third of patients knew of a family member who had past or present tuberculosis.

One quarter of responders stated that their first attendance had been at a **traditional healer.** The issue will be returned to when the focus group interviews are discussed in chapter 19. Those patients were more likely to be adults, and more likely to live far from the hospital, probably reflecting the relative availability of traditional healers, and the non-availability of allopathic services. Although only six percent stated an unprompted belief in traditional causes of the disease, 63%, specifically asked, agreed that this was a cause. It seemed that **female patients** tended to believe either that the cause was spread from people with disease, or they did not know. These views are somewhat contradictory. They were more likely to attend clinics first, which would seem logical as clinics are nearer to their homes. Children were more likely to attend hospital, reflecting their mothers actions, and probably their concern to seek a higher level of care for their sick children.

Patients attending "treatment" clinics for their follow-up tuberculosis treatment said it cost less in travel and waiting times, and in money, and the vast majority preferred that source of care. **Hospital attenders** took longer to reach there, waited far longer, had more to pay for transport, stated more problems, and half would have preferred clinics. These results seem to provide adequate justification for decentralisation of tuberculosis services.

Successful treatment outcomes were related, in multivariate analysis, to the presence of supporters and first time treatment, as well as to the stated belief in germs and spread of disease from person to person, and in some level of formal education. This would justify attention to information and education on tuberculosis for communities. These results did not show any relationship between outcomes and traditional beliefs about the disease.. Such beliefs may not be readily identifiable, but do exist, as became apparent in the group interviews (chapter 19). Farmer has stated that causal beliefs about tuberculosis are not predictive of adherence to treatment, predictors being fundamentally economic.[271]

CHAPTER 19

GROUP INTERVIEWS

This chapter includes:

Introduction
Objectives
Methods
Results
Discussion
Conclusions

19.1 Introduction

Interviews with individuals provide answers to questions, but are limited in that they do not explore attitudes and perceptions, and do not allow the subject to listen and respond to views of others from the same population. The opinions of interviewees who are reticent, for whatever reason, to share their views, are not heard in these research situations. This applies especially to taboo subjects.

A focus group interview is a qualitative method of studying a particular topic using an in-depth discussion by a small group of people, under the guidance of a facilitator. Group members are usually a purposive sample of the population, selected because they have characteristics in common.[402] Such methods have been in use for market research. However the application to social science is rather new.

This qualitative study method has a particular role in studying attitudes and experiences. It is useful to complement quantitative studies to answer questions of "why" and "how",

rather than "how many".[403] They allow participants to explore issues of importance to them, initiated by a series of planned open ended questions. There is no discrimination against those who cannot read or write. The fact that focus groups for social science and related subjects are relatively new on the research scene, means that methods do not have empirical backup. Issues such as the number of sessions with each group, and group composition are still debatable. It is suggested that groups should be as homogeneous as possible, to allow discussion on issues in common to members. The ideal size is between four and 12 people. A facilitator, who should be trained in the technique, needs to explain the purpose, pose the questions, following which that person has a role only in facilitating discussion, encouraging non-participant involvement, keeping the discussion within the broad topic, clarifying and summarising. An appointed research scribe, not part of the group, should record everything said.[403] Where possible discussions should be tape recorded, and written transcripts of the tapes, as well as notes made by the scribe, analysed. Analysis is a process of drawing out themes from the discussions, distinguishing between individual opinions and group consensus.

Focus groups do have limitations. There is a chance of introducing errors when preparing transcripts from tapes, especially when different languages are used. Results need to be interpreted with caution, as they may not indicate attitudes of beliefs of the whole population. However if carefully selected, groups may reflect generally held opinions.[402] A number of focus group studies have been reported, and have demonstrated the power of the method in investigating people's opinions and attitudes. Groups of women in Bombay were shown to have different perceptions of their health priorities from health

professionals, with significant implications for health services delivery.[265] Tuberculosis researchers in Pakistan, Vietnam and the Philippines uncovered a stigma (for patients and staff) and fear relating to the disease, with consequent delays in accessing treatment, and patients problems with treatment adherence.[257, 261, 264] Priority research areas in tuberculosis for the 21st Century, as identified by the Centers for Disease Control and Prevention, USA, are community knowledge, "myths and misconceptions" about the disease, and social and cultural factors that affect adherence.[404]

The present study sought to complement the findings from interviews on individual patients with group interviews.

19.2 Objectives

To explore perceptions and attitudes about tuberculosis of patients and community members, specifically beliefs about the cause, attitudes to those affected, and problems with taking treatment.

19.3 Methods

Training course for interview facilitators:

A course in qualitative research methods was organised for the researchers involved. They were the research nurse and interviewers (these three individuals were to have responsibility for the group interviews). A number of staff from Tintswalo and the neighbouring district hospital, and the Health Systems Development Unit were invited to participate in a course, conducted over eight days, organised in three sessions over an

eight week period, by an experienced qualitative researcher attached to Soul City, part of the Institute for Primary Health Care in Johannesburg.

Selection of focus groups:

Several different groups were selected for the focus group study. The numbers in the 14 groups, the dates and venues are listed in table 59. Individuals within each group were not selected, so recruitment involved explaining the purpose to various groups who were tuberculosis ward patients, community groups, and interested people, and inviting them to attend on a set date.

TABLE 59: FOCUS GROUP INTERVIEWS: GROUPS AND DATES

Date	Group	Sexes	No. in Group	Venue
July 95	Indunas	M	10+	Dixie
Aug 95	Community	M+F	10	Hluvukani
Aug 95	Community	M+F	15	Gottenburg
Sept 95	TB patients	M	8	Tintswalo
Sept 95	Traditional healers	M+F	8	Cottondale
Sept 95	TB patients	F	4	Tintswalo
Sept 95	TB patients	M	9	Tintswalo
Oct 95	TB patients	M	9	Mapulaneng
Jan 96	Traditional healers	M+F	12	Acornhoek
Feb 96	TB patients	M	12	Tintswalo
Mar 96	Traditional healers	M+F	15	Timbavati
Apr 96	Student nurses	F	15	Tintswalo
May 96	TB patients	M	5	Mapulaneng
May 96	Workers	M	12	Timbavati

Measurements:

Each group was limited to not more than 15 people. Discussions were held outside the ward (for hospital in-patients), or in some community setting, usually under a tree. They lasted not more than 1 hour. Audio-recording of interviews was done (except for three groups when the tape recorder did not work). Each group discussion had a facilitator and a scribe, who had been trained. These were the research nurse, and the two interviewers. The audio-record was transcribed within a day of the discussion. Questions were posed around the following broad topics:

1. What is TB, and what causes it?
2. How do patients feel when they have TB and what are the attitudes of others to people who have TB?
3. How can it be prevented?
4. How should it be treated and where, and what are the problems in completing treatment?

Analysis was done by a group consisting of the research team of five people and two experienced focus group workers from Soul City. Themes were identified in the written records, cut up and glued together and discussed.

Limitations:

There may have been some bias in results of group discussions with patients who had been in hospital for varying periods, subject to information and education about tuberculosis and who may have been reticent to discuss "traditional" beliefs in a hospital setting. The researchers were aware of these possibilities and tried to ensure impartiality, and to encourage free discussion. For community groups outside the hospital, there was the possibility that discussion would have been limited because of the association of the researchers with the health system. In fact the two male interviewers were not health workers, and all facilitators were skilled in introducing the topic objectively, explaining interest rather than prejudice. The nurse did not wear a uniform when facilitating these group interviews.

19.4 Results

Results will be presented as a summary of analysed discussion transcripts, interspersed with direct quotations of what was said. The term TB is used in this section, as that is how people refer to tuberculosis.

WHAT IS TB AND WHAT CAUSES IT?

Local people believe there are two types of "TB" disease, with similar but not identical features, with different causes. There is the "medical" type disease, as known to hospital and clinic staff. Some say that this is a serious illness, others say it is not, because early treatment can cure it. There were some who spoke of this disease being caused by a germ, resulting in a illness with a cough, spreading from person to person, diagnosed by X-rays, and not amenable to cure by traditional healers. Many believe it is contracted from working on mines and in dusty work places, in fields when ploughing by tractor, in cement works, and in kraals where cow-dung is newly laid. Fumes from chemicals in work situations, including insecticides and paint fumes, are also though to be related. People also believe it affects people who drink excessive amounts of alcohol, especially "strong" alcohol as opposed to local beer, largely because heavy drinkers do not eat good food. It is associated with smoking cigarettes, and can be contracted from sharing cigarettes with an affected person. Children who are exposed to cigarettes can develop disease. If air from a person with TB is breathed in, this can result in TB. This spread happens in adults and in children. Some people are puzzled about TB, because they do not remember being in contact with anyone with the disease. TB is similar to what is known culturally as "6 month cough" in children.

The other type of TB has, for many people, a traditional origin. "We Africans believe strongly in this (traditional belief about the origin of TB)" A disease, with features similar to "TB" is transmitted sexually and called "Tindzaka". When there is a death in a family, if a member of that family has sex with someone who is not a family member, those two people will get a sickness called "Tindzaka". This is not exactly the same as TB, but it causes coughing. It happens if a man sleeps with a woman when she is still in her black clothes (in a period of mourning) after her husband has died. Another reason for getting sick when someone dies, is if someone, usually a woman, fails to observe the custom of abstaining from sex for the period stipulated by the elders of the family, then prepares or serves food to others. The persons who eat that food get this sickness called "Tindzaka". Patients with this sickness cough, often with blood, always look down, and are shy. The whole body swells up including the abdomen and knees, they are pale with long nails. It can be fatal if not treated within a month. No doctor can cure this. If they are given an injection, they can die. A traditional healer can treat it within two days.

There is a disease called "Mafulari" (Makhuma), which is caused by ancestors turning against a person who has disregarded traditional customs. It is difficult to distinguish between Mafulare and Tindzaka.

If a woman, recently delivered of a baby sleeps with her husband within 6 months of the birth, that child will develop TB. Similarly, if a woman has sex within 3-6 months of aborting, or after her recently delivered child had died, that can cause TB in the man. He develops a cough, is unable to pass urine, and frequently dies within 2-4 days. That sickness is called Rixixa, and only occurs in males. Only a traditional healer can cure that sickness.

"It is difficult to tell people what you have done when you get Rixixa or Tindzaka. That is why there are a lot of deaths due to these conditions." People who have Tindzaka and Rixixa must not delay in going to traditional healers for treatment. Going first to hospital causes a delay. Traditional healers must be the first people to be consulted when a person gets sick. They give medicines to wash the family members after a death. Some have been charged R100.

Young women today often disregard what their elders tell them. Nurses give out contraceptives, and tell them they can sleep around. In this way TB results.

