The limits to patient compliance with directly observed therapy for tuberculosis: a socio-medical study in Pakistan

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SUMMARY

Complying with the prescriptions of the directly observed therapy (DOT), one of the components of the Global Tuberculosis Programme of the WHO, is problematic for many patients. The factors leading to patient (non-) compliance with DOT are placed in a structural equation model.

The study is based on a survey carried out in one general hospital in the Punjab province of Pakistan, amongst all sputum positive pulmonary TB patients (n = 621) who arrived at the TB unit from September 1997 to October 1998.

The tested sequence of manifest variables and latent constructs shows that the social stratification perspective has to be extended by the stigmatization perspective. The advantages of universally applying DOT will increase even further when the latter perspective is involved in the analysis of non-compliance. There is a real danger that the patients reached by selective DOT will be stigmatized even more. Copyright © 2002 John Wiley & Sons, Ltd.

KEY WORDS: compliance; DOTS; stigmatization; TB control; Pakistan

INTRODUCTION

Persons who develop tuberculosis have to conquer not only a disease but overcome deeply entrenched prejudices. Tuberculosis is a chronic infectious disease caused by the tubercle bacillus. However, tuberculosis has never been merely a biological phenomenon. When the first campaigns for eradicating tuberculosis were set up in

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the industrialized West in the 19th century, TB was primarily regarded as a social disease. Tuberculosis has become an increasing problem around the world in recent years. The WHO Report on the Global Tuberculosis Epidemic warned about the gravity of the epidemic: between 2.5 and 3.5 million deaths each year, making a total of 30 million deaths during the 1990s or one quarter of all preventable adult deaths (WHO, 1998; Reichman and Tanne, 2001). It simultaneously alerts us to the danger that stigma sends the TB epidemic underground. The present study examines social barriers and health beliefs that influence TB patients’ compliance with their treatment in Pakistan.

BACKGROUND

The ‘Directly Observed Treatment, Short-course’ (or DOTS) strategy is a multifaceted intervention and not a simple strategy consisting of watching the ingestion of medication. This strategy acts as the cornerstone of the Global TB Programme of the World Health Organization and is generally considered to be one of the most rapidly expanding and successful health interventions of the 1990s (Volmink and Garner, 1997; WHO, 1997). It seeks first and foremost to implement a standardized short-course chemotherapy using regimens of 6–8 months, for at least all confirmed smear positive cases. Good case management includes directly observed therapy (DOT) during the intensive phase for all new sputum smear positive cases, the continuation phase of rifampicin-containing regimens and the whole retreatment regimen. DOT is a practical method for supporting the patient and the family to ensure that the patient adheres to treatment and successfully completes treatment. In addition to applying DOT, government commitment to sustained TB control, sputum smear microscopy to detect infectious cases, a regular, uninterrupted, supply of quality anti-TB drugs and a monitoring and reporting system to evaluate treatment outcomes, is widely regarded as the fundamental basis of the DOTS strategy (Raviglione et al., 1995; Raviglione, 2001; Porter and Ogden, 1997; Small and Fujiwara, 2001; Pungrassami et al., 2002).

A medical regimen is imposed to ensure optimum progression of illness behaviour, i.e. to ensure that the patient recovers as soon as possible. When patients succeed in conforming their illness behaviour to the medical regimen, they are compliant. Patient compliance can assume many forms, ranging from demands for cooperation in diagnostic procedures despite anxiety and pain, through taking drugs on schedule and otherwise following a prescribed regimen, to abandonment of social and familial obligations to the needs of the health system (Hyde, 1988). Recent literature contains a number of synonyms for the term ‘compliance’ (Volmink and Garner, 1997). Some authors now use the term ‘adherence’ to emphasize the fact that the following of a medical regimen is the independent choice of the patient. Sometimes the term ‘concordance’ is used to stress the active exchange of information, negotiation and spirit of cooperation in the relationship between illness behaviour and medical regimen. Since the treatment of tuberculosis does not always imply an independent choice of the patient and an active exchange of information between patient and health professional cannot be taken for granted, we prefer the
term ‘compliance’ in this context. As long as patients act as they should and conform to therapeutic prescriptions, they can continue to function socially without any problems. However, as soon as the threshold of acceptable norms is crossed, deviant behaviour replaces legitimate illness behaviour and society’s integrative capacities gradually disappear.

