

Treatment adherence among tuberculosis patients

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The main aim of this article is to provide insight into the determinants of treatment adherence among pulmonary tuberculosis patients. The study was conducted at nine clinics in the Free State province of South Africa. The quantitative evidence shows that stigmatisation, the socio-economic circumstances of patients, and migrancy all play important roles in explaining non-adherence. The qualitative evidence identified some of the factors affecting adherence as lack of knowledge about TB, the non-sustainability of educational campaigns, the side-effects of drugs, hunger, lack of family support, the stigma attached to TB, the attitude of health care workers and the long delay before diagnosis. Based on this evidence, recommendations are made for a number of provider-, patient- and community-centred interventions to improve adherence.

Behandelingsnakoming van tuberkulose-pasiënte in die Vrystaat, Suid-Afrika

Die hoofdoel van hierdie artikel is om insig te verskaf in die determinante wat 'n rol speel in die nakoming van behandelingsinstruksies by pulmonêre tuberkulose pasiënte. Die studie is onderneem by nege klinieke in die Vrystaat provinsie, Suid-Afrika. Die kwantitatiewe bevindinge dui daarop dat stigma, die sosio-ekonomiese omstandighede van die pasiënt en migrasie 'n belangrike rol speel by die verklaring van die nie-nakoming van behandelingsinstruksies. Sommige van die waargenome faktore wat die nakoming van behandelingsinstruksies beïnvloed, soos gebaseer op die kwalitatiewe bevindinge, sluit in gebrekkige kennis omtrent TB, die nievolhoubaarheid van opvoedkundige programme, nuwe-effekte van medikasie, honger, gebrekkige gesinsondersteuning, die stigma gekoppel aan TB, die houding van gesondheidsorgwerkers en die lang vertraging alvorens 'n diagnose gemaak word. Voortspruitend uit hierdie bevindinge word aanbevelings gemaak rakende 'n aantal verskaffer-, pasiënt- en gemeenskapsgeentreerde intervensies wat die nakoming van behandelingsinstruksies kan verbeter.

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According to Southern Africa Tuberculosis Control Initiative¹ (SATCI 2000: 2):

[T]uberculosis hardly needs any introduction. At least, not in Africa. The debilitating bacteria of this curable, yet terminal disease, dictate the lives of thousands of people in Southern Africa.

Globally, TB kills 5 000 people a day and more than 2.3 million a year (WHO 2001: 1). More than 8 million people contract TB each year, about 2 million of these in sub-Saharan Africa. This number is rising rapidly as a result of the HIV/AIDS epidemic (Wilkinson 1999: 155). In South Africa, the long-term trends of TB (expressed by the annual incidence rates from 1990 to 2001) are striking. It starts with an incidence rate of 145/100 000 in 1990 (Van Rensburg *et al* 1992: 181), then displays a sustained and relatively sharp rise, reaching a peak in 1998 with an incidence rate of 338/100 000, and an extreme high of 362/100 000 in 2001 (Dept of Health 2002a: 1).

Treatment outcomes — sometimes called patient outcomes — including changes in patients' current and future health status, are considered the "end result" of health care provision (Wojner 2001: 6). Against the background of increasing numbers of TB cases and poor completion rates, in 1996 the National TB Control Programme in

1 This is an adapted version of a paper read at the conference Tuberculosis: A multidisciplinary approach to research, policy and practice, C R Swart Auditorium, University of the Free State, Bloemfontein, 11-12 November 2004. In essence, this study is part of a more comprehensive three-year study, the Joint Research Project on Tuberculosis Control in the Free State, South Africa: From Infection to Cure. This comprehensive study focuses on the "patient career", the socio-economic environment and the health care system. It is being conducted in the context of the South African-Flemish Bilateral Scientific and Technological Co-operation Programme.

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South Africa adopted the World Health Organisation's (WHO) worldwide strategy of DOTS, or Directly Observed Treatment, Short Course (Bamford 1999: 316). Effective treatment keeps patients from dying of TB and prevents transmission to other members of society. Treatment of active TB involves taking multiple anti-TB drugs for five days a week, for at least six months (Rieder 2002: 10-1). The aim of the DOTS strategy is two-fold. First, it aims at successful treatment of 85% of detected smear-positive TB cases. Secondly, it aims to detect 70% of such cases (WHO 2001: 3). This is to be achieved by means of the five elements of the WHO's DOTS strategy, namely political commitment, laboratory improvement, direct observation of treatment, improved drug supply, and improved reporting systems. DOTS programmes often also encompass other interventions, such as offering incentives and enablers to patients, tracing defaulters, using legal sanctions to enforce adherence, adopting patient-centred approaches to health care delivery, motivating and supervising staff, and raising additional external funding (cf Buchanan 1997; Jaramillo 1999; Volmink *et al* 2000). Therefore, DOTS involves much more than just the direct supervision of tablet-taking, first introduced by tuberculosis specialists more than 40 years ago (Volmink *et al* 2000).

In South Africa, TB treatment services are offered free of charge at the primary level in public sector health care facilities, yet completion rates have been slow to improve. Many factors may lead to poor adherence. On the surface, it appears that treatment outcomes for TB patients are an indication of the quality of care they receive. However, various authors have acknowledged that the complex interactions of a wide range of personal, socio-economic, infrastructural and community factors determine patient behaviour.² As such, and in terms of social learning theories, adherence is also a "function of cues and consequences in the context of the social system" (Hovell *et al* 2003: 1791). In fact, TB may not be cured and may recur if patients do not take their medication for the full treatment period. Such patients may also become resistant to the drugs, and transmit drug-

2 Cf Farmer 1997; Pablos-Méndez *et al* 1997; Jaramillo 1999; Khan *et al* 2000; Mata 1985; Meulemans *et al* 2000; Malotte *et al* 2001; Needham *et al* 2001; Thorson 2001; Demissie *et al* 2003; Hovell *et al* 2003; Jaiswal *et al* 2003.

