# What are the reasons for patients not adhering to their anti-TB treatment in a South African district hospital?

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#### **Abstract**

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Introduction: TB is a major health problem in South Africa, with increasing numbers of patients notified, inadequate successful treatment rates and an emerging problem with resistant strains. This study was conducted at a District Hospital in KwaZulu-Natal where the successful treatment rate was as low as 23%. The aim of this study was to identify key factors at the hospital that may affect adherence to TB treatment and to recommend interventions that could improve adherence.

Methods: The study design was a case control study using prospectively collected data. Information was collected over an 8-month period, when the patients started their anti-TB treatment, according to the known factors that influence TB adherence. The patients were then followed up to determine those who did not adhere to their treatment, and those who successfully completed treatment. The two groups involved, therefore, were the controls (those who did adhere) and the cases (those who did not adhere). The data previously collected were then compared for significant associations with the controls and cases.

Results: Data were obtained from 159 TB patients, 105 (66%) were adherent and 54 (34%) non-adherent. The following variables showed a significant association (p < 0.05) with non-adherence: higher level of education; distance from the hospital; time taken to travel; the method of transport; satisfaction with the hospital; food security; income; the smoking of tobacco and/or marijuana; the patients' perspective and beliefs; HIV testing and status; functional status; social support; the relationship with the TB nurse; depression score; and self-rating of confidence. A stepwise logistic regression was performed, and only two variables remained significantly associated: travel time (OR7.9, 95%Cl 1.4-44.1) and the relationship with the TB nurse (OR2.6, 95%CI 1.3-5.1).

Conclusions: The most important recommendation is to improve the relationship between patients and TB nurses through training in communication skills. A more holistic assessment of patients would help identify issues such as depression, and a more patient-centred approach would help to understand and address patient's concerns, beliefs and expectations. It may also be important to ensure that management and administrative systems support a more patient-centred approach. It may be important to encourage the recruitment of family physicians who are trained in communication skills and a patient-centred approach, to work in the rural areas, where they can mentor and teach other colleagues and staff. More needs to be done in terms of helping patients to access facilities through transport, or in making services more available at the community level through DOTS (Directly Observed Treatment) supporters and adequate home-based carer support.

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## Introduction

The World Health Organization (WHO) declared tuberculosis (TB) a global public health emergency in 1993, and since then has intensified its efforts to control the disease worldwide. The African region has the highest TB prevalence rate (363/100 000 population) and, within the region, South Africa has the highest rate (998/100 000 population). After HIV/AIDS, TB is the second most widespread disease in South Africa. Although TB and HIV frequently co-exist, in 2006 only 32% of TB patients were tested for HIV. Concern about the number of multiple-drug resistant cases is increasing.1

Although successful treatment rates for new smear-positive cases have improved over the last 10 years, at 71%, they are still below the target of 85%. Unfavourable treatment outcomes therefore comprise around 29%of cases, with defaulting and deaths (218/100 000/year) the commonest reasons for such treatment being unsuccessful.1

Within the country there are also wide variations in the performance of TB services. This study was performed at a District Hospital in rural KwaZulu-Natal, which was reported to have a dismal successful treatment rate of 23%. The aim of this study, therefore, was to identify factors in this setting that were associated with poor adherence and which might point towards effective interventions to improve TB outcomes.

Factors linked to adherence can be grouped into those related to socioeconomic circumstances and conditions; those related to the patient; those related to the health workers and health system; and those related to the disease and its treatment.2 These factors from the literature are summarised in Table I.