There are many ways to deviate from the medical regimen prescribed by the DOTS strategy. People can ignore TB symptoms and fail to seek treatment. Treatment can be postponed until the disease has become very severe indeed. However, there are also other, less radical ways to be non-compliant and to reduce the likelihood of a cure. It is quite easy, for example, to forget to go to the doctor or be careless about keeping appointments. Some people adapt medication to suit themselves and simplify the treatment plan. The supervision, which forms an intrinsic part of the DOTS strategy, can be changed coincidentally or systematically.

According to Bayer and Wilkinson (1995), it is essential to take into account the socio-cultural context in which this dysfunctional behaviour is displayed. Not everyone feels strongly about missing an appointment, adjusting medication or avoiding supervision. Patients may have to contend with side-effects, such as nausea and sleepiness. Many fail to take their medicine on time because they are either homeless or mentally ill, as a result of alcohol or drug abuse, or because they are refugees. The risk of non-compliance remains even if intermittent treatment increases the patient’s comfort. According to Weber (1996), the main reason for failing to keep up the regimen is quite clear: patients who commence treatment become non-infectious and already start to feel better after a few weeks. As a result, they tend to weigh the costs of continuing treatment and opportunity costs differently, more in favour of short-term interests, and they no longer feel the need to endure the discomforts of the treatment, thereby increasing the growth of multidrug-resistant TB, so that treatment nearly always fails and patients almost certainly suffer a relapse of the disease.

Another important reason for the non-compliant behaviour of TB patients is related to their stigmatization (Liefooghe et al., 1995; Liefooghe et al., 1999; Meulemans, 2001). Stigmatization occurs when people are given a negative social label that identifies them as deviant, not because their behaviour violates norms but because they have personal or social characteristics that lead others to exclude them (Mason et al., 2001; Johnson, 1995). Goffman (1990) distinguished three different types of stigma. First there are abominations of the body, the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs and dishonesty. Finally, there are the tribal stigmas of race, nation and religion, these being stigmas that can be transmitted through lineage and equally contaminate all members of a family. These three types of stigma can be said to occur in the medical sphere. Examples are the tangible social tensions surrounding TB as a result of its infectiousness, making everyone at risk, the coughing fits, sweat attacks, phlegm, and the emaciated ‘skin and bone’ body. The contagiousness of TB is an important factor for fear and thus stigmatization, because having a TB patient around can potentially destroy many more people in the family as they catch TB as well. However, although tuberculosis patients are stigmatized by their disease, it does not mean there are no other apparent sources of stigmatization. The power of the concept ‘stigmatization'
is such that it targets all social spheres where negative social labels can be assigned to discredit behaviour and turn people into outcasts. The stigmatization caused by the disease immediately breaks out of the medical sphere and is influenced by all areas of life from that point on. Research, furthermore, reveals that stigmatization even continues to complicate the lives of the stigmatized even as treatment improves their symptoms and functioning. The stigma does not disappear with the disease. It is perpetuated by other sources (Fife and Wright, 2000; Link et al., 1997). In this study the factors leading to patient (non-) compliance with TB treatment will be integrated into a model and we will examine the way these factors affect the behaviour of TB patients attending a general hospital in the Punjab province of Pakistan.