Matebesi & Booysen/Treatment adherence among tuberculosis patients resistant TB to others (Giuffrida & Togerson 1998: 189). Drug-resistant TB is difficult and expensive to treat. Thus, the most important step in preventing drug-resistant disease is to ensure that patients are cured at the first attempt. This has provided a major impetus for research into the study of factors that determine patients' treatment adherence (Pablos-Méndez 1997). For perhaps the first time, the world is facing a health threat to which the only effective response is behavioural as well as medical (Cockerham 2001: 131).

Treatment outcomes in new smear-positive pulmonary tuberculosis (PTB) patients in South Africa reveal that the cure rate nationally has slowly improved from 56.6% in 1997 to 62.9% in 2000. However, the cure rate in the Free State has shown a rapid increase from 49% in 1997 to 66% in 2000. Interruption rates remain high in the country, however, despite slow decreases from 18.6% in 1997 to 15.8% in 2000. This perhaps explains the steady increase in the percentage of pulmonary TB patients dying while on treatment (from 6.3% in 1997 to 8.3% in 2000). In 2000, the Free State had the third-highest percentage of deaths (10.2%) after the Gauteng Province and Mpumalanga (Dept of Health 2002a: 1-3). Increased interruptions lead to more serious illness among TB patients and to increased infectivity within their communities (Needham *et al* 2001: 256). Clearly, improvement is needed, especially within resource-poor settings such as the Free State province. The purpose of this article is to identify factors that explain adherence to treatment, or the lack thereof, among TB patients in this province.³ Section 1 describes the research design and methods employed. Sections 2 and 3 report the quantitative and qua-

3 In the recent literature the term "adherence" has come to be preferred to the term "compliance" (first used in the 1960s), which has formed the basis of professional discourse on the topic since the 1970s (Lerner 1997), since the latter term has the "unfortunate connotation that the patient is docile and subservient to the provider" (Volmink & Garner 1997: 1403). According to Farmer (1997: 349), the term "compliance" also "exaggerates patient agency, for it suggests that all patients possess the ability to comply — or to refuse to comply — with anti-tuberculosis therapies". In this article, therefore, we use the terms adherence and non-adherence, rather than compliance and non-compliance to describe patient behaviour.

litative evidence on determinants of adherence. The results are discussed in section 4, while section 5 concludes with some recommendations.

1. Research design and methods

The study was conducted using a combination of quantitative and qualitative research methods. Face-to-face interviews and focus group discussions (FGDs) were conducted with pulmonary tuberculosis patients at nine primary health care clinics. The study endeavoured to recommend interventions at policy and practice levels. For this reason, health care policy-makers were involved in the conceptualisation and design of the study. They are also part of the ongoing collaboration between the Centre for Health Systems Research & Development (CHSR&D) and the Free State Department of Health.

1.1 Study areas

The survey was conducted at nine primary health care clinics in three geographical areas or health districts in the Free State province: Goldfields, a gold mining area; Qwaqwa, a previously “independent” black homeland area, and Thaba Nchu, a typical small town in the vicinity of a large African settlement (Van Rensburg & Redelinghuys 2001). The areas were purposively selected to represent different regions of the Free State, and to include rural and urban areas. Together, the selected areas represent the broad spectrum of socio-economic and socio-cultural variables impinging on TB patients’ treatment outcomes.

1.2 Population and sample

The population of the study was clinic-based pulmonary TB patients. The patients interviewed at the clinic level were sampled on the basis of a multistage design. A sampling frame — a list of clinics with a high burden of PTB patients during the initial two quarters of 2001 — was obtained from the Department of Health.⁴ Thereafter, a stratified random sample was utilised to ensure that specific characteristics were represented. The sample was stratified according to the

4 The focus was on such clinics, due to the need to recruit as many patients as possible for the study.

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category of patient, and patients were sampled in proportion to the total number of each type of patient on the TB register at each clinic.⁵ Tuberculosis patients were stratified according to the following four categories:

- new patient — intensive phase,
- new patient — continuation phase,
- re-treatment patient — intensive phase, and
- re-treatment patient — continuation phase.

Table 1: Category of patient by gender (%)

	Male	Female	Total
Category of patient:			
New patients	76 (63)	74 (75)	150 (68)
Re-treatment patients	45 (37)	25 (25)	70 (32)
<i>Total</i>	<i>121 (100)</i>	<i>99 (100)</i>	<i>220 (100)</i>
Type of re-treatment patient:			
After previous cure	24 (53)	13 (52)	37 (53)
After previous treatment completion	8 (18)	7 (28)	15 (21)
After previous treatment interruption	10 (22)	2 (8)	12 (17)
After previous treatment failure	3 (7)	3 (12)	6 (9)
<i>Total</i>	<i>45 (100)</i>	<i>25 (100)</i>	<i>70 (100)</i>

The study population comprised 220 pulmonary tuberculosis patients. Table 1 presents their characteristics by category and gender. Fifty-five percent of patients interviewed were male and 45% female. The majority of patients were new (68%), while almost a third were re-treatment patients (32%). Of the latter, just more than half were on re-treatment following a previous cure (53%), while just more than a fifth (21%) were on re-treatment following treatment completion.

5 Visser *et al* (2000: 225) maintain that stratified sampling “provides greater control over the composition of the sample, assuring the researcher of representativeness of the sample in terms of the stratified variables”.