The District Hospital involved in the current study is one of two district hospitals serving the subdistrict of Ndwedwe in rural KwaZulu-Natal, which has a population of approximately 153 000. Primary care is offered by five clinics and a community health centre. Unemployment



#### Socio-economic factors

#### **Negatively associated factors:**

- Lack of effective social support networks and unstable living circumstances<sup>3</sup>
- · Social factors such as poverty, unemployment, and migrancy may limit the amount of social support and create instability in people's lives
- High cost of medication
- High cost of transport

#### **Patient-related factors**

## **Negatively associated factors:**

- Cultural beliefs about illness and treatment<sup>4,5</sup>
- Ethnicity, gender and age have been linked to adherence in various settings<sup>6</sup>
- Criminal justice involvement
- · Involvement in drug dealing
- · Mental disorders such as depression or alcohol abuse

#### Health care team/health system factors

## **Negatively associated factors:**

- Poorly developed health services7
- · Inadequate relationship between health care provider and patient
- · Health care providers who are untrained, overworked, inadequately supervised or unsupported in their tasks

## Positively associated factors:

- Good relationship between patient and health care provider8
- Availability of expertise
- Links with patient support systems
- · Flexibility in the hours of operation of treatment centres

#### **Condition-related factors**

#### **Negatively associated factors:**

- · Asymptomatic patients
- Complex treatment regimen
- Adverse effects of medication and toxicity<sup>9</sup>

## Positively associated factor:

Knowledge about TB<sup>10</sup>

is at 26%; 24% have no schooling; 70% have no access to municipal water; 78% have no electricity; and only 16% of households earn more than R800 per month.11

The hospital is run by general doctors and nurses, and, at the time of the study, there was only one DOT (Directly Observed Treatment) supporter working in the community. The TB clinic is run by a registered nurse and two enrolled nurses, who look after the TB out- and in-patients. The clinic registers 30 to 40 new patients a month. The workload is high and the nurses experience stress due to the multiple tasks involved, staff shortages and patient numbers.

# Methodology

An observational study design collected data from all newly registered TB patients as they started their anti-TB treatment. The questionnaire was administered by a research assistant and addressed the following factors:

Patient-related factors: Age; gender; cultural beliefs; problems with the police; alcohol use ([AUDIT] Alcohol Use Disorders Identification Test score);12 tobacco smoking and substance use; depression (ICD-10 criteria); education; self-rated confidence in the ability to adhere to treatment; HIV testing; HIV status; and use of antiretroviral medication. Their functional status and the degree of dependency due to their illness were determined.

Socio-economic factors: Urban or rural location; income; employment; food security; social grants; and perceived social support (Multidimensional Scale of Perceived Social Support).13

Health service factors: Satisfaction with the hospital (cleanliness; waiting times; attitude of staff); relationship with the TB nurse; and barriers to accessing care.

The questionnaire was validated with clinic staff and piloted with patients prior to use. Data were collected over an 8-month period, and during this period 280 patients were registered. However, data were only obtained from 159 of the patients, due to the impact of a public sector strike during the data collection period and the need to replace the research assistant.

Patients were then followed up to determine those who did not adhere (cases) and those who successfully completed treatment (controls). Adherence was defined as those patients who were still taking their anti-TB treatment at the end of the intensive phase. Those who died or were transferred during the intensive phase were excluded. The data collected at baseline were then analysed for significant associations with adherence.

Data were collated in Excel and analysed by a consultant statistician, using Statistica 8 at the Centre for Statistical Consultation at Stellenbosch University. Categorical variables were analysed using contingency tables and Chi Square testing. Ordinal and continuous variables were analysed using ANOVA (analysis of variance) and the Mann-Whitney p value.

Ethical clearance was given by Stellenbosch University and permission to conduct the research was obtained from the Department of Health. Consent was obtained both verbally and in writing in either English or Zulu. Additional consent was obtained from parents or legal guardians for those under 18 years of age. Confidentiality was ensured by using only the folder number to match questionnaire data with adherence and no patient identifiers were used in subsequent data analysis.

# **Results**

Of the 159 patients, 105 (66%) were adherent and 54 (34%) nonadherent. Forty-seven (30%) were retreatment patients. Most (56%) of the patients were male. Nearly all (97%) lived in the rural areas and were Zulu-speaking (100%). Their mean age was 34.3 years, and the standard deviation was 12.2.