A type of cough in children called "inkakha" can be cured by traditional healers using donkey milk, cameleon soup, gum tree bark and bitter spinach.

There are similarities between the traditional sickness, and TB. That is why "black" and "white" doctors must come together and discuss their management.

ATTITUDES ABOUT TB AND PEOPLE WHO HAVE TB:

There is a fear of spread from affected people. People who have TB should abstain from sex or from kissing, and often are not well enough for sex. This can cause family disorganisation, because partners of patients look elsewhere for sexual gratification. African people share the same plates and cups. TB can spread in this way, especially if the person is not on treatment. Before the person is diagnosed, this is a problem.

Patients with TB feel guilty because they can spread it. Some know that if they are on treatment, it will not happen.

"Anyone can get TB, so we should not be afraid of it".

PREVENTION OF TB:

"Some say that TB can be prevented if people stop smoking and drinking alcohol". Regarding the association with mining and dust, "we cannot stop working on the mines, as we need the work." Once a person has TB, it is difficult to prevent spread in the family when all eat together. Family members must be checked for TB.

TREATMENT OF TB and associated problems:

There are contradictions about treatment. Some believe that hospital treatment is essential, but many say that most people attend traditional healers first. "Most of us patients start treatment at the traditional healers". In a group of 9 male patients, 6 had been first to a traditional healer.

"A person who has TB should go to hospital for treatment. We have heard this on the radio." "When a person with TB is taking treatment, they cannot spread the disease." It was said that patients who were very sick, and recovered with treatment have stated that people with TB should take their treatment regularly. Some people are dishonest about taking treatment, not telling relatives that they are not taking their treatment. Proper treatment means taking tablets as the nurses tell us. Many difficulties in taking treatment as prescribed were described:

"It is really difficult to take treatment every day." (Some said it is not difficult.) "Some people stop taking treatment when they feel better." Patients say they cannot have sex while on treatment. "At the hospital no-one discussed this." Fears include spreading TB, and that red urine affects sex. Abstinence is difficult for 6 months, so many stop taking pills. Pills cause other side effects, especially vomiting and dizzyness in some people,

which makes it difficult to continue. If sick people react to treatment (injections), the disease is not TB, but is Tindzaka or Mafulare. Going to hospital for treatment is difficult because of the cost of transport. "I would prefer to take treatment at the clinic." "Nurses must be careful how they treat patients, especially older men. If they are disrespectful, people stop taking treatment. In addition, they do not always explain the treatment well." "I stopped taking treatment for TB because the clinic nurses scolded me, so I started drinking heavily." "Alcohol makes a person forget to take pills."

Patients who move out of an area to work or to attend school stop taking treatment. Some believe that treatment should not be from supporters outside the family, as they are afraid of being bewitched. Others say supported treatment from the nearest shop or relatives is best. Patients would like nurses to discuss with them who they would prefer as supporters.

19.5 Discussion

It is apparent that people's perceptions of tuberculosis vary widely. There are those who have the concept of germs, spread from others, and treatment using "Western" drugs, having learned this from some source. However, there is widespread belief in this community that there is an association between a serious tuberculosis-like illness and disobeying traditional norms and practices after a family death, and after a woman has aborted. This illness, it is strongly believed, can only be managed by traditional healers. In the same way as it is believed that delaying traditional healer treatment is dangerous for this type of illness, others recognise that delay in receiving hospital pills will prevent cure and promote the spread to family and community members. Of concern is the possibility

that the association between tuberculosis and sexually spread HIV-infection will confirm in many people's minds the sexual nature of tuberculosis, and further stigmatise the tuberculosis and HIV problems. References to a sexual link with tuberculosis such as identified in this study was not found in the literature, other than in the report of Buch, who studied tuberculosis patients at Tintswalo hospital in the 1980s, and outlined the same traditional beliefs as were found in this study.[345] The general stigma associated with the disease is frequently cited. Nichter has described "weak lungs", and the reluctance of Philippino patients to discuss their illnesses.[264] Jenkins found that Florida American Africans say it is a disease that affects "bad people".[256] Ndeti, writing about East Africans, describes 50% of people presenting for traditional methods of treatment. He argues that patients can be torn between traditional community and medical staff influences, which differing views can have negative effects on treatment adherence.[269] This dichotomy may well exist for people in the Tintswalo district.

Other suspected causes are heavy physical activity or injury, or witchcraft.[269] Interviews with South African patients identified beliefs including alcohol excesses, smoking of cigarettes or dagga, inhaling fumes, and poor food intake. No patients described a direct association with the infectious sexually transmitted diseases. The closest was "infidelity" by only 5% of respondents.[267] This confirms opinion of Nichter that cultural beliefs and practices are specific to groups.[264]

There are many logistic issues that prevent people taking pills for many months. The shame and disgrace of having a disease because of improper behaviour must be a potent

factor in preventing early presentation to hospital. The sensitive difficulties relating to having sex while on treatment, and the perceptions that side effects prove the cultural nature of the sickness would make adherence to treatment problematic. An important issue raised by patients, that supporters who are from outside the families of patients may be able to perpetrate witchcraft, demands careful discussion of supporters with each patient. The results of discussions with groups of patients and community members confirmed and expanded on information provided by individual patients where only 25% stated their belief in a traditional cause of tuberculosis. The focus group evidence leads to the conclusion that individual interviewees were reticent to discuss their true feelings with interviewers, who were associated, despite their attempts to counter this, with the health services.

19.6 Conclusions

There is a great need for further clarification by health workers about beliefs and perceptions of tuberculosis by local communities, as these clearly constrain prompt presentation and successful treatment outcomes. Lack of understanding and impatience with local practices and beliefs are harmful to patient-health worker relationships. It is recommended that doctors and nurses have a responsibility to determine local beliefs, and to interact, and, as far as possible, to collaborate with traditional practitioners for the benefit of their patients. Otherwise patients will receive confusing messages, and will have to make their own choices about treatment. Cultural ideas being more ingrained into the fabric of a society, will dominate, unless feasible, logical and acceptable complementary solutions to illness are provided.

SECTION 5

CONCLUSIONS AND RECOMMENDATIONS

This section will summarise the study conclusions and discuss key aspects that influenced the results, and make recommendations for tuberculosis service delivery for this and other rural districts. The chapters included are:

20. Conclusions, Issues and Constraints concerning tuberculosis management in this district
21. Recommendations for good, sustained tuberculosis control

CHAPTER 20

CONCLUSIONS, ISSUES AND CONSTRAINTS CONCERNING TUBERCULOSIS MANAGEMENT IN THIS DISTRICT

This chapter includes:

Study Conclusions

Issues and Constraints

20.1 Conclusions

* *There was an improvement after intervention in treatment outcomes of those patients who lived in the district served by Tintswalo hospital*

* *The improvement was not confined to those patients attending decentralised treatment clinics, but was shown to occur for all patients, whether receiving hospital-based or clinic-based treatment. This shows that decentralised tuberculosis services can work well when managed efficiently.*

* *A community-based support system was implemented, and worked well. Supporters in patients' communities are easily accessible, and were shown to positively influence treatment outcomes.*

* *A high rate of resistant disease was measured. This was not surprising, considering the erratic management and drug taking of patients during previous years. It is essential that this new epidemic of MDR be prevented and well managed.*

* *There was no improvement in treatment outcomes for patients resident outside the district. Patients have the right to have good health services within the district in which they are resident. There must be clearly defined areas of responsibility for services, with availability and accessibility for patients. Good referral systems for inter-district referrals is essential.*

* *The diagnosis of tuberculosis on the basis of sputum microscopy was an improvement on how this was done in the earlier period of the study (1992-1994). However the rate of monitoring during and at the end of treatment was unaccepatable low (55% were tested at two months,and 30% at the end of treatment), even for those patients attending the hospital regularly.*

* *Interviews with patients, both individuals and groups, and with groups of community members, revealed that there are traditional beliefs about the origin and treatment of tuberculosis that must impact on case-holding and case-finding*

* *Interviews also showed that there were a number of access problems experienced by patients, and that community clinics, or decentralised services were preferred by most*

20.2 Issues and Constraints

The study has measured processes and outcomes over a 4 year period during which there was a change in the district tuberculosis control programme from poor to good.

In order to formulate feasible and useful recommendations on the provision of tuberculosis

health services for this and other rural districts, a number of important issues need to be considered. These are:

How was this improvement achieved?

* **What were the main constraints in the process?**
* **How can the improvements be sustained and further improvements achieved?**
* **How can the perspectives and needs of the community and of patients, be incorporated into the planning and implementation of services?**

20.2.1 How was this improvement achieved?

* **The general effect of the research team and their resources:**

This district was part of the poorest province in South Africa, and was suffering from the inequities of the old *apartheid* system. As such, resources, both material and managerial were limited. Little was being achieved without a policy, a tuberculosis control programme and the essential infrastructure including transport, training materials, laboratory networks. There was limited knowledge about the disease control and international warnings about the severity of the global epidemic.

The research project provided policy guidelines, endorsed by international documents and a visit from a team of WHO and local experts on tuberculosis team during 1995. The research nurse visited every intervention clinic on a regular basis to train, support and monitor the staff. She was independent of the erratic supply of hospital transport, with the use of a research vehicle. The research team including the interviewers, who were stimulated by employment and by continuing training and monitoring, spread their enthusiasm to the hospital and community tuberculosis workers. Tuberculosis became an

interesting and acceptable area in which to work. Comfortable research office space was shared with the service staff.

A computerised data base of all patients and their management was set up by the researchers. This preceded the new national register system. Before this data base, there had been no means of measuring outcomes or processes, and with no measures, no incentives to improve poor results. The service team had full access to his data base, and used it to plan their visits and assess results.

The insistence on accurate and timeous data collection and recording, and for patient-centred care set a standard for health workers.

* **The manageable size of the study area**

The defined area of one district with 12 clinics and 200-300 patients per year made the study manageable. It acted as a useful "demonstration" district, with results of interventions generalisable to other rural districts.

* **Staff training**

Clinic nurses received training and education about tuberculosis from the researchers, both continually at individual clinics, and at three formal training sessions. The latter were organised for a total of 83 nurses, including senior district managers, with the objective of providing basic training in tuberculosis management for every professional nurse working at a district clinic, and for managers who had overall responsibility for the services. Two sessions were for staff of "treatment" clinics, and the third for nurses of all the other district clinics. The sessions included practical exercises and role plays, and were evaluated by the nurses as very useful.

* **Supervision and monitoring of the intervention clinics**

Regular weekly visits were made to every intervention clinic. The research nurse examined every tuberculosis patient clinic card for details of sputum monitoring, supporter attendances (these were copied onto clinic cards from the patients' cards), and clinic attendances with clinical details documented at each visit. Drug supplies were inspected, and patient management issues and problems were discussed with staff. The author visited each clinic every three months for the same purpose.