Table 2: Characteristics of focus group participants

Characteristic	Sample (n)	Percentage (%)
Gender:		
Male	45	53
Female	40	47
<i>Total</i>	85	100
Category of patient:		
New patients	61	72
Re-treatment patients	24	28
<i>Total</i>	85	100
Employment status:		
*Employed	7	8
Unemployed	78	92
<i>Total</i>	85	100
Lived with someone who has/had TB:		
Yes	31	36
No	54	64
<i>Total</i>	85	100

* Including 3 pensioners

For the sample of the FGDs, patients still on treatment were randomly selected from the TB registers in terms of their various illness stages. FGDs were conducted with 7-8 participants at each of the nine clinics. Those under the age of 16 and those who had been treated for less than 2 months were excluded because they were perceived to be “less experienced” about having TB. In total, 85 patients participated in the FGDs. Table 2 presents their characteristics. Of the 85 participants in the nine groups, 53% (n=45) were male. The ages of the participants ranged from 18 to 57. The vast majority (72%, n=61) were new patients (patients who had never been treated for TB before), and only 8% (n=7) were employed. Thirty-six percent indicated that they were living or had lived with someone who had or had had TB before they were diagnosed as having the disease.

1.3 Data collection and analysis

The Research Committee of the Faculty of the Humanities (UFS) approved the ethics of the study. Permission to conduct the survey was also obtained from the Free State Department of Health and the relevant district managers. The moderator, who is the first author of this paper, telephonically informed the staff of the selected clinics of the study. He also personally visited the clinics 3 days before the FGDs to draw the sample and to make the necessary logistical arrangements. All the participants gave informed consent for the interviews.

Structured, face-to-face interviews, guided by interview schedules, were conducted with the 220 clinic patients. Five trained fieldworkers conducted these interviews with the patients at the selected clinics. Interviews were conducted in the language of the patients and the completed questionnaires were edited immediately for quality assurance. Interviews lasted approximately an hour and were conducted under difficult conditions, including the following:

- First, tuberculosis patients at certain clinics only took their medication early in the morning. This constrained and complicated the fieldwork logistics.
- Secondly, the non-availability of extra rooms at clinics forced fieldworkers to conduct interviews with two or three patients in one room.
- Thirdly, due to the long interview schedule, some patients asked to be excused for a few minutes but never returned. In such instances, interviews were conducted with patients on the reserve sampling list.
- Lastly, the fieldwork manager not only had to provide support and supervision to fieldworkers, but constantly also had to allay their fears of contracting tuberculosis.

Data on the treatment outcomes of these patients were collected from the tuberculosis registers at the clinics during October and November 2002.⁶ Bivariate analysis was used to compare adherent and non-adherent patients in terms of certain key characteristics, including socio-demographics and a number of possible determinants of adhe-

6 Complete outcomes data were missing for one patient.

rence. The χ^2 and t -tests were used to assess the statistical significance of these differences in categorical variables and continuous variables, respectively. Multiple logistic regression was employed in investigating the determinants of adherence, controlling for the possible confounding effects of other variables. Data were analysed using SPSS 10.1 and Stata8 statistical software.

A moderator (the first author) and an experienced note-taker facilitated the nine focus group discussions (FGDs) during February 2003. Before each FGD session, the moderator welcomed the participants and told them about the purpose of the FGD. The participants felt confident and at ease, and spoke freely as they already knew one another. The sessions, which usually lasted one hour, were conducted in the languages of the participants (Sotho and Tswana), and taped-recorded with the participants' consent. The FGDs began with general questions before focusing on more specific questions as they progressed (the funnel approach), using a topic guide to ensure that the same areas were covered in each focus group. The questions covered whether participants knew about TB before being diagnosed; how or where they learned about TB; their knowledge of health education campaigns, and perceived factors affecting adherence. The group interaction allowed for a more in-depth understanding of patients' beliefs about adherence than could have been gained from individual interviews. The recordings were later transcribed and translated into English. Another researcher who had not participated in the study re-translated the English version for comparison, and the necessary corrections were made. Field notes were written immediately after each FGD.

2. Quantitative evidence on determinants of adherence

For the purpose of this analysis, adherence was defined as uninterrupted taking of prescribed medication. In terms of treatment outcomes, adherence refers to successful outcomes and cases where treatment was interrupted for at least two months. Successful outcomes include cured patients who are smear negative at, or one month prior to, the completion of treatment and on at least one previous occasion, as well

Matebesi & Booysen/Treatment adherence among tuberculosis patients as patients who have completed treatment, but whose smear results are not available on at least two occasions prior to completion of treatment.

Table 3: Patient treatment outcomes

Outcome	Sample (n)	Percentage (%)
Cured	120	55
Completed treatment	53	24
Failed treatment	12	6
Interrupted treatment	11	5
Transferred out	10	5
Died	13	6
Missing	1	1
<i>Total</i>	<i>220</i>	<i>100</i>

Note: Failed treatment refers to patients who remained or once again became smear positive at five months or later during treatment. Transferred out refers to patients transferred to another clinic, whose treatment outcome is not known. Died refers to patients who died for any reason during treatment. The total does not add up to 100% due to rounding.

Table 3 describes the treatment outcomes for the total study population. This analysis, therefore, focuses on a comparison of the 173 patients with successful outcomes and the eleven patients who interrupted their treatment (n=184), a sub-sample that constitutes almost 80% of the 220 patients interviewed in the study.

Table 4 reports the results of the bivariate analysis. The two groups of patients are compared here in terms of a wide range of socio-demographic and household characteristics, as well as variables approximating the determinants of adherence expounded in the quantitative literature.⁷ The descriptive statistics of these variables and the meaning of index variables for the sub-sample of patients are described in detail in Appendix 1.

7 Cf Farmer 1997; Pablos-Méndez *et al* 1997; Jaramillo 1999; Malotte *et al* 2001; Thorson 2001; Demissie *et al* 2003; Hovell *et al* 2003; Jaiswal *et al* 2003.