Thirty-nine (25%) of the patients reported that they had had no schooling. Only 4 (2%) had post-matriculation additional qualifications. Fifty-nine (37%) of the households reported receiving no income and a further 82 (52%) earned less than R1 000 a month. One hundred and twenty eight (80%) were unemployed, 22 (14%) had full-time and 9 (6%) had part-time employment. Food security was a problem for 67 (42%) of the patients and 52 (32%) received social grants. Most patients accessed the hospital by taxi [126 (79%)] or by walking [32 (20%)].

Approximately half the patients had attended a traditional healer or intended to do so in the future and a quarter believed that their TB was due to poisoning or a curse. Only 100 (63%) believed in an association of TB with HIV. Although 143 (90%) believed that their TB could be cured with medication, 47 (30%) of the patients were not confident about completing their TB treatment.

One hundred and seven (67%) of the patients had been tested for HIV, of whom 89 (83%) tested positive. Of those who tested positive only 17 (19%) were taking antiretrovirals (ARVs). A relatively large number of patients [51 (32%)] were too sick to work, but could look after



themselves at home, and 7 (4%) required help with the activities of daily living such as getting to the toilet or getting dressed. The remaining 101 (64%) were able to function normally at work and/or at home. Fifty-one (32%) of the patients smoked tobacco, 47 (30%) used alcohol, and 12 (7.5%) used marijuana.

The association of categorical variables with adherence is shown in Table II. Defaulting from treatment was significantly associated with the distance from the hospital, having to walk to the hospital and the time taken to get to the hospital. Lack of food was also associated with poor adherence. No schooling was associated with poor adherence, but employment status and the provision of social grants were not. A history of smoking tobacco or marijuana was associated with poor adherence.

Beliefs about being poisoned or being cursed were significantly associated with poor adherence. Although having already consulted a traditional healer was not associated with poor adherence, an expectation of having to consult a traditional healer in the future was. A belief that their illness could be completely cured with medication was associated with adherence.

While testing for HIV was associated with better adherence, being HIV positive was associated with poorer adherence and taking ARVs was not associated.

Having a previous history of TB or having previously completed TB treatment was not associated with defaulting or adherence.

Analysis of three ordinal variables (school grade obtained, income category and functional status) is shown in Table III. The mean rank sum of the ordinal scale was used to compare adherent and non-adherent patients. No significant association was found between school grades and adherence, but a higher income and a poorer functional status were significantly associated with non-adherence.

Table II: Associations between categorical variables and adherence

Variable	Categories	All (n = 159)		Adherent (n = 105)		Chi square test
		n	%	n	%	p value
Gender	Women	70	44	49	70	0.35
	Men	89	56	56	63	
Higher education	No schooling	39	25	6	15	< 0.01
	No higher education	116	73	95	82	
	Higher education qualification	4	2	4	100	
Location	Rural	154	97	101	66	0.48
	Urban	5	3	4	80	
	Walking	32	20	9	28	< 0.01
Method of transport to hospital	Taxi	126	79	96	76	
	Bus	1	1	0	0	
History of provious TD	Yes	47	30	31	66	0.98
History of previous TB	No	112	70	74	66	
Reported completing previous	Yes	31	66	22	71	0.31
TB treatment $(N = 47)$	No	16	34	9	56	
Difficulty with accessing hospital due to difficulty in getting time off work	Yes	24	38	12	50	0.78
	No	135	85	93	69	
Difficulty with accessing hospital, due to cost of transport	Yes	130	82	83	64	0.20
	No	29	18	22	76	
Difficulty with accessing	Yes	42	26	7	17	
hospital, due to distance from hospital	No	117	74	98	84	< 0.01