* **Follow-up of non-attending patients**

Clinic nurses were trained to identify any patient who missed a monthly clinic appointment within one or two days. Strategies for follow-up that involved clinic staff action were encouraged. Although emphasis was laid on the clinic staff taking responsibility for the follow-up, their lack of transport and their preoccupation with the daily load of sick patients at the clinic were limiting factors. It became clear that the back-up of researchers, was needed. Where necessary the research nurse went to patients' homes and to their supporters to discuss the problems.

* **Interest and cooperation of clinic nurses**

Most clinic nurses were interested in the new decentralised tuberculosis service, and keen to help their patients. They completed the cards carefully, and some made special efforts in tracing non-attenders. They were receptive to advice and support, and clearly pleased to have regular supportive and instructional visits, and to have colleagues with whom they could discuss their work. The full day training sessions held at a nearby hotel, away from the work situation, were especially popular.

* **Cooperation of hospital and community tuberculosis staff**

The key to the good treatment outcomes throughout the district, not confined to "treatment" clinics, was the cooperation and enthusiasm that developed among the senior nurses in the hospital tuberculosis ward and among the community tuberculosis team consisting of a nurse and two health educators. They all attended the training sessions, and set up regular meetings (monthly and more often as necessary) with the research team to discuss the control programme and issues arising. The ward sister fulfilled an important role in informing the researchers about discharged patients. Help was provided by the researchers in describing and reorganising the roles of the community tuberculosis staff, so that they performed more effectively and efficiently.

* **Support of laboratory staff**

The laboratory staff had not previously been informed or consulted about tuberculosis work. Once they were invited to training sessions, and quality control systems were set up through the research programme (with their cooperation), the turn-around time for specimens improved. Measuring quality of laboratory work did not form part of the study, but a quality control system set up by the South African Institute of Medical Research as a result of the research, had results which were said to be excellent.

* **Availability of drugs**

Anti-tuberculosis drugs were erratic in supply before the research project. Combinations drugs were unused and unknown. The pharmacist, with the help of the newly established provincial drug supply system, eventually responded to suggestions of the researchers and cooperated to ensure that all recommended drugs were available. Issues of supplies for up

to five months were given to the research nurse to take to "treatment" clinics to be stored for patients who attended there.

* **Interest and willingness of community supporters**

The social system in this district whereby many community members took responsibility for one another was an asset to the tuberculosis supporter system. With appropriate initiation from research and service health workers, a variety of lay-people became supporters, and successfully trod the path to cure or completion of treatment with many patients.

20.2.2 What were the constraints in the process?

There were a number of factors that constrained the process of decentralising tuberculosis services to district clinics. These could be classified as factors in the physical and social environment of this area, health services deficiencies, and research deficiencies and limitations.

* **Physical and social environmental factors**

Major constraints for the provision of all health care in this district are the long distances from where people live to the hospital and to clinics along bad, dangerous roads, and where public transport is expensive.

The researchers became aware of the social and cultural beliefs that were barriers to early health service attendance, both because the disease was stigmatised through local beliefs that the cause was unacceptable behaviour, and because traditional healers had to be consulted. Until different health care providers cooperate, patients will be torn, and will

present to clinics and hospitals with late stage tuberculosis.

* **District management deficiencies**

In the absence of a district health system, management was actually that of the hospital. The district suffered from a number of management deficiencies, many consequent on the previous system of "homelands", two of which, Lebowa and Gazankulu, had formed part of the previous area of the district. Any initiatives that communities or health workers might have shown had been stifled by this system, so that demotivated staff and absent resources were the norm. Exceptions existed of course, at management and implementation levels.

The newly established provincial government could not be expected to facilitate immediate changes in attitudes or behaviours. Health service management was hospital-based, and there was poor understanding and limited activity around community services, including clinic management. Resources and support for clinics were minimal. As with many government services, senior staff spent long hours travelling to and attending meetings called at short notice at head office, with resultant disruption of routines, tiredness and frustration.

The research initiative met opposition from such managers. This was not overt, but manifest in lack of active support for the new decentralised system, failure to ensure accountability of clinic staff for their actions in tuberculosis patient management and failure to be seen supporting the work, resulting in confused lines of authority for clinic staff. Organising training sessions (at no cost to the hospital) was difficult as managers would not commit themselves to allowing staff to attend, and failed to help with forward planning. Much time and energy was expended in diplomatic negotiations, and in trying

to understand the underlying issues.

The old Lebowa clinics, under Mapulaneng hospital, posed particular problems. Drug and vaccine supplies were irregular, empty shelves were the norm, staff felt and were incompetent as they had to send patients away. The causes were multiple, including poor ordering, theft at various levels en route to clinics, and "lack or money". Water supplies for clinics were inadequate, indeed frequently non-existent. Accommodation facilities for clinic staff were below standard.

* **Perceptions of researchers by district health workers**

Although it was not stated, the behaviours of managers and clinic staff, and experiences of academics working in the related University project, led the researchers to believe that they were perceived by some as temporary sojourners in the district working for academic recognition. Noone was impolite enough to state this, but it must had been part of the apparent demotivation that constrained full involvement. One had sympathy for health workers in difficult and constantly challenging situations, whose standards were being questioned, and who were being asked to do more in quantity and quality, without apparent personal satisfaction. This applied equally to senior district staff.

* **Researchers as service providers**

The researchers assumed the role of tuberculosis service providers for "treatment" clinics. This, although discussed and agreed upon before the project started, inevitably caused some problems. Staff of the "treatment" clinics became accountable to the researchers, without the visible support of the hospital community nursing managers. The researchers had tried, without success, to organise management presence at an introductory meeting

at each of the clinics involved.

Another issue was that tuberculosis services became "verticalised", with a specific team discussing only that disease and its management. This could have lost credibility for the comprehensive approach, and may have alienated the researchers from clinic staff who had a number of responsibilities apart from management tuberculosis.

* **Absence of districts and a functional district health system**

Productivity depends on clear work structures and lines of accountability. During the period of the study, the district system did not exist. In fact the three proposed districts of the Bushbuckridge sub-region were still non-functional in the first quarter of 1998! The hoped for changes in boundary lines of responsibility, described since 1994, did not occur, causing confusion and frustration of health staff, and contradicting the training on the district system that the researchers and others carried out. The delays were partly due to the need to ensure democratic decision-making by communities unused to involvement in local government. As a result of the non-district system, there was further demotivation of the clinic nurses, for whom this would have the greatest impact.

The (old) Mhala area clinics, many kilometers distant from Tintswalo hospital, remained the responsibility of that hospital's community health staff. They had neither staff capacity, time, nor vehicles to service these far areas, while assuming an increased load of work with responsibility for areas closer to the hospital (previously under Mapulaneng hospital). They had gained work load, but lost none. In fact it was surprising that the hospital-based community team managed to improve tuberculosis management, as they did. Referrals of patients who lived outside the proposed district was very difficult, as authorities responsible for other areas were far away, there was no means of

communication (senior staff were not even allowed to telephone other authorities from the hospital ward to enact referrals), and these other authorities were not clearly defined.

* **The limited role of clinics in tuberculosis patient management**

During the period of the study, any patient who attended a clinic, and in whom tuberculosis was suspected, was asked to go to Tintswalo hospital for diagnosis, and initiation of treatment, usually as an in-patient. Only on discharge was the patient referred back to the clinic for continuation of the course of treatment, to be referred back to the hospital again for final assessment and discharge from treatment. The clinic staff saw the patients only three, four or sometimes five times at monthly visits, with roles limited to clinical assessment, checking of supporter attendances (and copying the supporter's ticks from the patient card to the clinic card), and making the next appointment. Clinic staff had no contact with supporters. Without the research team, who did random visits to patients and supporters, non-attendances of patients at their daily supporter visits would not have been identified until the next monthly clinic visit. Patients who failed to attend for their monthly appointments would be identified within a few days of the failure by clinic staff, but in the absence of time and transport to trace those patients at home, clinic staff would be powerless to act, and would need to contact the district tuberculosis team for them to seek out such patients. Contact was dependent upon reliable communication systems from the clinics, the ability of the district team to access transport, and upon sufficient district staff assigned to tuberculosis work. Frequently all three of these factors were absent. The role of clinic staff was thus limited, and frustrating for professionals trained in a comprehensive patient approach.

* **Failure to monitor sputum bacteriology during and at the end of treatment**

Sputum tests during and at the end of treatment (2 and 5-6 months for new patients) were part of the research (and the national) policy, but were not done, despite the availability of the research nurse to transport the specimens. This was a combined deficiency of the researchers who failed to insist, and to remind clinic nurses about the timeous collection of specimens, and of the clinic nurses who did not accept responsibility for doing this. There was no help from management who should have insisted on the implementation of this policy.

* **No organised laboratory network**

Tuberculosis services, as with many other clinic-based services, are dependent on a rapid and reliable laboratory link. The absence of an organised system of delivery of sputum specimens to the district laboratory, and the return of results within 48 hours, has been noted as a major constraint in many parts of the world.[85] The absent district system, long distances, bad roads, the tuberculosis control programme with emphasis on bacteriological diagnosis only just emerging, and inadequate organisational and management skills meant that there was no network.

For "treatment" clinics, the researchers themselves provided the transport for specimens to the laboratory and results back. Out during the last six months of the study, made strenuous attempts to get the service to organise the link. Suggestions were to utilise senior community nurses on supervisory visits, the hospital pharmacy team delivering drugs to clinics, ambulances transporting patients, or even local taxis. A system was never set up, since it was beyond the capacity of the researchers to establish this. The Tintswalo hospital laboratory was not part of the SAIMR network, so the improvements

taking place in other provinces, notably Gauteng and Mpumalanga (personal communications Drs. L Floyd and E Balt respectively), were not a feature of this area.

* **Inadequate organisation and management of the community supporter system**

The organisation of the supporter system was well managed at an individual level by the research nurse or the hospital community team. They selected an person acceptable to the patient, informed that person what was expected, and made occasional visits to monitor the process of daily attendance. However, the process was unsystematic, and without community consultation. The considerable resources within the community could be better accessed and utilized if volunteers within villages were formally recruited and trained, so that they formed a team, ready for the task of supporting tuberculosis patients as needed. They could play a part in general health promotion, including the Extended Programme of Immunisation, nutrition, home-based management of diarrhoeal disease, family spacing, tuberculosis and other disease case-finding, and environmental control.

The system whereby patients attended clinics to fetch their tablets, and took these to their supporters, was illogical, and must have seemed so to patients. It would have been better for drugs to be taken to supporters, or for them to collect these at the clinic. These aspects needed further discussion and trials to formulate a district supporter plan.