SETTING

The setting for this study was the Bethania Hospital in Sialkot, Pakistan (Figure 1). The hospital is situated in the Punjab province at the east of the Islamabad–Lahore axis. Since its founding in 1964 by Flemish Capuchin Fathers as a mission hospital, Bethania Hospital has made an enormous effort to detect and treat tuberculosis patients from the region. It is currently a 215-bed front-line and referral hospital, providing medical and surgical services. One hundred beds are reserved for a specialized TB unit. It has a ward for men and a ward for women, its own outpatient department, sputum laboratory, dispensary and registration unit. About 75% of patients are recruited from a catchment area of 50 km around the centre of the city of Sialkot.

The National Tuberculosis Control Programme in Pakistan (Directorate of Tuberculosis Control, 1995) proposes short-course chemotherapy for all sputum positive cases for a duration of 8 months. The guidelines distinguish three main categories of patients: category I patients are new AFB smear positive cases; category II refers to smear positive relapses and failures after 8 months short-course chemotherapy; while category III refers to sputum smear negative and extra-pulmonary cases, and to children who cannot produce sputum. The guidelines recommend...
for category I patients a daily treatment of four drugs during the intensive phase of 2 months (HRZE), followed by a 6 month daily intake of two drugs (HT).\(^1\) Given the limited availability of thioacetazone in Pakistan, many centres replace it by ethambutol or streptomycin. The recommended treatment schedule for category II patients contains five drugs during the initial phase (HRZES), extends the initial phase with 1 month (HRZE) and adds rifampicin during the whole duration of the continuation phase (HRT). Category III patients receive three drugs daily during the first 2 months (HRZ) followed by two drugs daily for the next 6 months (HT). Sometimes ethambutol is substituted for thioacetazone. Although efforts have been made lately to disseminate and apply these guidelines more broadly, Pakistan is still notorious for its poor TB control, absence of a policy supporting the WHO DOTS strategy, much malpractice in private practice and a poorly accessible low-quality public health care system (Khan et al., 2000; Ghaffar et al., 2000; Uplekar et al., 2001; Sen and Sen, 1998; Zaidi, 1999; Zaidi, 2001; Thaver et al., 1998; Green et al., 1997).

In the treatment regimen applied in Bethania Hospital, hospitalization is emphasized during the intensive phase of treatment. Ambulatory patients had bi-monthly follow-up visits during the intensive phase of 2 months. All patients were treated on an ambulatory basis during the continuation phase and had monthly appointments to collect their drugs and for a check-up. Patients living within 15 km of the hospital were visited by the field worker if they were late for more than 2 days. Those residing beyond this distance were invited by a letter to visit the hospital to collect their drugs.

**METHODOLOGY**

**Sampling procedure**

The study is based on face-to-face interviews carried out at Bethania Hospital, amongst all sputum positive pulmonary TB patients \(n = 621\) who presented themselves at the TB unit from September 1997 to October 1998. The patients were interviewed at three fixed moments: at the start of the treatment, after 1 month, after 2 months and followed-up until the end of the treatment. Every interview was performed by a social worker belonging to a team of four. Since the duration of the treatment was 8 months, the last patients finished their treatment by the end of June 1999. During the interviews, based on questionnaires consisting predominantly of closed questions and a small number of open questions, information was gathered about the demographical and socio-economic profile of the patients, social support provided by different networks, the patients’ key values, their knowledge of TB and their perception of the curability of the disease, stigmatization and compliance.

**Proposed model**

The proposed model could be described as a two-step model. First, an explanation is sought for the ways in which TB patients are stigmatized. In our model (Figure 2) we

\(^1\)E, ethambutol; H, isoniazid; R, rifampicin; S, streptomycin; T, thiacetazone; Z, pyrazinamid.
Outline four variables based on past research. First, we hypothesize that older patients are more stigmatized than younger ones, and second that women are more stigmatized than men (Connolly and Nunn, 1996). Third, we include a latent construct ‘support from family’. The basic hypothesis is that a decrease of support from a patient’s family will be associated with an increase in stigmatization. Lastly, the fourth factor is a knowledge-related construct. It is assumed that the less one agrees that TB is a curable disease, the more one will be stigmatized.