Table 4: Comparison between adherent and non-adherent patients

Variable	Adherent (%)	Non-adherent (%)	P
Mean household size	4.3	4.7	0.267
Gender:			
Male	91 (52.6)	10 (90.9)	
Female	82 (47.4)	1 (9.1)	0.013
Mean age (years)	37.7	42.7	0.077
Marital status:			
Married	66 (38.1)	5 (45.4)	
Single	107 (61.8)	6 (54.5)	0.629
Housing:			
Formal	132 (76.3)	9 (81.8)	
Informal	29 (16.7)	1 (9.1)	
Traditional	12 (6.9)	1 (9.1)	0.786
Mean years of education	7.8	7.1	0.255
Mean monthly household income (Rand)	1205	1345	0.670
Financial support received while on treatment (Rand)	478	305	0.233
Access to medical aid	9 (5.2)	0 (0.0)	0.437
Re-treatment patient	50 (28.9)	7 (63.6)	0.016
Paid to access treatment	1 (0.6)	1 (9.1)	0.008
Main breadwinner	64 (36.9)	5 (45.4)	0.574
Currently employed	58 (33.5)	5 (45.4)	0.419
Previously employed	25 (14.4)	2 (18.1)	0.735
Income loss due to illness (Rand)	1832	5415	0.075
Travel time to clinic (minutes)	25	28	0.346
Away from home during treatment	15 (8.7)	3 (27.2)	0.045
Number of migrants in household	0.1	0.3	0.008
Ever in jail	16 (9.2)	4 (36.3)	0.005
Able to eat before taking tablets	158 (91.8)	10 (90.9)	0.911
Access to piped water in dwelling	141 (81.5)	11 (100.0)	0.117
Tablet-taking supervised	156 (91.2)	10 (90.9)	0.971
Side-effects experienced	172 (99.4)	11 (100.0)	0.800
Crowding index	2.2	2.2	0.491
Stigma index	0.236	0.545	0.042
Tuberculosis knowledge index	5.156	5.545	0.150
Service quality index	1.628	1.666	0.576

According to the results presented in Table 4, nine variables showed statistically significant differences between adherent and non-adherent patients ($P < 0.10$). First, female patients were more likely than male patients to adhere to treatment. Secondly, younger patients were more likely to adhere to treatment than older patients. Thirdly, patients on re-treatment were less likely to adhere to treatment. Fourthly, patients who had to pay a fee to access health care services for diagnosis or treatment were less likely to adhere to treatment. Fifthly, patients who reported higher loss of income due to their illness were less likely to adhere to treatment. Sixthly, patients who were away from home during treatment and patients from households including many migrant workers were less likely to adhere to treatment. Non-adherence was also more likely among patients who had spent some time in jail, this indicator having been used here to approximate risk behaviours not assessed in detail in the questionnaire (eg, alcohol and substance abuse). Finally, non-adherence was also more likely among patients who reported perceived stigmatisation (the stigma index is defined in Appendix 1).

Table 5 reports the results of the multiple logistic regression used to determine the relative importance of various determinants of adherence when controlling for the effect of other variables. The overall model was statistically significant ($P = 0.059$) and explained 44% of observed differences in adherence. The dependent variable is dichotomous: 1=adherence and 0=non-adherence. The independent variables in the model included a wide range of socio-demographic and household characteristics of the patients, as well as variables approximating the determinants of adherence expounded in the quantitative literature. After adjusting for possible confounding effects, a total of eight variables featured as statistically significant determinants of adherence ($P < 0.10$). These include only two of the variables which exhibited statistically significant differences between adherent and non-adherent patients in Table 4. As was the case with the bivariate analysis, the likelihood of adherence was higher where perceived stigmatisation was lower. In addition, the likelihood of adherence was significantly higher among patients who were not on re-treatment. The results also point to the role played by the socio-economic circumstances of patients in explaining differences in adherence. Patients

Table 5: Multiple logistic regression results: determinants of adherence

Variable	Odds ratio (OR)	P	Confidence interval (95%)
Household size	0.407	0.044	0.170 - 0.978
Gender (male=1, female=2)	12.433	0.145	0.420 - 368.443
Age	0.966	0.643	0.833 - 1.120
Marital status (married=1, single=2)	1.088	0.936	0.142 - 8.340
Years of education	1.078	0.710	0.725 - 1.605
Monthly household income (Rand)	1.000	0.488	0.999 - 1.001
Financial support received while on treatment (Rand)	1.004	0.029	1.000 - 1.008
Re-treatment patient (yes=1, no=0)	0.141	0.095	0.014 - 1.407
Paid to access treatment (yes=1, no=0)	0.012	0.153	0.000 - 5.214
Currently employed (yes=1, no=0)	0.031	0.039	0.001 - 0.840
Previously employed (yes=1, no=0)	1.151	0.920	0.074 - 17.783
Income loss due to illness (Rand)	1.000	0.375	1.000 - 1.000
Travel time to clinic (minutes)	1.014	0.718	0.941 - 1.093
Away from home during treatment (yes=1, no=0)	0.259	0.430	0.009 - 7.418
Number of migrants in household	0.860	0.932	0.027 - 27.711
Ever in jail (yes=1, no=0)	0.375	0.415	0.035 - 3.963
Able to eat before taking tablets (yes=1, no=0)	46.962	0.077	0.658 - 3,353.973
Tablet-taking supervised (yes=1, no=0)	30.327	0.100	0.521 - 1 764.489
Crowding index	2.876	0.351	0.313 - 26.415
Stigma index	0.221	0.045	0.051 - 0.965
Tuberculosis knowledge index	0.151	0.075	0.019 - 1.207
Service quality index	1.355	0.700	0.289 - 6.355
Sample (n)			170
LR Chi^2 test (P)			33.17 (0.059)
Pseudo R ²			0.436

Note: Access to medical aid and piped water were excluded from the analysis, given that not one non-adherent patient had access to medical aid and that all non-adherent patients had access to piped water. The experience of side-effects was likewise excluded, given that these all non-adherent patients experienced these.

who had access to more financial support in the form of social grants, a pension, remittance income, a salary or other income while on treatment were more likely to adhere to treatment. Patients who were usually able to eat before taking their tablets or who were members of smaller households (which generally face relatively lower resource constraints) were also more likely to adhere to treatment. Employment status, moreover, posed a barrier to adherence, with patients who were currently employed being less likely to adhere to treat-

ment. Importantly, patients whose tablet-taking was supervised were more likely to adhere to treatment. The association between adherence and the TB knowledge index (defined in Appendix 1), although statistically significant, did not exhibit the anticipated sign. One would have expected the likelihood of adherence to increase in line with the patient's knowledge of TB. However, adherence was here associated with less knowledge of TB, which may reflect some spurious correlation, given the relatively crude nature of the knowledge index employed for this purpose (see Appendix 1).