A further important issue was the lack of any incentive for supporters. This would not necessarily be monetary, but could take the form of certificates presented at an annual function, transport allowances, or badges to denote membership of supporter groups. The strength of the community "care group" movement that contributed significantly to the control of trachoma in northern South Africa, was the authority and status given to members.[405]

* **Poor provincial government commitment**

District management and commitment, even had these been present and adequate, would have been very difficult without provincial government commitment to a national tuberculosis policy, and appropriate allocation of resources, including provincial management and training staff. Only towards the end of the project in mid-1996, were provincial tuberculosis co-ordinator/manager and trainer posts filled.

* **Non-involvement of hospital medical staff**

Although tuberculosis case management, community control and the research project were presented and discussed at at least three formal doctors' meetings at Tintswalo hospital, doctors did not award the disease priority status, and remained distant from the community-based system. Patients were often started on treatment without microscopy confirmation of diagnoses, sometimes with incorrect drugs, and occasionally discharged without notification or referral to the tuberculosis ward for notification and registration. Both clinical diagnosis and death certification (as discussed in chapter 17) sometimes incorrectly included tuberculosis when it was unproven or unlikely. It may well have been missed occasionally when it was present.

20.2.3 How can the improvements be sustained and further improvement achieved?

An operational model for the analysis of tuberculosis control programmes has been described.[406] The model states 8 steps: motivation (of patients to present to health facilities), selection (of suspect cases for smear microscopy), examination (of smears in the laboratory), sensitivity (of smears), prescription (of correct treatment), treatment

(patient obtains correct treatment), regularity (adherence) and effectiveness (probability of cure).

This model for good tuberculosis control and management requires efficient and effective actions of health workers at a number of levels. District, provincial and national management commitment and support means training of staff, and the provision of the infrastructure required for diagnosis and treatment, as well as those resources required for efficient follow-up of non-adherent patients, and for routine supervision of clinic staff.

The roles of district health workers need clear definition. An effective tuberculosis programme presupposes the existence of a functioning district health system, the acceptance of the priority status of tuberculosis at all levels of the health service, good district service management, which includes well managed and well motivated health personnel. The suggested roles of different levels of health staff are described hereunder.

The district clinic nurse

A clinic nurse has many duties in the provision of primary care to the people served by a district clinic. Regarding tuberculosis, which is best integrated within these duties, the nurse must be able to:

+ decide which patients have suspected tuberculosis
+ confirm the diagnosis, using the laboratory network
+ treat patients with confirmed disease
+ organise clinic drug supplies
+ refer patients with clinical problems or those who require hospitalisation
+ contact the appropriate person (district co-ordinator or hospital clinicians) for

clinic-based management problems

+ record all processes and outcomes on the relevant tuberculosis programme forms

+ follow-up patients who have adherence problems during treatment, or call on the district tuberculosis coordinator to help with this

The clinic should be organised according to the needs and comfort of the patients and the staff. It is well described that patients respond well to a relationship with the care provider. It is thus best for the same nurse to see the same tuberculosis patients for the duration of their treatment, as far as can be organised. It may be useful to have a tuberculosis patient day once a week, or alternatively to structure visits any day of the week.

For a district with a population of up to 250 000 people, with rates of tuberculosis of 200-300 per 100 000 population (double that measured over the last 5 years in the Tintswalo district, and allowing for the rise with the HIV epidemic), there would be 500-750 patients per year, or 250-375 at any one time. The Tintswalo study showed that 28% of patients lived close to the hospital, leaving 72% who would require treatment at one of the 12 district clinics. Assuming equal distribution of patients attending the clinics, between 15 and 20 could be on treatment at each. At clinics in more densely populated villages, this number could be 30. If each attended monthly on one specific day, there would be about five to eight patients per clinic day. This number would seem manageable, even in the context of clinics delivering comprehensive services. If the rise in incidence is more than double that in the early 1990s, and if case-finding rates improve, numbers will be higher, which is a good reason to ensure an efficient system now.

The district communicable disease coordinator

This district-based health worker should have responsibility for all communicable diseases in a district, including malaria, meningitis, typhoid fever, diarrhoeal disease, haemorrhagic fevers, tuberculosis and any others. The job includes a knowledge of the district population, its distribution, health problems, and the health services. The role of this person is to:

+ train health staff about tuberculosis and its management
+ train tuberculosis patient supporters and organise appropriate incentives
+ visit all clinics in a district on a regular basis to teach and to supervise clinic staff
+ respond to calls for help in tracing non-attending patients
+ monitor laboratory and drug supply systems, and report problems to district management

Once the tuberculosis control programme was functioning well, with all clinic staff trained, the routine visits of one or sometimes two clinics per day could be completed in a few hours, so that all district clinics would be visited once in two weeks. This would leave time for training, and for tracing non-attenders at their homes.

Given the responsibilities for other communicable diseases, and outbreak investigations, the task may be too much for one person. An additional district staff member, at the level of a health educator, or nurse should assist. Both would require transport, always a limiting factor in the past. However, an efficient programme with cure rates exceeding 80%, would make the use of adequate staff and transport resources cost effective, particularly if other, less common communicable diseases and good surveillance and outbreak response systems are simultaneously managed in the district.

District management:

District management has to take responsibility for the provision of the infrastructure, upon which a tuberculosis control programme depends. Clinic staff and the district communicable disease coordinator need to be consulted and to report problems, but district management should plan and organise the systems for:

* Laboratory network
* Drug supplies
* Vehicles
* Stationery
* Staff management

An efficient and reliable **laboratory network** between clinics and district laboratory is essential. In many urban areas, a daily collection service from clinics has been arranged, with results faxed back within 24 hours.(Gauteng province, personal experience) In rural districts such a service may be less easy to implement. For those new patients not sick enough to be referred for admission to hospital, and who are to be diagnosed at clinics, bacteriological results should be available within one or two days, so that treatment can start as soon as possible. This requires transport of specimens for which innovative ways of reaching the laboratory must be devised. They may include using health workers on supervisory visits, delivering drug supplies, or fetching patients in ambulances. It may necessitate specific communication with the district tuberculosis team, or the use of local taxis. Whatever the means, it has to be reliable. There is no reason why fax machines could not be installed and functional in every clinic for the results. The costs of organising a laboratory network would be balanced by savings in the short and long terms.

Another district management responsibility is the regular and timeous **delivery of drugs for tuberculosis**, as well as essential drugs for primary care use, to every clinic. Tuberculosis drugs were not available on shelves of "treatment" clinics in this study, for reasons described by hospital management as related to rules about dispensing drugs. These were not logical to researchers, and should be overcome without difficulty. The supply for each patient attending "treatment" clinics had to be hand-delivered by the research team.

Vehicles for the district communicable disease coordinator and assistant must be available for routine visits to clinics and supporters, for collecting specimens if required, and for tracing non-attending patients. The problem with sharing vehicles with other services is non-availability in times of need. Again a functioning control programme will cost far less that one which does not promote cure.

The provision and delivery of all **stationery** required for the tuberculosis control programme is the responsibility of district management. Without attention to this seemingly small detail, the ability to monitor and evaluate the programme is lost, and staff become demotivated and confused.

The descriptions of roles and responsibilities above assumes a comprehensive role for clinic staff to manage tuberculosis, different from their limited role during this study. The increased responsibility for correctly diagnosing and treating tuberculosis, and the ability to evaluate progress of each patient should provide greater incentives to clinic nurses. Given the public health impact of this disease, the responsibility is large, but

should not be overwhelming for professionals required to manage a number of life threatening, as well as routine problems which include dehydrated infants, complicated birth deliveries, ordering of drugs and equipment, and responding to community needs and demands.

Adaptations would have to be made for those patients requiring hospitalisation for clinical or risk of interruption reasons, and for those on re-treatment regimens, for whom daily streptomycin injections are needed, either in hospital or from district clinics.

The logistics and the infrastructure described above require good planning, organisation and budgeting by district management.

Staff motivation and factors that demotivate are complex, although in many rural primary health care environments, problems are not difficult to identify. Herzberg's motivation-hygiene theory, based on a study of 200 professionals, proposes that motivators (achievement, recognition, work, responsibility and advancement) lead to satisfaction at work.[407] For maximum satisfaction, and thus productivity, from clinic nurses, attention needs to be paid to their "job-enrichment" factors. They certainly have work and responsibility, but little recognition and sense of achievement because of the remoteness of their posts, and the lack of management presence to acknowledge the challenges and difficulties of their jobs. Herzberg's "hygiene" factors, which he found to be most frequently quoted causes of dissatisfaction, are those related to the context of work. Named problems were with company policy and administration (management), technical supervision, salary and relationships with supervisor. Researchers studying nurses working at Agincourt Health Centre, one of the health facilities in Bushbuckridge, under Tintswalo

hospital management, found that the absence of close supervision and effective management impacted negatively on their morale, exacerbating feelings of isolation.[408] The work context of clinic nurses does not always meet the needs of Maslow's hierarchy theory.[409] Some basic physiological needs may be covered, but acceptable accommodation, and adequate water and sanitation are often absent. Many clinic buildings in the Tintswalo district were in a poor state, certainly not conducive to high standards of productivity. Safety and security are often not assured, nor, at the next level of need, is a need to belong to a group catered for. The isolation and loneliness of professional life in far distant clinics, away from relatives and friends, without means of transport and often without any form of communication, can be profound. The higher needs of Maslow include the motivational factors of Herzberg already mentioned - status recognition and self-fulfilment.

The World Health Organisation have stated that "if health personnel are to provide a caring service, it is necessary for the public health services to show that it too cares".[410] Much is lacking in both the physical and social environment, and in the professional management of nurses assigned to work in rural clinics of Bushbuckridge, and in many other areas, both rural and urban.

20.2.4 How can the community and patient perspectives be incorporated into planning and implementing tuberculosis services?

This study identified some consistent beliefs about the origin of tuberculosis among local communities. Health workers confined to facilities, especially if they do not come from the community they serve, are in danger of missing important information that impacts on the management of diseases. They all have a responsibility to consult community groups

and leaders, and traditional healers, and to work with and through local beliefs and customs in order to provide an acceptable effective service. Traditional healers should be educated about the medical treatment of tuberculosis, and persuaded to refer their clients to clinics or hospitals for concurrent medical management. Continuing attempts to de-stigmatise the disease through community-based education would facilitate early patient presentation and treatment adherence.

CHAPTER 21

RECOMMENDATIONS FOR GOOD, SUSTAINED TUBERCULOSIS CONTROL

The findings of this study prompt a number of recommendations. In keeping with the principles of integrating all primary care activities, some are general health service recommendations, others relate specifically to tuberculosis. Many would be generalisable to other districts in South Africa, and perhaps to other developing countries.