Difficulty with accessing	Yes	38	24	3	7	< 0.01	
hospital, due to travel time involved	No	121	76	102	84		
Previous problem with police	Yes	5	3	5	100	0.03	
	No	154	97	100	65		
	Unemployed	128	80	84	66		
Employment status	Part-time	9	6	7	78	0.12	
	Full-time	22	14	14	64		
Pocoiving a cocial grant	Yes	52	33	39	75	0.09	
Receiving a social grant	No	107	67	66	62	0.09	
Food insecurity at home	Yes	67	42	29	43	< 0.01	
Food insecurity at nome	No	92	58	76	83	< 0.01	
Smokes tobacco	Yes	51	32	25	47.1	. 0.01	
Smokes lodacco	No	108	68	81	75	< 0.01	
Cmalcaa mariiyana	Yes	12	8	3	25	0.04	
Smokes marijuana	No	147	92	102	69	< 0.01	
Believes their illness is due to	Yes	40	25	4	10	- 0.01	
poisoning	No	119	75	101	85	< 0.01	
Believes their illness is due to	Yes	39	25	4	10	< 0.01	
a curse	No	120	75	101	84	< 0.01	
Intends to consult a traditional	Yes	74	47	54	73	0.08	
healer now	No	85	53	51	60		
Intends to consult traditional	Yes	84	53	42	50	< 0.01	
healer in the future	No	75	47	63	84		
Believes that TB is associated with HIV	Yes	100	63	73	73	< 0.01	
	No	59	37	32	54		
Believes that TB can be cured with medication	Yes	143	90	99	69	< 0.01	
	No	16	10	6	37		
HIV test performed	Yes	107	67	79	74	< 0.01	
	No	52	33	26	50		
HIV result (N = 107)	Positive	89	83	63	71	0.03	
	Negative	15	14	14	93		
Taking ARVs (N = 89)	Yes	17	19	10	59	0.14	
	No	72	81	53	74		

Table III: Association of ordinal variables with adherence

	Mean rank			
Variable	Non-adherent (n = 54)	Adherent (n = 105)	p value	
School grade passed On scale from 1 to 12	75.0	82.5	0.32	
Income 1. Less than R500 pm 2. R500–R999 pm 3. R1 000–R1 500 pm 4. More than R1 500 pm	95.1	72.2	<0.01	
Functional status  1. Even though I am sick, I can do everything I usually do at work and at home.  2. I am unable to work normally, but can look after myself at home.  3. I need help occasionally to look after myself (e.g. with getting to the toilet; with getting dressed).  4. I need help every day to look after myself (e.g. with getting to the toilet; with getting dressed)  5. I am in bed most of the time.	95.8	71.8	<0.01	

The association between continuous variables and adherence are shown in Table IV. Adherence was significantly associated with better social support from family and significant others, but not from friends. It was also associated with a good relationship with the TB nurse. Higher



Table IV: Results for continuous variables comparing adherent and nonadherent TB patients

	Non-	adherent	Ad	Mann-		
Variable	Mean	95% CI	Mean	95% CI	Whitney p value	
Age	31.2	28.0-34.0	35.9	33.3–38.4	0.09	
Number of previous episodes of TB	0.37	0.20-0.54	0.37	0.25-0.49	0.91	
Social support from family score	3.92	3.40-4.43	5.60	5.38-5.81	< 0.01	
Social support from significant other score	2.80	2.24-3.36	4,91	4.61-5.21	< 0.01	
Social support from friends score	1.66	1.38–1.94	2.17	1.81-2.53	0.27	
Relationship with TB nurse score	5.20	4.85–5.54	6.68	6.50-6.87	< 0.01	
Patient satisfaction score	5.06	4.80-5.33	5.96	5.90-6.02	< 0.01	
Audit score for alcohol	1.33	0.04-2.62	2.18	1.27-3.08	0.23	
Depression score	7.14	6.28-8.00	2.55	1.88-3.22	< 0.01	
Confidence in ability to complete treatment score	3.01	2.39-3.64	5.64	5.42-5.86	< 0.01	

patient satisfaction with the service at the hospital was also significantly associated with higher levels of adherence. A higher depression score was associated with non-adherence, while there was no significant difference in the AUDIT score for alcohol use between the groups. The patients' own self-rating of their confidence in completing treatment was significantly associated with their actual ability to adhere.