3. Qualitative evidence on determinants of adherence

As stated earlier, the participants reported their ideas freely, and it was easy for them to respond to the questions. All the questions seemed relevant. However, despite the relaxed atmosphere during all the FGDs, questions relating to side-effects of TB drugs, lack of family support, and the stigma attached to the disease evoked much stronger reactions from the participants than the other questions.

3.1 Knowledge of TB and educational campaigns

Mixed reactions concerning knowledge of TB emerged from the group discussions. In most instances, participants who had had TB before, and/or lived with a contact (someone who has TB), were more likely to know what TB is, than those with no personal history of TB treatment or any close contacts. However, further analysis reveals that the participants' understanding of TB was not always in agreement with biomedical knowledge:

Female: Yes, I know what TB is all about. I have heard many people talking about it. But for me, it is a family thing. It has been there for some time in the family. I think I have inherited it from my parents ...

Male: My mother passed away while still taking TB treatment ... I have [had] TB for the past three years despite having completed treatment on all occasions. If you have TB you have got it, there is nothing that can cure it. That is the way of this disease.

Concern was expressed about how one can become ill with TB more than once (recurrent TB):

Male: I am really disappointed. I have been cured before, but no one at the clinic can tell me why this disease keeps on coming back. The only thing that I am told, is how to take my medication ...

Female: My grandmother first had TB. She has since passed away. I was previously cured, but after six months, I became ill again. I was sent to Santoord [TB hospital]. On my return, my brother was also diagnosed with TB. He later also passed away ... this thing wants to eat us all. Something has to be done. I really do not know why it keeps on coming back.

Participants were also asked to mention any health information/intervention campaigns that they knew of. Many participants mentioned nurses, doctors, radios, newspapers, television, family members, and friends as their most important sources of information about TB. Only a few were aware of TB health education activities in their areas.

3.2 Side-effects of drugs

When asked what factors led to non-adherence to the treatment regimen, the reason most strongly emphasised by the majority of the participants tended to be the physical side-effects of TB medication. Another factor was the patient's subjective negative experience with the medication, which is not often communicated to health care providers, for fear of reprisal. The following quotations capture the feelings cited by participants:

Male: These tablets let one's body itches [*sic*] for the whole day. I know someone who interrupted his treatment because of this problem. I told the nurses about the side-effects and they gave me other tablets. But the problem is my situation is even worse now ... I console myself by rubbing myself with cabbage or orange bags.

Female: Since I have started taking this TB medication, my body is full of pimples and sores. The rash is very painful. The nurses told me that it is the nature of TB ... the side-effects will go away with time. The itching is bearable from Friday to Monday [treatment is not taken over weekends]. But when we start taking treatment on Monday, the irritation starts all over again ... it seems as if these tablets do not want you to stop taking them....

Female: ... and when we report these side-effects, nurses will always retort: 'Hey you! You are a nuisance and childish, you have to experience side-effects because you have been drinking alcohol', even if that is not the case.

3.3 Hunger and lack of family support

The majority of the patients who were employed at the time they became ill mentioned that they had resigned or been dismissed. In most cases these patients were breadwinners who not only had to face hostile family members, but also a spell of hunger as a result of the medication:

Male: The problem is that we have to come to the clinic every day for medication. What is the role of the DOTS supporters? Sometimes we are tired ... These tablets make you very hungry. Even now I am hungry ... Some patients may just decide to stay away from the clinic if there is no food at home.

Female: We sometimes need to be pushed, but we do not get support from family members. These tablets are eating everything left in your stomach. At times I really feel like not coming to the clinic.

Family members also seem to shun the company of patients in the household:

Male: I have been afraid to tell them at home about my TB status. Ever since they found out that I have TB, I have to cook my own food in my tiny sleeping room. I have been instructed not to take utensils that I use out of my room ... I am also not allowed to come into close contact with the children ...

3.4 Stigma

The existing socio-cultural barriers and taboos associated with TB have also been found to be major factors conducting to poor completion rates. This problem is exacerbated by the link between TB and AIDS:

Male: I arrive early in the morning so that people could not see me. I used to conceal my illness from people. It was only my mother and wife who knew why am I am so often visiting the clinic. People think that we are the filthiest people ... it was really difficult to accept that I have TB.

Female: If people can see you carrying your [treatment] card, they will start to gossip about you. I have once overheard someone saying, 'Look at that beautiful girl who is carrying a TB card'. I used to conceal the card in a brown envelope.

Male: Ever since I have been diagnosed with TB, my life has turned upside down. My wife once packed all her belongings because she told me I am dishonest about my status. She strongly believed that I know I am infected with AIDS and not TB. Even if we can go now

to my place, you will detect that things are not OK between us ...
I previously defaulted but realised it is not going to help.

It is evident that certain perceptions about TB not only contribute to non-adherence, but also have the potential to discourage prospective patients from taking anti-TB drugs:

Female: There is a widespread perception in the community that the very same TB tablets cause AIDS ...

3.5 Patient behaviour

It is interesting to note that participants did not only see factors outside their control as leading to non-adherence. Alcohol abuse by TB patients, together with hours of clinic operation, were perceived to be the most common reasons for non-adherence and treatment interruption:

Male: The clinic operation time is a hindrance. How would someone who starts drinking early in the morning visit the clinic? Some patients consume alcohol daily. They would rather decide to interrupt their treatment, rather than discarding their drinking habit.

Female: It is the third time that I am sick with TB. I used to drink non-stop, from early in the morning till sunset ... This went on for three months. Alcohol is really a big problem ...