GENERAL HEALTH SERVICE RECOMMENDATIONS

Commitment to tuberculosis control as a priority for health services

A functioning district health system

Incentives and support for health workers

Task definitions and protocols for management of common health problems

Communication systems

Supervisory visits

Management of material resources - drugs, equipment, water and buildings

The need for good management is a recurring theme in this thesis.

* A prerequisite in the context of tuberculosis is commitment by management to the priority status of this disease, recognition that the incidence will increase, that the disease is preventable by cost-effective means, and that tuberculosis care is best integrated within a district primary care network.

* The creation of a functional district health system is fundamental to all health care

delivery.

Staff and material resources need good management.

* Staff management starts with recruitment of appropriately trained and experienced health personnel. Much has been debated around issues of incentives for doctors who work in remote areas, but little attention has been given to salary supplementation, opportunities for promotion, extra leave and other forms of recognition for the onerous duties that nurses perform in rural primary care settings. Staff rotations should be considered, balancing the desire to give clinic nurses a break from work in remote areas with the need for some permanency and continuity of care. It certainly seems disadvantageous to leave a nurse at the same clinic for years on end.

* Tasks to be performed should be clearly defined, with protocols, training and retraining on the management of common important health problems (including tuberculosis). This aspect is important too for staff at other levels in the district, including district communicable disease coordinators and district management. Protocols on how to manage common health problems and their complications must be available, together with resources for implementation. Essential components are equipment, telephones, fax machines, and ambulances as well as available consultation services with technical guidance.

* There must be open communication channels between all clinics, the district communicable disease coordinator, the district headquarters and the hospital, to use routinely for common health problems and their complications.

* Regular supervisory and monitoring visits by district managers, notably the communicable disease coordinator and the community health nursing manager, are

essential to motivate staff, to address their problems, and to check that work is being performed according to set standards.

* Clinics cannot function without drugs, vaccines, equipment, constant water supplies and buildings in reasonable repair. Functioning systems for procurement and distribution of drugs and equipment have to be in place, with delegated responsibilities for their maintenance.

SPECIFIC TUBERCULOSIS SERVICE RECOMMENDATIONS

Train all health workers in tuberculosis management

Decentralise tuberculosis care to district clinics

Organise laboratory network for diagnosis and monitoring

Organise community supporters

Provide district support for community outreach functions

Keep standardised records at clinic level, to be collated at district level

Transfer patients efficiently from one district to another

Within the context provided by good general management, there are specific recommendations for tuberculosis management emanating from this study.

* All health workers, including nurses, doctors, managers, laboratory workers and pharmacists, must be trained in the management of tuberculosis. Education at tertiary and other levels for all health workers must include management of patients with tuberculosis, as well as the principles of the national and international control programmes. Continuing education with on-site training is an essential component to maintain standards and interest. Manuals must be produced, and

courses coordinated and standardised at the national tuberculosis directorate, with extra resources supplied as necessary to provinces unable to supply the needs.

* Tuberculosis can be and should be managed at district clinics by nurses trained in how to diagnosis and treat the disease. There is no reason why they should not have responsibility, with supervision and appropriate advice for problems, for managing suspects, making a definite diagnosis and initiating and continuing treatment. Simplification of treatment regimens currently recommended by the South African tuberculosis control programme has been suggested by many experts.

* Systems of transport and communication between all clinics and the district laboratory is essential for a functioning tuberculosis programme. Innovative ways and systems must be developed to supply drugs and other requisites, and to collect specimens, all of which will benefit the delivery of comprehensive health care.

* All patients should have supporters. Community members make excellent supporters, but need training, incentives, monitoring and evaluation.

* Backup support for recruiting community supporters, and for following up non-adherent patients will always be needed. To provide transport at each clinic for clinic staff to do this themselves is probably not cost-effective. At district level it would be, if the staff responsible for tuberculosis was also responsible for other communicable diseases, surveillance systems and outbreak responses.

* Completion of the various cards, register and regular reports should also be done by clinic nurses, who will find the reports easier and more acceptable when some modifications are made, and with continuing training. The district communicable disease coordinator should monitor the correct completion of all forms, and collate those of all clinics into a district report.

* Transfer of patients who are leaving the district should be facilitated by encouraging those with intended movements to discuss where they are going. Transfers to other services must be formalised with appropriate documentation and direct communication to the receiving health services. Work should proceed on implementing a national computerised register of all patients with tuberculosis, which will facilitate transfers as well as record details of current and previous treatment of all patients.

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APPENDIX A: TABLES

A1 TREATMENT OUTCOMES AND SEX - NEW SMEAR POSITIVE PATIENTS (1992-94)

SEX	COMPLETED	INTERRUPTED	DIED	TOTAL
Female	42 (66%)	16 (25%)	6 (9%)	64 (31%)
Male	97 (68%)	36 (25%)	10 (7%)	143 (69%)
Total	139 (67%)	52 (25%)	16 (8%)	207 (100%

A2 TREATMENT OUTCOMES AND AGE GROUPS - NEW SMEAR POSITIVE CASES (1992-94)

AGE GROUP in yrs	COMPLETED	INTERRUPTED	DIED	TOTAL
0-14	3 (60%)	1 (20%)	1 (20%)	5 (2%)
15-29	40 (66%)	17 (28%)	4 (7%)	61 (29%)
30-59	75 (70%)	25 (23%)	7 (7%)	107 (52%)
60 +	21 (62%)	9 (26%)	4 (12%)	34 (16%)
Total	164 (79%)	65 (31%)	19 (9%)	207 * (100%)

* excludes 3 transferred cases

A3 TREATMENT OUTCOMES AND DISTANCE FROM TINTSWALO HOSPITAL, NEW SMEAR POSITIVE PATIENTS (1992-94)

DISTANCE in kms	COMPLETED	INTERRUPTED	DIED	TOTAL
0-9	49 (65%)	21 (28%)	5 (7%)	75 36%
10-25	62 (76%)	15 (18%)	5 (6%)	82 40%
26-49	19 (61%)	7 (23%)	5 (16%)	31 15%
50 +	8 (44%)	9 (50%)	1 (6%)	18 9%
TOTAL	138 (67%)	52 (25%)	16 (8%)	206 100%

A4 DISTANCE FROM TINTSWALO HOSPITAL AND AGE GROUPS (1994-96)

AGEGROUP (years)	DISTANCE CATEGORIES (kms)				TOTAL
	0 -9	**10-25**	**26-49**	**50+**	
0-14	17 (37%) 12%	9 (20%) 8%	19 (41%) 15%	1 (2%) 4%	46 11%
15-29	27 (30%) 19%	26 (29%) 22%	32 (36%) 25%	4 (4%) 15%	89 21%
30-59	84 (37%) 58%	68 (30%) 58%	61 (27%) 48%	17 (7%) 63%	230 56%
60+	16 (33%) 11%	14 (29%) 12%	14 (29%) 11%	5 (10%) 19%	49 12%
Total	144 (35%)	117 (28%)	126 (30%)	27 (7%)	414

A5 DISTANCE FROM TINTSWALO HOSPITAL AND SEX (1994-96)

DISTANCE (kms)	FEMALE	MALE	TOTAL
0-9	38 (26%) 31%	106 (74%) 36%	144 (100%)
10-25	34 (29%) 28%	83 (71%) 28%	117 (100%)
26-49	45 (36 37%	81 (64%) 28%	126 (100%)
50+	5 (19%) 4%	22 (81%) 8%	27 (100%)
TOTAL	122 (29%) 100%	292 (71%) 100%	414 (100%)

A6 DISTANCE FROM TINTSWALO AND PATIENT CATEGORY (1994-96)

DISTANCE (kms)	NEW PATIENTS	RE-TREATMENT PATIENTS	TOTAL
0-9	129 (90%) 37%	15 (10%) 24%	144 (100%)
10-25	92 (79%) 26%	25 (21%) 40%	117 (100%)
26-49	104 (83%) 30%	22 (17%) 35%	126 (100%)
50+	26 (96%) 7%	1 (4%) 2%	27 (100%)
TOTAL	351 (85%) 100%	63 (15%) 101%	414

A7 AGES AND TREATMENT GROUPS

Age Group	TREATMENT GROUP				TOTAL
	Treatment Clinic	Control Clinic	Hospital	Outside District	
0-14	16 (35%) 12%	12 (26%) 16%	10 (22%) 8%	8 (17%) 9%	46 (11%)
15-29	22 (26%) 17%	19 (21%) 25%	26 (29%) 22%	22 (25%) 25%	89 (21%)
30-59	79 (34%) 60%	36 (16%) 48%	70 (30%) 58%	45 (20%) 52%	230 (56%)
60+	15 (31%) 11%	8 (16%) 11%	14 (29%) 12%	12 (24%) 14%	49 (12%)
TOTAL	132 32%	75 18%	120 29%	87 21%	414 100%

A8 SEX AND TREATMENT GROUPS

Sex	TREATMENT GROUP				TOTAL
	Treatment Clinic	Control Clinic	Hospital	Outside District	
FEMALE	37 (30%) 28%	21 (17%) 28%	34 (28%) 28%	30 (25%) 34%	122 (100%) 29%
MALE	95 (33%) 72%	54 (18%) 72%	86 (29%) 72%	57 (20%) 66%	292 (100%) 71%
TOTAL	132 (32%) 100%	75 (18%) 100%	120 (29%) 100%	87 (21%) 100%	414 (100%) 100%

A9 AGES AND TREATMENT SUPPORTERS

AGEGROUPS (years)	SUPPORTED		NOT SUPPORTED		TOTAL	
	n	%	n	%	n	%
0-14	41	13	4	6	45	12
15-59	238	75	58	81	296	76
60+	37	12	10	14	47	12
Total	316	100	72	101	388 *	100

* excludes patients transferred out, and those who died before supporters could be organised

A10 SEX AND TREATMENT SUPPORTERS

SEX	SUPPORTED		NOT SUPPORTED		TOTAL	
	n	%	n	%	n	%
Female	95	30	20	28	115	30
Male	221	70	52	72	273	70
Total	316	100	72	100	388 *	100

* excludes patients transferred out, and those who died before supporters could be organised

A11 NEW AND RETREATMENT PATIENTS AND SUPPORTERS

	NEW PATIENTS	RETREATMENT PATIENTS	TOTAL
NO SUPPORTER	62 (81%) 23%	15 (19%) 26%	77 23%
SUPPORTED	213 (84%) 77%	42 (16%) 74%	255 77%
	275 (83%)	57 (17%)	332 * 100%