The second step in the model is the causal explanation of compliance (Burman et al., 1997). The model distinguishes three factors. The first factor, i.e. intake medicine, concerns compliance to therapeutic standards solely with regard to the use of medicine. This factor divides patients into two groups after answering the question ‘Have you ever, since the last visit, forgotten to take your medicines, even for one day?’ with a yes or no. The second factor, i.e. regularity of treatment, refers to the regularity with which patients comply with their obligations in the successive stages of their treatment. This factor is measured by adding the number of missed (late for more than 2 days) appointments with a health professional during the first 2 months of treatment. Patients are classified as irregular if they have missed at least one appointment. The third factor, i.e. the duration of therapy, refers to the potential to persevere and complete these stages until full recovery. Patients are classified into three categories to express the level of deviation from the 8 months norm. Defaulters lie under the norm since they interrupted their treatment. Patients whose treatment was compulsorily extended because their therapy failed, are classed over the norm. Those who adhered to the therapy for the full 8 months are the norm.

The outcome variable compliance is viewed from a dichotomous viewpoint. Compliant patients completed their therapy in full and as a general rule also underwent, at the end of treatment, a test confirming them as sputum smear negative. Non-compliant patients did not complete their therapy so a sputum test was not carried out. When implementing DOT, these variables become very important, because the system explicitly requires the strict intake of medicine, regular visits to health
professionals and an effort sustained over many months. It would be interesting to
examine the other factors affecting compliance such as the quality of interaction
between patients and staff. It is important to include this kind of interaction in the
study when comparing, for example, the effect of DOT on the success of tuberculosis
treatment with that of self-supervised treatment. Although our research focused on
compliance with DOT, research designs should also be drawn up for self-supervised
patients (Zwarenstein et al., 1998).

Manifest variables. The model to be estimated is a non-standard model (Hatcher,
1994: 423). It consists of several manifest variables that account for a part of the
structural portion of the model. In other words, we assume that these manifest
variables are perfect measures for the constructs they express. Before we turn our
attention to the latent constructs in the model, we first want to give an overview of its
manifest variables.

There are three exogenous manifest variables. Sex and age are measured in a
straightforward way: men and women on the one hand, and a patient’s age expressed
in years on the other. Occupation is measured on an ordinal scale. All occupations
are placed on a social stratification scale thus allowing them to be situated on a
higher or lower societal level. At the lower range of the scale are housewives,
unskilled and skilled workers. In the middle range are cottage industry workers,
tenant farmers, civil servants, white-collar workers and small business owners.
Finally, at the higher end of the scale are land-owning farmers and large business
owners. The ordinal character of the scale might pose some problems since struc-
tural equation modelling requires interval measurement. However, we included
the occupations scale for two reasons. The first is theoretical: we suspected that
occupation would be an important determinant in the model we proposed. Second,
the scale was developed in Pakistan and fits the specific situation very well, however,
we were not able to prove equal and exact distances in the scale.

Latent constructs. In the model we used four latent constructs. Before discussing
the measurement model in more detail, we concentrated on the different items for
each endogenous construct. The family is an important factor in the social
environment of the TB patient. Therefore, we tried to include the support of the
family within the model. Since most patients were married (62%), we had to deal
with both the family and the family-in-law.

Support from the family-in-law was not included extensively in the research. We
could only include a latent factor ‘support from family-in-law’ based on two indi-
cator variables. We are aware that the latent construct is not firmly measured in this
way. However, the results of the measurement model (Table 1) are acceptable (scale
composite reliability, $\rho_c = 0.67$). The indicator variables from the construct are mea-
sured on a five-point scale (no influence at all–strong influence).