Further, many participants mentioned the harm alcohol does to the body. They explained that people who consume excessive amounts of alcohol usually do not eat well. This weakens the body, which could lead to other diseases. One participant said:

Male: If you do not eat, you give TB the power. If you eat well, it will not affect you that badly. I know because I have also experienced the negative impact of alcohol on one's health.

The majority of the participants said that pure stubbornness is the only reason why patients do not adhere to their treatment regimen. Some participants indicated that in order for patients to adhere, they need economic resources and certain personal resources, such as feeling able to focus exclusively on the treatment plan.

3.6 Health services factors

The following health services factors were mentioned as encouraging non-adherence: the non-availability of TB medication at some clinics, the attitude of health care providers, and the delay in diagnosis. Participants commented:

Female: The biggest problem at this clinic is the non-availability of treatment. There was a time when we did not receive treatment for two weeks [showing card]. I marked my card in red in order to remember the days we did not get treatment. I really wanted to make sure that my card was not being completed for treatment that I did not receive. What are the stock control measures at this place? We are being slowly murdered. [On inspection the card indicated that the patient had not received medication for 13 days].

Male: Sometimes one finds it difficult to wake up because of tiredness. When you send someone to collect your medication at the clinic, there is no co-operation from the nurses. They insist that one has to come to the clinic irrespective of your circumstances ... Inasmuch as we understand that we had to come to the clinic, our physical strength prevents us to do [*sic*] this at times ...

Participants reported having different experiences of the attitude of health care providers:

Male: The attitude of nurses is also not helping the situation. When you are in the waiting room, you will wait and wait and wait. Sometimes they are just sitting and chatting. The fewer they are in the consultation room, the better. They also have a tendency to harass TB patients in front of others.

Male: I have been treated well since I started my treatment at this clinic. The nurses are very helpful. They treat us like their own children ...

In terms of late diagnosis as a factor encouraging non-adherence, participants reported that they would go three or four times to a doctor before being diagnosed with flu. Some participants indicated that doctors did not often inform them about the diagnosis: "They are only interested in giving us injections". More sadly, it was evident that some of the participants had consulted various conventional health care providers before being diagnosed with TB:

Female: I went to three different doctors. The first one told me I have flu. The symptoms persisted, and after three days, I returned to him. He gave me another injection. The second one did not even bother to tell me what the problem was ... I vomited all the medication. It was only after the last doctor at the clinic sent me for X-

rays, that I was diagnosed with TB ... The problem is you have to pay R80.00 each time you consult a doctor.

3.7 What is needed to improve adherence?

In response to the question of what would improve adherence, participants mentioned information provision, education and altering the treatment plan. In particular, the majority of respondents felt that TB health education campaigns should be provided from the same "platform" as HIV/AIDS. They stressed that such campaigns should focus on all members of society, and not only on TB patients. They also felt that educational programmes, both in and out of school, could influence pupils and students through the curriculum. They further indicated that former TB patients could be used as ambassadors of TB control initiatives, being invited to give speeches at church and community gatherings.

The participants concluded that the treatment plan is too long. There was also a strong feeling that more effective drugs, with fewer side-effects, should be provided. The groups considered the services provided by DOT supporters to be limited to the provision of medication. They believed that it would be beneficial to delegate more responsibility (for the provision of information and health education) to DOT supporters.

4. Discussion

Increased adherence is one of the main goals of any TB programme, including the South African NTCP. Internationally, a range of strategies has been employed to improve adherence. Some of these are aimed at changing the behaviour of health staff, eg by training, motivation and supervision. Other strategies, in turn, are aimed at the patient, eg education, reminders and prompts for attendance, financial incentives, supervision of tablet-taking and tracing defaulters (Volmink & Garner 1997). Results from the quantitative and qualitative research reported here suggest that several impediments still need to be addressed in order to achieve this objective, in terms of both provider- and patient-related barriers to adherence. These impediments present a potential invitation for health care authorities, managers

and health care providers to play a greater role in the management and treatment of TB patients. However, for rates of adherence to improve in practice, patients' views and any barriers to adherence need to be understood, in order to implement appropriate interventions.

The evidence points to the role played by the socio-economic circumstances of patients in adherence. In fact, early research reported that the strongest predictors of adherence were economic rather than cognitive or cultural factors (Farmer 1997), a point of view shared by Jaramillo (1999). Patients with access to more financial support while on treatment were more likely to adhere to treatment, as were patients who were generally able to eat before taking their tablets. This raises the question of whether incentives and enablers in the form of food coupons or bus tokens could be employed to overcome certain impediments to adherence (Buchanan 1997), especially for patients from poor communities. According to Jaramillo (1999), poverty alleviation can play an important role in achieving tuberculosis control in developing countries.

Other economic factors can also act as impediments to adherence. The quantitative evidence shows that the likelihood of adherence is lower among patients who are employed while on treatment or who experience a significant loss of income due to treatment. Thorson (2001) likewise reported that male patients, in particular, were likely to interrupt their treatment due to work commitments. (Our own results also found female patients more likely to adhere to treatment than male patients, although gender was not a significant determinant of adherence when the effect of other variables was controlling).

In addition, structural economic factors also seem to play a negative role in adherence, in particular the migrant labour system and internal migration. Patients who were away from home during the course of their treatment or from households including higher numbers of migrant workers were less likely to adhere to treatment (ie to interrupt their treatment for two months or longer). According to Kok *et al* (2002), the internal migration patterns operating in South Africa in 1996 continued to mirror those of the apartheid era. Furthermore, people who have been migrants are likely to continue to migrate, given that "migration becomes institutionalised through the formation and elaboration of networks" (Kok *et al* 2003: 26). This

highlights the need to devise appropriate strategies for the successful transfer of migrating patients from one health facility to another, so as to ensure that they complete their treatment.