* pulmonary disease patients

A12 TREATMENT GROUPS AND SUPPORTER CATEGORIES

Supported	Treatment Clinic		Control Clinic		Hospital		Outside District		Total	%
	n	%	n	%	n	%	n	%		
SHOP	43	35	28	43	41	45	11	30	123	39
FAMILY	36	29	20	31	33	36	16	43	105	33
CLINIC	24	19	6	9	1	1	6	16	37	12
NEIGHB	12	10	4	6	6	7	4	11	26	8
TEACHER	4	3	2	3	2	2			8	3
WORK	2	2	3	5	1	1			6	2
CHURCH	1	1	1	2	4	4			6	2
CHW	1	1	-	-	-	-			1	
INDUNA	1	1	1	2	1	1			3	1
HOSP	-	-	-	-	2	2			2	1
TOTAL	124	100	65	100	91	99	37	100	317	101

A13 TREATMENT OUTCOMES OF NEW SMEAR POSITIVE PATIENTS FOR 1992-94, CATEGORISED ACCORDING TO INTERVENTION STUDY GROUPS

PLACE FOR TREATMENT	COMPLETED	INTERRUPTED	DIED	TOTAL
INTERVEN-TION CLINICS IN DISTRICT	45 (74%)	11 (18%)	5 (8%)	61 (100%) (38% of in-district pats.)
CONTROL CLINICS IN DISTRICT	34 (67%)	12 (24%)	5 (10%)	51 (100%) (32% of in-district pats.)
TINTSWALO HOSPITAL DISTRICT PATIENTS	33 (69%)	14 (29%)	1 (2%)	48 (100%) (30% of in-district pats.)
TOTAL IN DISTRICT	112 (70%)	37 (23%)	11 (7%)	160 (100%) (78% of all pats.)
TINTSWALO HOSPITAL OUTSIDE DISTRICT 10-25 kms	11 (85%)	2 (15%)	0 (0%)	13 (100%)
TINTSWALO HOSPITAL OUTSIDE DISTRICT 26-49 kms	7 (47%)	4 (27%)	4 (27%)	15 (100%)
TINTSWALO HOSPITAL OUTSIDE DISTRICT 50+ kms	8 (44%)	9 (50%)	1 (6%)	18 (100%)
TOTAL OUTSIDE DISTRICT	26 (57%)	15 (33%)	5 (11%)	46 (100%) (22% of all pats.)
GRAND TOTAL	138 (67%)	52 (25%)	16 (8%)	206 * (100%)

* excludes 3 transfers and 1 patient with missing data

A14 TREATMENT OUTCOMES AND SEX - ALL PATIENTS (1994-96)

SEX	CURED AND COMPLETED	INTERRUPTED	FAILED	DIED	TOTAL
FEMALE	94 (79%)	15 (13%)	2 (2%)	8 (7%)	119
MALE	208 (73%)	47 (17%)	14 (5%)	15 (5%)	284
TOTAL	302 (75%)	62 (15%)	16 (4%)	23 (6%)	403 *

A15 TREATMENT OUTCOMES AND SEX - NEW SMEAR POSITIVE PATIENTS (1994-96)

SEX	CURED AND COMPLETED	INTERRUPTED	FAILED	DIED	TOTAL
FEMALE	39 (85%)	4 (9%)	2 (4%)	1 (2%)	46 (26%)
MALE	96 (72%)	22 (17%)	7 (5%)	8 (6%)	133 (74%)
TOTAL	135 (75%)	26 (15%)	9 (5%)	9 (5%)	179 * (100%)

* excludes 4 new smear positive patients transferred out

A16 OUTCOMES AND AGE GROUPS - NEW SMEAR POSITIVE PATIENTS (1994-96)

AGE GROUP in years	CURED AND COMPLETED	INTERRUPTED	DIED	FAILED	TOTAL
0-14	3 (75%)	1 (25%)	0	0	4 (2%)
15-29	41 (91%)	4 (9%)	0	1 (2%)	45 (25%)
30-59	79 (70%)	20 (18%)	8 (7%)	6 (5%)	113 (63%)
60+	12 (71%)	2 (12%)	1 (18%)	2 (12%)	17 (10%)
TOTAL	135 (75%)	26 (15%)	9 (10%)	9 (5%)	179 (100%)

A17 TREATMENT OUTCOMES AND HOSPITAL ADMISSIONS (1994-96)

HOSPITAL ADMISSION	COMPLETED & CURED	INTERRUPTED	DIED	FAILED	TOTAL
N0	35 (73%)	10 (21%)	1 (2%)	2 (4%)	48 (13%)
YES	267 (79%)	49 (15%)	7 (2%)	13 (4%)	336 (88%)
TOTAL	302 (79%)	59 (15%)	8 (2%)	15 (4%)	384 * (100%)

* excludes 11 transferred and 19 for whom admission information not available (of these, 15 died, 1 failed, 3 interrupted)

A18 TREATMENT OUTCOMES AND DURATION OF STAY IN HOSPITAL, ONE WEEK AND MORE (1994-96)

DAYS IN HOSPITAL	COMPLETED & CURED	INTERRUPTED	DIED	FAILED	TOTAL
1-6	17 (71%)	5 (21%)	1 (4%)	1 (4%)	24 (7%)
7+	250 (80%)	44 (14%)	6 (2%)	12 (4%)	312 (93%)
TOTAL	267(79%)	49 (15%)	7 (2%)	13 (4%)	336 (100%)

A19 TREATMENT OUTCOMES AND DURATION OF STAY IN HOSPITAL, ONE MONTH AND MORE (1994-96)

DAYS IN HOSPITAL	COMPLETED & CURED	INTERRUPTED	DIED	FAILED	TOTAL
1-27	157 (77%)	34 (17%)	6 (3%)	7 (3%)	204 (63%)
28+	110 (83%)	15 (11%)	2 (2%)	5 (4%)	132 (37%)
TOTAL	267 (79%)	49 (15%)	8 (2%)	12 (4%)	336 (100%)

A20 TREATMENT OUTCOMES AND TREATMENT SUPPORT, NEW SMEAR POSITIVE CASES (1994-96)

SUPPORT	COMPLETED	INTERRUPTED	DIED	FAILED	TOTAL
YES	120 (84%)	15 (10%)	1 (1%)	7 (5%)	143 (84%)
NO	15 (54%)	11 (39%)	0	2 (7%)	28 (16%)
TOTAL	135 (79%)	26 (15%)	1 (1%)	9 (5%)	171 * (100%)

* excludes 5 transfers and 8 deaths

TABLE 21: COMPARISON OF PATIENTS WHO HAD 3, 2, 1 AND NO INTERVIEWS

VARIABLE		All 3 inter-views n=185		Two inter-views n=103		One inter-view n=17		No inter-view n=22	
		n	%	n	%	n	%	n	%
AGE (years)	<15	19	10	15	15	1	6	3	14
	15-59	146	79	76	74	12	71	18	82
	60+	20	11	12	12	4	24	1	5
SEX	Male	129	70	77	75	12	71	17	77
	Female	56	30	26	25	5	29	5	23
DISTANCE (kms)	0-9	92	50	52	51	10	59	12	55
	10-25	70	38	37	36	5	29	6	27
	26-49	23	12	14	14	2	12	4	18
TREAT-MENT OUTCOMES	Cure/ Compl.	163	88	84	82	3	18	3	14
	Interr	9	5	10	10	6	35	10	46
	Transf	2	1	2	2	3	18	1	5
	Died	0	0	5	5	5	29	8	36
	Failed	11	6	2	2	0	0	0	0

A22 SEX AND EDUCATIONAL STATUS

SEX	HIGHEST EDUCATION ACHIEVED			
	Informal	Primary	Secondary	Total
FEMALE	37 (43%) (28%)	24 (28%) (29%)	25 (29%) (29%)	86 (100%) (28%)
MALE	96 (44%) (72%)	59 (27%) (71%)	62 (29%) (71%)	217 (100%) (72%)
TOTAL	133 (44%)	83 (100%) (27%)	87 (29%)	303 (100%) (100%)

A23 PERCENTAGE AGREEMENT FOR SAMPLE OF FIRST AND REPEAT INTERVIEWS

VARIABLE		% AGREEMENT
INTERVIEW 1:		
Address		88
Treatment place		100
Facility first attended		75
Attended:	clinic	75
	trad healer	100
	faith healer	100
	hospital	100
Treatment:	frequency	75
	duration	100
Problems anticipated		88
Belief in cause (open question)		38*
Belief:	spread	88
	inadequate treatment	75
	mines	88
	poor nutrition	63*
	alcohol	100
	smoking	100
	food quality	75
Previous TB		88
Family TB now/previous		100/88
Type of work		57*
Education		67*
Post-school education		83
Household size		50*
No. under 15 yrs		33*
No. under 5 yrs		17*
No earning		83
Old age pensioners		67*
Disability pensioners		100
No. sick		83
INTERVIEW 2		
Supporter presence / who		100/73
Transport to hospital clinic		55*
Satisfaction with hospital/clinic		100

VARIABLE	% AGREEMENT
INTERVIEW 2 contd.	
Time to reach supporter	27
Post-hospital consult:	
trad healer	73
faith healer	100
another hospital	100
another clinic	91
private dr.	100
INTERVIEW 3	
Attending supporter	67*
Problems attending supporter	100
Cost	100
CLINIC PATIENTS	
Place attended	100
Time to reach	0*
Transport	50*
Cost	0*
Waiting time	0*
Staff care	100
Preference	100
HOSPITAL PATIENTS	
Transport	90
Cost	67*
Waiting time	0*
Staff care	100
Problems	44*
Preference	67*
GENERAL	92
Difficult treatment	93
Side effects	54*
Staff kind	69*
Trad healer role	93

* < 70% agreement

TABLE 24 SUMMARY OF BIVARIATE ANALYSIS OF TREATMENT OUTCOMES AND VARIABLES n=296

VARIABLE	OUTCOME		p	OUTCOME	p
	Cured / Compl.	Interrup / Failed/Died		Interrup/ Failed	
Education: n=296					
Informal	111	21		14	
Formal	137	27	0.89	24	0.36
Informal & primary	177	35		25	
Secondary	71	13	0.82	13	0.48
Below std 9 & 10	32	4		4	
Std 9 or 10	216	44	0.37	34	0.68
Age (years): n=319					
0-5	16	4		4	
6+	237	62	0.93	44	0.39
0-15	33	5		5	
16+	220	61	0.22	43	0.61
0-29	89	11		11	
30+	164	55	0.004	37	0.09
0-59	226	56		41	
60+	27	10	0.31	7	0.43
15-29	56	6		6	
30+	164	55	0.009	37	0.6
15-59	193	51		36	
60+	27	10	0.40	7	0.47
Sex: n=319					
Female	78	13		6	
Male	175	53	0.074	42	0.009
Work: n=319					
Unemployed	90	24		14	
Employed	163	42	0.90	34	0.39
Manual	120	29		22	
Other employed	43	13	0.55	12	0.29
Skilled/semi-skilled	43	13		12	
Manual	120	29	0.55	22	0.29