The second latent construct is the support a patient receives from his own family
(scale composite reliability, $\rho_c = 0.52$). This construct is based on three indicator
variables, the first two rated on a five-point scale (strongly discourage–strongly
encourage), the third asking about financial support (No, Yes).
<table>
<thead>
<tr>
<th>Itema</th>
<th>Item description summary</th>
<th>Standardized loading</th>
<th>$t$-value</th>
<th>Variances</th>
<th>Residual variances</th>
<th>$R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support family-in-law ($\rho_c = 0.67$)</td>
<td></td>
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<td></td>
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<tr>
<td>Famlaw1</td>
<td>How much will the opinion of your family-in-law influence your decision to finish or not the whole treatment? (First time)</td>
<td>0.74</td>
<td>10.26</td>
<td>1.46</td>
<td>1.43</td>
<td>0.50</td>
</tr>
<tr>
<td>Famlaw2</td>
<td>How much will the opinion of your family-in-law influence your decision to finish or not the whole treatment? (Second time)</td>
<td>0.69</td>
<td>9.96</td>
<td>1.36</td>
<td>1.46</td>
<td>0.52</td>
</tr>
<tr>
<td>Support family ($\rho_c = 0.52$)</td>
<td></td>
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<tr>
<td>Fam1</td>
<td>To what extent does your (own) family encourage or discourage you in taking daily your medicine (First time)</td>
<td>0.59</td>
<td>10.04</td>
<td>0.21</td>
<td>0.11</td>
<td>0.35</td>
</tr>
<tr>
<td>Fam2</td>
<td>To what extent does your (own) family encourage or discourage you in taking daily your medicine (Second time)</td>
<td>0.49</td>
<td>8.53</td>
<td>0.20</td>
<td>0.07</td>
<td>0.25</td>
</tr>
<tr>
<td>Fam3</td>
<td>Does your family support you financially for the cost of your treatment (transport/drugs/consultation fee/tests/...)?</td>
<td>0.45</td>
<td>7.98</td>
<td>0.07</td>
<td>0.02</td>
<td>0.19</td>
</tr>
<tr>
<td>Stigmatization ($\rho_c = 0.64$)</td>
<td></td>
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<tr>
<td>Stigma1</td>
<td>It is a disgrace for the family to have a family member with TB (First time)</td>
<td>0.58</td>
<td>11.29</td>
<td>2.29</td>
<td>1.17</td>
<td>0.34</td>
</tr>
<tr>
<td>Stigma2</td>
<td>It is a disgrace for the family to have a family member with TB (Second time)</td>
<td>0.72</td>
<td>13.82</td>
<td>1.69</td>
<td>1.68</td>
<td>0.50</td>
</tr>
<tr>
<td>Stigma3</td>
<td>Even your best friends sometimes desert you when you have an infectious disease, like TB (Second time)</td>
<td>0.52</td>
<td>10.12</td>
<td>2.27</td>
<td>0.92</td>
<td>0.29</td>
</tr>
<tr>
<td>Belief in curability of TB ($\rho_c = 0.68$)</td>
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</tr>
<tr>
<td>Belief1</td>
<td>TB is easy to cure</td>
<td>0.80</td>
<td>15.01</td>
<td>0.09</td>
<td>0.16</td>
<td>0.65</td>
</tr>
<tr>
<td>Belief2</td>
<td>TB is a common disease</td>
<td>0.55</td>
<td>10.99</td>
<td>0.16</td>
<td>0.07</td>
<td>0.30</td>
</tr>
<tr>
<td>Belief3</td>
<td>TB is a difficult disease and hard to cure</td>
<td>0.57</td>
<td>11.23</td>
<td>0.17</td>
<td>0.08</td>
<td>0.32</td>
</tr>
</tbody>
</table>

*Scale composite reliability: $\rho_c = [(\Sigma \lambda)^2 \cdot \text{var} (\zeta)] / [(\Sigma \lambda)^2 \cdot \text{var} (\zeta) + \Sigma \theta_i]$. (Bagozzi and Yi, 1988: 80). Fit statistics for measurement model of 11 indicators for four constructs: $\chi^2 (87) = 149.93$, $p = 0.00$; GFI = 0.97; RMR = 0.037; CFI = 0.96; PNFI = 0.52; NNFI = 0.93; RMSEA = 0.039.
A six-point scale (don’t agree at all–strongly agree) was used to rate seven statements about stigmatization both at the onset of the treatment (first time) and after 2 months’ treatment (second time). The statements were as follows:

1. If someone has TB, he/she avoids talking about it with other persons.
2. If a young person catches TB, he/she will experience the consequences for the rest of his/her life.
3. It is difficult to earn your living after recovering from TB.
4. People who are treated for TB, should talk to others about it.
5. After recovering from TB, everyone treats you in the same way as before.
6. It is a disgrace for the family to have a family member with TB.
7. Even your best friends sometimes desert you when you have an infectious disease, like TB.

Two of these statements were most appropriate for measuring latent construct stigmatization (scale composite reliability, $\rho_c = 0.64$), i.e. statement 6, which scored both at the onset of the treatment (first time) and after 2 months’ treatment (second time), and statement 7, scored after 2 months’ treatment (second time). Again, the family plays an important role in this construct. If a person agreed strongly with statement 6, it is assumed that he feels stigmatized by his family. The same goes for stigmatization by friends (statement 7). The respondents could indicate whether they agreed with the premise that very good friends left them because of their disease. The more they agreed, the more stigmatized they were.

The questionnaire also included questions which tested the TB patient’s medical knowledge, such as ‘Can you give the name of your disease?’, ‘Can you explain how a person gets TB?’, ‘How long do you believe it will take before you can have a normal life again?’ However, the explanatory value of these knowledge-related questions was very limited and became interesting only when questions were selected which expressed willingness to act as circumstances dictated. The last latent construct in the model therefore expresses the patient’s belief in the curability of the disease and in knowing how to handle its complexity (scale composite reliability, $\rho_c = 0.68$). It is a factor consisting of three indicator variables in which patients were asked to give their opinion on the complexity of their situation. All indicators were measured on a five-point scale (strongly disagree–strongly agree). The indicator statements dealt with the opinion on the curability of TB (TB is easy to cure), the commonness of TB (TB is a common disease) and with the difficulty of TB as a disease itself (TB is a difficult disease and hard to cure).

The measurement model shown in Table 1 provides a reasonable fit to the data. The $\chi^2$ test of exact fit is significant, where the objective is to achieve a non-significant $p$-value. However, Hatcher (1994: 289) indicates that a significant $\chi^2$ does not make the measurement model inadequate. The $\chi^2$ ratio shows that the ratio of the $\chi^2$ value and the degree of freedom is lower than 2 (1.7). This indicates that the $\chi^2$ test is within acceptable limits (Marsh et al., 1988). In terms of validity of the constructs, convergent validity is evidenced by the large and significant loadings of the items on their posited indicators. Further evidence of convergent validity is shown in Table 2. None of the correlations between the latent constructs are too high to challenge the convergent validity of the constructs.
Table 2 also indicates the discriminant validity, because the confidence interval (± 2 standard errors) around the correlation estimate between any two latent constructs never includes 1.0 (Anderson and Gerbing, 1988: 416). The Variance Extracted Test also shows the discriminant validity of our constructs. This test compares the variance extracted from two latent constructs with the square of the correlation between these two constructs (Fornell and Larcker, 1981). Discriminant validity is shown when the explained variance is greater than the squared correlation. We compared all pairs of factors and they all showed an acceptable variance extracted.

RESULTS

DESCRIPTION OF THE SAMPLE

The 621 patients were composed of 56.5% men and 43.5% women. Almost seven patients out of ten were younger than 40 (Table 3). As far as the nuclear family is concerned, 62% of patients were married, 31% were single, 5% widowed and 2%...
divorced. The skills-base of the patients was very low: more than half did not receive any formal education and the problem of illiteracy among older female patients was particularly acute.