In the qualitative evidence reported here, TB patients were asked to reflect on their own experiences. Most participants knew that TB is a contagious disease, but some had an understanding of it which deviated from biomedical knowledge. The mass media, nurses, family members and friends were identified as their main sources of information on TB. However, the majority of the participants were unaware of any health education activities concerning the disease in their area. Metcalf (1991: 1) already noted more than a decade ago that although TB is contagious, it has not yet ignited the same public alarm as acute diseases such as HIV/AIDS.

Considering the profound effect that TB has on patients in terms of effort and time — with some suffering for more than five years — a key feature of the disease that became evident in this study is the irritation that goes with the treatment. The side-effects described by participants included bodily pain, pimples and sores. Some study results suggest that adherence rates may be adversely affected by unreported side effects rather than by the amount of medication prescribed. A study by Grant *et al* (2003) revealed that unreported side effects and a lack of confidence in the immediate or future benefits of treatment were significant predictors of sub-optimal adherence. It was concluded that health care providers should not hesitate to prescribe multiple agents in order to achieve adequate control of diseases such as hypertension.

The pressing question with regard to TB treatment is: will patients who have reported severe side-effects continue to take their medication? Gregson (2002: 461) states that, generally, treatments are abandoned not because they do not work well enough, but because they are “too much trouble to take”. Imagine having to take TB treatment for six months, mostly on an empty stomach, as it is the case for many TB sufferers in South Africa. Clearly, adherence will be poor, because most patients will choose to stay away from the clinic, rather than taking tablets which lead to even worse hunger spells. The studies of Schiffman & Zervakis’ (Doctors Guide 2000) on the taste of drugs found that the innate desire to derive pleasure from tasting

food is so strong that people sometimes stop taking life-saving medication simply because it tastes bad or ruins the flavour of otherwise enjoyable foods.

A study by Herman *et al* (2000: 74-5) showed that as treatment regimens become more complex (swallowing between one and four large tablets daily for six to eight months), it becomes more difficult for patients to adhere to them. Some patients may fear that they will develop a psychological or physical dependence on the medication. In such instances health care providers may be viewed as unhelpful and, as Kane (2002:) states, as obstacles to a cure. The revelation that patients did not receive their medication for almost two weeks, because it was not available at the clinics, gives cause for grave concern. Not only the lives of already suffering patients were endangered, but such a failure is also a huge blow to the government's commitment to providing an uninterrupted supply of quality anti-TB drugs along with sustained TB control.

Another notable finding was the roles played by stigma and by social support, which featured in both the quantitative and qualitative evidence as significant determinants of non-adherence. Studies from the Philippines (Nichter 1994) and Vietnam (Johansson *et al* 1996; Long *et al* 2001) indicate that adherence is associated with social support from family or others. The present study has shown that participants' families sometimes isolate them. One common form of isolation, which was also noted by Long *et al* (2001), is the separation of cooking utensils and bowls. The roles of stigma and social support in influencing the outcomes of treatment for TB has been emphasised by Liefoghe (2000) and Thorson (2001). According to Love (2002: 12), patients who live with supportive family members are more likely to complete treatment. The present study has also shown the need for a constructive family environment, which may increase the amount of support and guidance available to patients. Stigmatisation is also reinforced by the required daily visits to primary health care clinics. Liefoghe *et al* (1995), Long (2000) and Demissie *et al* (2003) have also shown that the community tends to isolate many patients and that adherence is affected by societal attitudes towards the disease. Demissie *et al* (2003: 2009) report further that the TB club approach to the delivery of treatment in rural North Ethiopia has had a "sig-

nificant impact on adherence to treatment and in building positive attitudes and practice in the community regarding TB".⁸ Based on the qualitative evidence, the association of TB with HIV/AIDS appears to be the main source of stigmatisation. The physical appearance of TB patients (slim body), which resemble that of AIDS patients, further compounds stigmatisation. With high rates (52%) of TB-HIV co-infection in the Free State (SATCI 2000: 14), the associated stigma may lead to adverse treatment outcomes.

Participants in focus group discussions also perceived the illness behaviour of patients as a factor encouraging non-adherence. Although it is commonly known that poverty is an important risk factor for TB globally (Long *et al* 2001:74), the present study has shown that TB patients often abuse alcohol, which impedes their treatment adherence. Evidence of this has also been reported by Pablos-Méndez (1997), Malotte *et al* (2001) and Hovell *et al* (2003). In fact, the South African Demographic and Health Survey of 1998 (Dept of Health 2002b: 238) indicates that 28% (n=8.3 million) of South Africans aged 15 years and older consume alcohol.

The health care provider-patient relationship has been shown to be an important determinant of adherence (Zwarenstein *et al* 1998; Vermeire *et al* 2001; Jaiswal *et al* 2003). Health care providers at clinics are an essential link between the programme and the patients, being responsible for providing treatment and maintaining registers. From the point of view of control, informed, motivated frontline health workers may contribute positively to treatment outcomes. Conversely, demotivated or ill-informed health workers may encourage patients to interrupt treatment and thus to further transmission of TB in affected communities. This study has revealed some important dysfunctional aspects of the attitudes of health care providers to TB

8 TB patients from a single village are organised into "clubs" of 3 to 10 patients by the local health-care worker. The members of each TB club have the same clinic dates for follow-up. The leader of the club ensures that all members attend the TB clinic and informs the clinic staff about absent members. In addition, TB clubs have both regular and ad hoc meetings at which they support each other and share their experiences of the disease with fellow members. The leaders of these clubs also solicit the help of community leaders to encourage patients to complete their treatment (Demissie *et al* 2003: 2012).

patients. According to Stein (2000), non-adherence may result from differing degrees of interest or expectation between the patient and the health care provider. Misperceptions or dissatisfaction with the relationship between the patient and the health care provider may also cause non-adherence.

The evidence presented in this study also reinforces the importance of the traditional key component of DOTS — the direct supervision of tablet-taking. Patients whose tablet-taking was supervised were more likely to adhere to treatment, all other things being equal. Supervised tablet-taking will thus remain a key component of the DOTS strategy to improve adherence and cure rates, given the increasing evidence of the role of such supervision in enhancing adherence (Jaramillo 1999; Chaisson *et al* 2001).