VARIABLE	OUTCOME		p	OUTCOME	p
	Cured / Compl.	Interrup / Failed/Died		Interrup/ Failed	
Time to reach supporter: n=319					
0 (same home)	81	9		9	
Rest (>0 mins)	172	57	0.003	57	0.06
Stated problems with treatment access: n=282					
Yes	28	12	0.0006	10	
No	217	25		22	0.005
How patients reached treatment source:					
Those nearest hospital (hospital treatment): n=101					
Walk	27	7			
Other	58	9	0.35		
Those on hospital treatment (Control treatment) n=64					
Walk	1	1			
Other	56	6	0.20		
Those on clinic treatment: n=117					
Walk	57	7			
Other	46	7			
CLINIC PATIENTS: n=74					
Time to reach clinic:					
< 30 mins	50	6			
30+ mins	15	3			
Cost to reach:					
0 - R3	61	8			
> R3	4	1			
0	37	2			
>0 (R1+)	28	7			
How reached:					
Walk	37	2			
Other	28	7			
Waiting time:					
<30 mins	51	14			
30+ mins	8	1			
Problems experienced					
Yes	6	59			
No	2	7			

VARIABLE	OUTCOME		p	OUTCOME	p
	Cured / Compl.	Interrup / Failed/Died		Interrup/ Failed	
HOSPITAL PATIENTS: n=112					
Time to reach:					
<30 mins	58	5			
30+ mins	43	6	0.32		
Cost to reach:					
0 - R3	72	7			
>R3	29	4	0.41		
0	29	4			
>0 (R1+)	72	7	0.41		
How reached: n=113					
Walk	30	4			
Other	72	7	0.54		
Waiting time:					
<30 mins	18	1			
30+ mins	83	10	0.40		
Problems experienced:					
Yes	28	2			
No	74	9	0.39		

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

COMMITTEE FOR RESEARCH ON HUMAN SUBJECTS (MEDICAL)
Ref: R14/48 (Registry)

CLEARANCE CERTIFICATE PROTOCOL NUMBER M940103

PROJECT	Record review of TB patients admitted to Tintswalo Hospital
INVESTIGATORS	Dr M E Edginton
DEPARTMENT	Community Health
DATE CONSIDERED	940128

DECISION OF THE COMMITTEE

Approved unconditionally

DATE 940204 CHAIRMAN .....
(Professor P E Cleaton-Jones)

* Guidelines for written "informed consent" attached where applicable.

==========

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10001, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee.

DATE..Nov 1993.....SIGNATURE.....

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

B2

Division of the Deputy Registrar (Research)

COMMITTEE FOR RESEARCH ON HUMAN SUBJECTS (MEDICAL)
Ref: R14/49 Edginton

CLEARANCE CERTIFICATE PROTOCOL NUMBER M 940806

PROJECT	Study to evaluate a striptest to detect the drug INH and its metabolites in urine of patients taking INH orally
INVESTIGATORS	Dr M E Edginton
DEPARTMENT	Community Health, Medical School
DATE CONSIDERED	940826

DECISION OF THE COMMITTEE *

Approved unconditionally

DATE 940830

CHAIRMAN. .....(Professor P E Cleaton-Jones)

* Guidelines for written "informed consent" attached where applicable.

c c Supervisor: Dr M E Edginton
Dept of Community Health, Medical School

Works2\other\neclear\ 940806

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10001, 10th Floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee.

DATE.....1/9/94.....SIGNATURE .....

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

COMMITTEE FOR RESEARCH ON HUMAN SUBJECTS (MEDICAL)
Ref: R14/49 (Registry)

CLEARANCE CERTIFICATE PROTOCOL NUMBER M940203

PROJECT	Tuberculosis in the Eastern Transvaal: a study in management
INVESTIGATORS	Dr M E Edginton
DEPARTMENT	Community Health
DATE CONSIDERED	940225

DECISION OF THE COMMITTEE

Approved with the attached condition

DATE 940302 CHAIRMAN .....
(Professor P E Cleaton-Jones)

* Guidelines for written "informed consent" attached where applicable.

==========

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10001, 10th Floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee.

DATE 8/3/94 SIGNATURE .....

QUESTIONNAIRE FOR DATA ENTRY INTO EPIINFO

name _____tb reg no. ##/ ###
age in years ## sex <A>address _____ nearest clinic _____
date treatment started <dd/mm/yy> treatment regime #
source of patient <A> if H state which _____ patient category <A>
diagnostic criteria <A > internat. code ###
sputum exam. pretreatmnt. 8 weeks 6 months
result date result date result date
smear <A> <dd/mm/yy> <A> <dd/mm/yy> <A> <dd/mm/yy>
culture <A> <dd/mm/yy> <A> <dd/mm/yy> <A> <dd/mm/yy>
resistance <A> <A> <A>
date of discharge from hospital<dd/mm/yy>
post-discharge treatment place _____
if supervised, who supervises _____, who organised _____
how did patient reach clinic _____
FOR CLINIC TREATMENT PATIENTS date first seen at clinic <dd/mm/yy>
subsequent clinic visits no. days supervsd trtmnt during mnth
scheduled actual
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
any hospital visits <dd/mm/yy> why_____
<dd/mm/yy> _____
<dd/mm/yy> _____
<dd/mm/yy> _____
final hospital visit for discharge <dd/mm/yy>
FOR HOSPITAL TREATMENT PATIENTS dates of attendance
scheduled actual days of supervision
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
<dd/mm/yy> <dd/mm/yy> ##
readmission for tb admission date <dd/mm/yy> discharge date <dd/mm/yy>
outcome <A> TRF # date <dd/mm/yy> HIV <A>
interview 1 <dd/mm/yy>
2 scheduled <dd/mm/yy>
actual <dd/mm/yy>
3 scheduled <dd/mm/yy >
actual <dd/mm/yy >

remarks _____
_____
_____
_____

REPORT OF PATIENT ATTENDANCES AND SPUTA RESULTS

DATE: _____

PATIENT'S NAME: _____ TB NUMBER: 9__/_____

CLINIC (name) OR HOSPITAL PATIENT: _____

DATE TREATMENT STARTED: _____

DATE DISCHARGED FROM HOSPITAL: _____

PATIENT TAKEN TO CLINIC BY: _____

DATE FIRST SEEN AT CLINIC: _____

SUPPORTER: _____

SUPPORTER ORGANISED BY: _____

ATTENDANCES:

SCHEDULED	ACTUAL	DOCTOR (D) PILLS (P)	CLINIC (C) HOSPITAL (H)	DAYS OF SUPPORT

SPUTUM TESTING:

INITIAL DATE	RESULT	2 MONTHS DATE	RESULTS

5-6 MONTHS DATE	RESULT

FINAL DISCHARGE: _____

URINE TEST DATA SHEET

NAME	TB NUMBER	ADDRESS	PLACE URINE COLLECTED	DATE OF COLLECTION	TIME OF COLLECTION	COLOUR	TEST RESULTS	COMMENTS

TINTSWALO TUBERCULOSIS PROGRAMME
DATA SHEET FOR INTERRUPTER CASE CONTROL STUDY

INTERUPPTER OR CONTROL

BASIC INFORMATION FROM RECORDS: (MEE to enter from records)

TB NUMBER...../9.. NAME.....

AGE..... GENDER M/F HIV P/N SOURCE..... CATEGORY.....

TB CODE..... SMEAR P/N CULTURE P/N

ADDRESS (name of village).....
FIRST ADMISSION/READMISSION F/R
If READMISSION, for first admission:

TB NO...../9.. DATE..... OUTCOME.....
FAMILY SIZE ..... POSITION OF THIS PATIENT IN FAMILY .....
Days in hospital TB ward .....
TB TREATMENT PLACE (clinic name/Tintswalo) .....

Supporter Category .....
Supporter attendance per month .....
Outcome:
Cure S
Complet.C1(monthly) C2(monthlyx1st 2m) C3(2-3monthly) C4
Interrupter I1 (incompl.1st 2m.) I2(complet.1st 2 m.only)
I3(never seen postdisc)
RHT from hospital..... RHT
Failed to return after passout FR

Other.....

ACCESS - INFORMATION ON TREATMENT PLACE: (MEE to ask CS/SN/HEds)
What is the best way to get from patient's home to the treatment

place .....
If best way is by taxi/bus,
How much does it cost to get from patient's home to that place

R.....
How long does it usually take .....
Are taxis/buses regular Y/N

If best way is walking,
How long does it take to walk (one way home to treatment place)

.....

INFORMATION FROM REPORT OF CONNIE/SELLITA/PHILLIP/SOLLY:
ANY PROBLEMS IDENTIFIED BY STAFF AS:

DISTANCE TO TREATMENT PLACE	Y/N
NO MONEY	Y/N
ATTITUDE/BEHAVIOUR OF STAFF AT TR. PLACE (fr.pt)	Y/N
ALCOHOL	Y/N
PATIENT AWAY AT WORK	Y/N
PATIENT CANNOT BE TRACED	Y/N

Other (say what) .....

.....

.....

INFORMATION FROM PATIENT INTERVIEW

First place attended for treatment before T C/TH/FH/AnotherH/GP/Other

Belief re TB (open) .....

Family TB NOW/PREVIOUS

Work type .....

Education (highest level) .....

Household size .....

Under 15.....Under 5 ..... OAPen ..... Disab.Pen .....

Household income R.....

Knowledge re treatment G/B

Treatment Place same as records Y/N

Supporter same as records Y/N

Clinic access by Walk/Taxi/Bus/Other.....

Clinic transport cost R .....

Clinic wait time .....minutes

Clinic staff problem Y/N

Other clinic problems Y/N what.....

Hospital access by Walk/Taxi/Bus/Other.....

cost R.....

wait time .....minutes

staff problem Y/N

other problems Y/N what.....

General statements (ring only if problem)

Pills difficult to take

Pills make sick

Nurses not good

Traditional healer essential

TINTSWALO DISTRICT TUBERCULOSIS PROGRAMME

Interview for all patients who live in the Tintswalo district before their discharge from hospital

Card No. | 1 | 1

Name of Patient: _____

TB Registration No. _____ | 9 | | | | | 2

Date of Admission | | | | | 9 | | 7

Date of interview | | | | | 9 | | 13

Date of discharge | | | | | 9 | | 19

Place of Interview: _____ | | 25

Address: Name of village/town _____ | | | 26

Exact address with landmarks: _____

_____

_____

Place for follow up treatment _____ | | | 28

Interviewer: Check records and/or ask ward sister where this patient is to receive follow-up treatment and write it here.