A stepwise logistic regression was performed on all the variables that showed a significant association with adherence. On completion of the regression, only difficulty with accessing the hospital due to travel time (OR 7.91 CI 1.4-44.1 p = 0.02) and the relationship with the TB nurse (OR 2.56 CI 1.3 - 5.1 p < 0.01) remained significant.

## **Discussion**

Improving adherence to TB treatment, and therefore TB cure rates, is a major programmatic and public health goal in South Africa. The study suggests that two key factors in achieving this goal are the relationship between patients and their TB nurses and the accessibility of the TB service in the rural areas.

## Relationship with the TB nurse

Key issues used to assess the relationship between the TB nurse and patient were giving enough time for the patient to ask questions and to obtain information that was important to them, discussing TB treatment in a sensitive and caring way and demonstrating empathy towards the patient's feelings and thoughts. The findings, therefore, imply that improving communication skills among nurses and supporting a more holistic approach to the assessment of patients are key to the improvement of TB adherence rates. A holistic approach recognises that many patients have important personal and contextual issues in addition to clinical ones. Disease-focused programmes, such as TB, tend to operate in terms of a public health orientation, rather than focusing on the individual patient. Patient-centredness has been re-emphasised as a core aspect of primary care services in the 2008 World Health Report.<sup>14</sup>

Communication skills training in the nursing curriculum is often deficient and some courses still refer to history-taking as "the interrogation".15

Skills such as the ability to ask open as well as closed questions, to encourage patient elaboration with a range of facilitative responses, empathise with reflective listening statements and summaries are some of the key elements.16

Family medicine training emphasises patient-centredness, holistic assessment and communication skills. A recent study has suggested that primary care nurses should receive additional training in family medicine. 17 Greater collaboration between primary care nurses and family medicine training programmes may well have other benefits, in terms of the shared understanding of roles, relationships and teamwork.

# **Understanding the individual**

Individual beliefs regarding causation and the role of traditional healers, concerns regarding the accessibility of the hospital clinic, satisfaction with the hospital, symptoms of depression and self-confidence may all play a role in patient outlook. Eliciting, acknowledging and discussing patient's beliefs and concerns can significantly improve adherence to TB treatment.<sup>18</sup> If one assumes that patients are more likely to be ambivalent about treatment, than clearly either for or against traditional or biomedical approaches, then health workers who are empathic, who impart useful information and who help resolve ambivalence may be more successful at supporting adherence.16

Patients who anticipated consulting a traditional healer, or believed that their illness was due to poisoning or a curse were found to be more likely to default. Presumably, this was because they were not convinced that their problem was really TB, or that it could be cured by medication. Such patients may also be less motivated to persist with treatment in the face of side-effects or slow response to initial treatment. Another study found that patients often consult with a traditional healer before presenting to the health care facility<sup>19</sup> or may present only when the traditional healer's remedy clearly shows that it does not work.20

A higher patient satisfaction score was associated with better adherence and when the individual questions are assessed, the main issues for patients appeared to be long waiting times, the general lack of cleanliness, poor conditions, and the lack of privacy. These findings are in keeping with those from other studies where factors such as hospital cleanliness, long waiting times and privacy were also cited as important barriers to adherence.21

# **Understanding the context**

From the contextual perspective, the degree of social support and food security in the household were important. Nurses therefore need to think about psychological and social issues in their interactions and not just the TB symptoms and treatment.