Finally, and perhaps most importantly, the quantitative evidence shows that patients undergoing re-treatments are less likely to adhere to treatment than those undertaking it for the first time, thus highlighting the role of non-adherence in exacerbating the MDR problem in South Africa. Hence, particular care needs to be taken to address the impediments to adherence mentioned above among patients undergoing re-treatment.

5. Conclusion

Non-adherence to treatment regimens poses a major challenge to TB patients, their families and the health care community. It results in poor treatment outcomes and increased costs. The evidence reported here highlights the fact that adherence is a function not only of the quality and availability of health care, but also of a variety of personal, socio-economic, infrastructural and community-related factors. Apart from alleviating poverty in an attempt to break down the socio-economic barriers to adherence, raising public awareness about the importance of making the lifestyle modifications which can prevent TB, and organising widespread dissemination of accurate information about the causes, prevention and health management of the disease may counter the myths and misconceptions surrounding it. In order to enhance patient adherence rates, TB control programmes in resource-poor settings such as the Free State province need to take cognisance

of the dysfunctional behaviour of health care providers, close contacts and TB patients. Patients should be encouraged to report the difficulties they face, rather than being afraid of being victimised. In this regard, the training of health care providers involved with TB at the primary level should incorporate aspects relating to patient behaviour.

This study has revealed some important factors which encourage non-adherence. Regarding the attitude of health care providers, expanded training in communication skills and optimal patient care, according to treatment guidelines, are needed, particularly in the light of the emergence of multi-drug-resistance TB. Such training should focus not only on nurses, but also on doctors. It is highly unlikely that effective short-term chemotherapy will be widely available in South Africa, or in the world, in the next ten years. Thus, behavioural change remains a viable means of improving treatment adherence and limiting the spread of infection. Studies around the world have shown that behavioural interventions such as health education can bring about a reduction in high-risk behaviour. The continuing increase in TB infection rates in South Africa suggests that health education, dissemination of information and attempts at communication have been either limited or not effective on a broad enough scale to achieve significant public impact. It is therefore recommended that current education programmes on TB should be revised by the South African Tuberculosis Control Programme in order to overcome the most important barriers relating to treatment adherence. More sustained health education campaigns should also be directed towards patients, their close contacts, health care providers and the community at large.

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Appendix 1: Descriptive statistics for adherent and non-adherent patients

Variable	Sample (n)	Mean	Standard Error	Confidence interval (95%)
Adherence (yes=1, no=0)	184	0.940	0.018	0.906 - 0.975
Household size	184	4.337	0.158	4.025 - 4.648
Gender (male=1, female=2)	184	1.451	0.037	1.379 - 1.524
Age	184	38.022	0.832	36.38 - 39.66
Marital status (married=1, single=2)	184	1.614	0.036	1.543 - 1.685
Years of education	184	7.837	0.251	7.342 - 8.332
Monthly household income (Rand)	184	1 213.641	75.079	1 065 - 1 361
Financial support received while on treatment (Rand)	184	467.891	56.212	356.9 - 578.7
Access to medical aid (yes=1, no=0)	183	0.049	0.016	0.018 - 0.081
Re-treatment patient (yes=1, no=0)	184	0.310	0.034	0.242 - 0.377
Paid to access treatment (yes=1, no=0)	184	0.011	0.008	-0.004 - 0.026
Main breadwinner (yes=1, no=0)	184	0.375	0.036	0.304 - 0.446
Currently employed (yes=1, no=0)	184	0.342	0.035	0.273 - 0.412
Previously employed (yes=1, no=0)	184	0.147	0.026	0.095 - 0.198
Income loss due to illness (Rand)	184	2 047.120	590.654	881.7 - 3 212.4
Travel time to clinic (minutes)	179	25.626	1.642	22.38 - 28.86
Away from home during treatment (yes=1, no=0)	183	0.098	0.022	0.055 - 0.142
Number of migrants in household	180	0.122	0.026	0.071 - 0.173
Ever in jail (yes=1, no=0)	184	0.109	0.023	0.063 - 0.154
Able to eat before taking tablets (yes=1, no=0)	183	0.918	0.020	0.878 - 0.958
Access to piped water in dwelling (yes=1, no=0)	184	0.826	0.028	0.771 - 0.881
Tablet-taking supervised (yes=1, no=0)	182	0.912	0.021	0.871 - 0.954
Side-effects experienced (yes=1, no=0)	184	0.995	0.005	0.984 - 1.005
Crowding index	183	2.265	0.087	2.094 - 2.437
Stigma index	184	0.255	0.043	0.171 - 0.339
Tuberculosis knowledge index	184	5.174	0.068	5.039 - 5.308
Service quality index	184	1.630	0.047	1.538 - 1.723

Notes: The *crowding index* was calculated by dividing the average household size by the number of rooms in which to sleep. The *stigma index* represents the number of times the patient indicated that the general reaction of his spouse/partner, family members, friends, community members, or neighbours, employer and co-workers, on learning about his/her illness, was negative or constituted rejection. The *tuberculosis knowledge index* represents the number of times the patient disagreed or strongly disagreed with the statement that one can stop taking TB medication when one feels better as well as the number of times the patient agreed or strongly agreed with the statements that (a) someone with TB who is not on treatment can infect other people, (b) TB can be cured, (c) TB affects men, women and children, (d) people living with a TB patient also need to be examined, (e) TB could be a symptom of HIV/AIDS. The *service quality index* represents the average score out of 5 on six questions related to the satisfaction of the patient with (a) the distance to the clinic, (b) the waiting time before he/she was helped, (c) the general appearance of the clinic, (d) the support or friendliness of clinic staff, (e) the amount of time health care workers spent with the patient during his/her consultation, and (f) the examination of illness.

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