TUBERCULOSIS ACTION

A1 Please tell me about places you went to when you got sick with TB, before you came to hospital. Have you been to a:

clinic	Yes	No	30
say where _____			31
traditional healer	Yes	No	32
faith healer	Yes	No	33
hospital other than this one	Yes	No	34
say which _____			35
private doctor	Yes	No	36
other place/person	Yes	No	37
say where/who _____			38

A2 Where did you go <u>first</u> when you got sick with this TB? ☐ 39

Tintswalo hospital	Other hospital	Clinic	Traditional healer
Faith healer	Private doctor	Other - say where	

TUBERCULOSIS KNOWLEDGE

K1 Please tell me about the treatment you must take for your TB:

For how long must you take the treatment?

_____

How often should you take the treatment? ☐ 40

_____

K2 Where will you go regularly to fetch your TB treatment after you are discharged from hospital? ☐ 41

_____

K3 Do you think you will have any problems in getting to the place where you will get your treatment? ☐ 42

Yes	No

K4 If yes, please explain _____ ☐ 43

_____

K5 Are there questions you would like to ask about your TB treatment ☐ 44

_____

_____

_____

(Interviewer: if you cannot answer the questions, ask someone qualified to do so)

TUBERCULOSIS CAUSE

C1 Why do you believe you got TB? ☐☐ 45

_____

_____

_____

C2 Do you think people get tuberculosis from:-

1	Bewitchment Neglect of ancestors	Yes	No	Don't know	47
2	Disobeying rules when family member dies	Yes	No	Don't know	48
3	Sexually transmitted disease	Yes	No	Don't know	49
4	Spread from people with TB Germs	Yes	No	Don't know	50
5	TB inadequately treated in the past	Yes	No	Don't know	51
6	Work in mines or dusty conditions	Yes	No	Don't know	52
7	Poor nutrition or diet	Yes	No	Don't know	53
8	Alcohol	Yes	No	Don't know	54
9	Smoking cigarettes	Yes	No	Don't know	55
10	Food or water contamination	Yes	No	Don't know	56
11	Other	Yes	No	Don't know	57

PREVIOUS TUBERCULOSIS

P1 Have you ever had TB before this time? ☐ 58

Yes | No

If yes,

P2 What year was this 19____ ☐☐ 59

P3 Where did you have treatment ☐ 61

_____

P4 For how long were you treated (in months)____ ☐☐ 62

FAMILY TB

F1 Is anyone in your family on treatment for TB now ☐ 64

Yes | No

F2 Has anyone in your family been on treatment in the past ☐ 65

Yes | No

WORK OUTSIDE THE HOME

W1 When did you last work for money? (write month and year)_____ [ ][ ][9][ ] 66

W2 For how many years have you worked for money in your life?
(Interviewer: write down all the different jobs and add up the total time worked)

_____

_____

_____

Total Time _____ [ ][ ] 70

W3 What is the main kind of work you have done? (Interviewer ask for the job the person has had for the longest) _____ [ ][ ] 72

_____

_____

Card No. [2] 1

TB Registration No. [9][ ][ ][ ][ ][ ] 2

EDUCATION

E1 What is the highest school standard that you passed eg Nil, SubA, SubB, Std1 - 10 _____ [ ][ ] 7

E2 Did you have any education or training after you left school [Yes | No] [ ] 9

E3 If yes, what was this _____ [ ][ ] 10

HOUSEHOLD INFORMATION

Tell me about the people in your household. (Tick appropriate squares)

	First name	Relationship to you	Year of birth	Age	Earning money	Old Age pension	Disability Pension	Sick now for 2 wks or more
1		yourself						Yes
2								
3								
4								
5								
6								
7								
8								
9								
10								
11								
12								
13								
14								
15								
16								
17								
18								

Subject's age ☐☐ 12
Total No. ☐☐ 14
Under 15 years ☐ 16
Under 5 years ☐ 17
Earning ☐ 18
Old age pension ☐ 19
Disability pension ☐ 20
Sick (other than patient) ☐ 21

How much money comes into your household each month (in Rands) _____ ☐☐☐☐ 22

Thank you for answering my questions.

TINTSWALO DISTRICT TUBERCULOSIS PROGRAMME

PATIENT INTERVIEW AT 8 WEEKS AFTER TREATMENT ONSET

Card No [3] 1

Name of Patient: _____

TB Registration No. _____ [9 | | | | |] 2

Date of interview: [| | | | 9 |] 7

Place of interview: _____ [ ] 13

If patient is under 15 years of age, name of mother or person interviewed on behalf of child: [ ] 14

_____

Are you currently taking treatment for TB? [ ] 15

Yes	No

If no:
Please explain why not [ ] 16

_____

If yes:
How often do you take your pills? _____ [ ] 17

Does someone supervise your treatment i.e. give you your pills? [ ] 18

Yes	No

If yes:
Who is your supervisor? [ ] 19

Name: _____

Position or relationship: _____

How long does it take you to go to your supervisor (in minutes) _____

Please explain _____ [ ] 20

When you go for a check up and to get more pills do you go to the

Hospital	Clinic

[ ] 22

How do you get to the clinic or hospital? _____ [ ] 23

_____

Do you have any problems getting to the clinic/hospital to fetch your pills?

Yes	No

24

If yes, please tell me about these problems.

25

What do you feel the pills do for you?

26

Why do you feel this?

27

For how many months must you take the pills? _____ (from start to finish)

28

Are you satisfied with the service you are getting at the clinic/hospital?

30

(Interviewer delete whichever is not applicable)

Yes	No

If no, please tell me about the problems.

31

Have you been to see any of the following since you were discharged from hospital?

Traditional healer	Yes	No	32
Faith healer	Yes	No	33
Another Hospital	Yes	No	34
Another clinic	Yes	No	35
A private doctor	Yes	No	36
Any other healer or service say which: _____	Yes	No	37

Do you have any questions about your sickness or things you would like to discuss?

38

(Interviewer if you cannot answer the questions, ask someone who can to see this patient.)

Thank you for answering these questions.

INTERVIEW SCHEDULE FOR TB PATIENTS WHO HAVE COMPLETED THEIR TREATMENT

Interview to take place at Tintswalo hospital at the time of final discharge

Interviewer: Introduce yourself, and explain that the patient has the right to refuse to answer questions, and that answers will be kept confidential.

Card No. [4] 1

Name of patient: _____

TB registration number [9][ ][ ][ ][ ] 2

Date of interview [ ][ ][ ][ ][9][ ] 7

Place of interview _____ [ ] 13

Patient's address: (name of village or place)

_____ [ ][ ] 14

Which is your nearest clinic (ask patient this)?

_____ [ ][ ] 16

SUPPORTER FOR TREATMENT

Have you been going daily to a supporter to get your treatment? Yes / No [ ] 18

If yes, who was that supporter?
[shop/ induna/ family member/ clinic nurse]

Say exactly who it was? _____ [ ][ ] 19

Did you have any problems getting to your supporter every day? Yes / No [ ] 21

If yes, please tell me about your problems.

_____ [ ] 22

Did it cost you money to go to your supporter every day? Yes / No

If yes, how much did it cost? (Rands and cents) _____ [ ][ ][ ] 23

WHERE HAVE YOU BEEN ATTENDING EVERY MONTH TO SEE A DOCTOR OR NURSE TO FETCH MORE PILLS? [ ] 26

_____

IF YOU HAD TREATMENT AT A CLINIC:

Which clinic did you go to? _____ ☐☐ 27

How long did it take you to get there? _____ ☐☐☐ 29
(In minutes)

How did you get there? _____ ☐ 32

How much money did you have to pay to get there?

(in Rands and Cents) _____ ☐☐☐☐ 33

How long did you have to wait at the clinic before you were seen by the nurse (in minutes)?_____ ☐☐ 37

Did the clinic staff look after you well? | Yes | No |

If no,please explain _____ ☐ 39

Please explain any problems you had in getting your treatment at the clinic?

_____

_____ ☐ 40

Would you have preferred to go to hospital for your treatment rather than to the clinic | Yes | No | ☐ 41

Whether person said yes or no, ask:-

Please explain why you have said this

_____

_____ ☐ 42

IF YOU HAD TREATMENT AT TINTSWALO HOSPITAL:

How long did it take you to get there? (in minutes)____ 43

How did you get there? _____ 46

How much money did you have to pay to get there? (in Rands and Cents) _____ 47

How long did you spend at the hospital (from the time you got to the ward until you left to go home)? (in minutes) _____ 51

Did the hospital staff look after you well?

Yes	No

54

If no, please explain _____ 55

Please explain any problems you had in getting your treatment at the hospital?

If yes, explain the problems _____

_____ 56

Would you have preferred to go to your nearest clinic for your treatment rather than to the hospital?

Yes	No

57

Please explain why you have said this (whether yes or no)

_____

_____ 58

GENERAL COMMENTS:

If one of your friends or a neighbour got TB, and he asked you about TB, what would you tell that person about the treatment for TB?

_____

_____

_____ ☐ 59

Would you tell him that TB pills are difficult to take?

Yes	No

☐ 60

Would you tell him that the pills sometimes make you feel sick?

Yes	No

☐ 61

Would you say the nurses at the clinic or hospital were good/kind/helpful?

Yes	No

☐ 62

Would you tell him he should go to a traditional healer?

Yes	No

☐ 63

Would you tell them anything else about TB or TB treatment?

_____

_____

_____ ☐ 64

Do you feel that your TB is now cured?

Yes	No

☐ 65

If no, please explain why not _____

_____ ☐ 66

Have you got a job earning money since you were treated for TB?

Yes	No

☐ 67

Interviewer:

Note yes or no here if this person came from Mozambique, and if possible about how long ago (in years). Do not ask the person directly.

Yes	No

☐ 68

How many years ago did he/she come _____? ☐☐ 69

Thank the patient for answering your questions.

REPORT ON PATIENT NOT FOUND WHEN LOOKED FOR AT HOME

FIRST VISIT/SECOND VISIT/THIRD VISIT (ring the one that applies)
Do not make more than 3 visits to try to find a patient

Name of patient..... TB no ...../9..

Did you find patient's home? Yes/No

Who was at the home? .....

If someone at patient's home, did they know the patient ? Yes/No

If they know patient, where did they say he/she was ? .....

.....

Does he ever come home? Yes/No

If yes, when will he next come home? .....

Is he/she well? Yes/No

Is he/she taking TB treatment? Yes/No

If yes, where does he get the pills? .....

If no-one was found at patient's home

Did neighbours or people nearby know the patient? Yes/No

If yes, did they know where he/she is? Yes/No

If yes, where did they say patient is .....

If patient is said to be somewhere else in the Tintswalo or the old Mhala district (even if outside our study area), look for the patient there and interview. If he is said to be beyond the Tintswalo or old Mhala area, don't look further.

Author Edginton M E
Name of thesis Tuberculosis In The Tintswalo District Of The Northern Province Edginton M E 1998

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