Social support from family and partners, but not from friends, was significantly associated with adherence.21 It is possible that more familyorientated care could lead to improved social support and adherence. It may be concluded that patients who do not receive emotional support and help with completing their treatment may be less motivated to adhere to treatment. Possible reasons for receiving less social support from family and partners are stigmatisation, especially if the person is co-infected with HIV; poor family dynamics; cultural beliefs in the family and the loss of close family members to HIV.

Surprisingly, a higher income was associated with poorer adherence. This result is difficult to interpret, but it is possible that those patients who were found to be relatively well off were worried about losing their



employment or earnings, and gave these concerns preference over treatment. However, difficulty in accessing the hospital due to work responsibilities was not significantly associated with adherence.

Poor food security was associated with poor adherence. The association with poor food security could imply that more attention be paid to the provision of nutritional support to patients with TB. This conclusion is supported by another South African study that found that successful completion of treatment was attributed to the availability of food, which prevented the side-effects which result from taking medication on an empty stomach.20

To what extent TB nurses asked about or addressed smoking cessation or other behaviour change with the patients participating in this study was unclear. However, a confrontational, authoritarian or directive approach to counselling may increase resistance to change and reduce the motivation to adhere to treatment.16 A large number of studies indicate that a poor provider attitude, such as scolding a patient for missing appointments, results in non-adherence.21 Smoking could also be associated with higher psychosocial stress and the use of marijuana may lead to a more disorganised lifestyle. Surprisingly, the AUDIT score for alcohol use was not associated with adherence, as the literature had suggested that alcohol abuse is an important factor. The total number of patients who consumed alcohol was 47 (30%), of whom 20 (43%) drank above the AUDIT cut-off score of 8 for harmful use.

#### Accessibility of the TB service

The time taken to get to the clinic remained the most important factor in accessing the service. In some circumstances, it may be justifiable to consider the possibility of admitting such patients, although in most hospitals there is a limit on the number of days that a patient should be hospitalised. Consideration should also be given to better transport options, or to the supply of more community-based services in the surrounding areas. During the study period, the hospital introduced an active tracer team to follow up defaulting patients in the community and to ensure that they continue with their TB treatment. This communitybased service has already started to reduce the interruption rate and improve accessibility. It should also be noted that a rigid insistence on daily observed treatment in patients who struggle with accessing the clinic may actually reduce adherence. Although DOT is national policy, the evidence that it is more effective than other systems is lacking.<sup>22</sup>

#### **TB and HIV**

Interestingly neither previous TB, nor reported lack of treatment completion was associated with non-adherence. However, completion of treatment was self-reported by the patient and may not be accurate. A recent study showed that the likelihood of developing MDR and XDR-TB was associated with previous treatment when there was no cure.<sup>23</sup>

Although testing for HIV was associated with better adherence, being HIV positive was associated with worse adherence. Being willing to undergo an HIV test could be a marker for those who see TB as a biomedical problem and who were better aligned with the medical perspective on treatment. The counselling involved in HIV testing was supportive of adherence in that it helped change the health beliefs of patients, through the provision of additional information. Being HIV positive may lead to the double stigma of having both TB and HIV/AIDS,<sup>24</sup> and a loss of social support from family and significant others, being sicker and less able to access the clinic and having to deal with more complex therapeutic regimens.

#### Limitations of the study

Some patients filled in the questionnaire after commencing TB treatment, and not immediately on registration. While this would not alter the replies to many of the questions, some of the questions, such as the self-rating of confidence, could be affected by when the question was asked in the course of treatment.

Although the intention was to administer the questionnaire to all participating patients during the study period, the sample size was reduced by the effect of a public service strike and the need to replace the research assistant towards the end of the data collection. Nurses were then asked to assist with the questionnaire and this may have affected the answers of some patients, as the interviewer may have been perceived as being less neutral than the research assistant.

Re-treatment patients (of which there were 47 in this study) are admitted to the hospital for the first two months and are then discharged to continue with the intensive phase at home. This means that re-treatment patients had less opportunity to default than new patients.

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