During the first month of treatment, 80% of patients were hospitalized; during the second month this number dropped to only 48%. One out of three regarded hospitalization as problematic. This group’s dissatisfaction was rooted both in economic and medical causes: they had to contend with financial problems, absenteeism, transport costs, found themselves in dire straits, doctors were considered as incompetent, the drag of life in the ward, etc.

One-third of patients were the family breadwinner. Remarkably, only one-fifth of patients came from a household with more than three economically active persons, considering that roughly 70% of households consisted of six and often more members. The small number of economically active persons within the extended families cannot be attributed to a large number of children, because roughly half of the patients had fewer than three children and 20% of households did not have any children under 12.

Throughout the analysis, the operationalization of belief in the curability of the disease often appeared as a variable with serendipity characteristics. This variable measures the confidence sick people have in solving their problem situation. Trust enables the complexity of a social system to be reduced: without further ado, the sick can rely on their partner, family, health professionals etc., to channel their medical regimen. It is clear that precisely this confidence is shattered by the TB stigma, thereby reducing belief in the curability of TB in general.

Correctly assessing the treatment’s duration is characteristic for patients who strongly believe in the curability of their disease. However, this element of information is certainly not common knowledge when the treatment starts. Only one in three patients is aware that the treatment will last several months. However, after 1 month this number doubles and after 2 months it increases even further. We established that patients with the lowest socio-economic status often did not possess the most rudimentary, objective, medical knowledge. On the other hand, persons who did not mind regular check-ups, a strict regimen of medication and the costs involved, who thought it would all be worthwhile and were confident their treatment would result in a cure, were not necessarily more skilled or had a higher professional rank. It would seem that another phenomenon or mechanism is active as far as belief in the curability of TB is concerned. Thinking exclusively in terms of social stratification or ‘lumping techniques of rejection together as ways of dealing with marginal categories’ (Douglas, 1994: 85) does not suffice to gain a better understanding of the ideal treatment conditions.

Compliance has to be viewed not only from the social stratification perspective but also from the stigmatization perspective. At the onset of the treatment and after 2 months’ treatment seven statements concerning stigmatization (see Latent constructs) were presented to the patients. The statement most people (more than 80%) agreed with, both at the onset of the treatment and 2 months afterwards, was: ‘If someone has TB, he/she avoids talking about it with other persons’. If someone contracts TB it is best to keep quiet about it. The statement only a minority (one out of four patients) agreed with, both at the onset of the treatment and after 2
months, was: ‘It is difficult to earn your living after recovering from TB’. The fact that only very few regarded their TB problem in terms of income is related to the fact that during this life-threatening situation, the treatment has absolute priority and takes precedence over all other forms of need.

When the onset of the treatment is compared with the situation 2 months later, there are no shifts in the statement’s ranking order. Only two statements point to a possible evolution during the first 2 months, but they do not really disrupt the ranking order in any significant way. This refers to the statement ‘People who are treated for TB should talk to others about it’: 68% agreed at the onset of the treatment, and 78% after 2 months’ treatment. Whilst 54% agreed at the beginning of the treatment with the statement ‘Even your best friends sometimes desert you when you have an infectious disease, like TB’, this dropped to 45% after 2 months’ treatment.

To render more precise the model as a whole, we will also focus on the single frequency distribution of the three variables in the tail of the model, i.e. intake medicine, regularity of therapy and duration of therapy, and of the outcome variable compliance. After subtracting from the 621 patients the number of patients who have died (6%), those who have transferred to another treatment centre (2%), and the tiny group of patients where the treatment failed (1%), 563 patients remained. According to our definition, 77% of the latter group were compliant and 23% were non-compliant. The number of missed appointments was used to indicate the regularity of the treatment: 48% of patients did not miss a single appointment, 34% missed only one and 18% missed various appointments. As far as the duration of the therapy is concerned, the norm of 8 months is achieved by 55% of patients; the norm is not achieved (<8 months) by 33% of patients and the norm is exceeded (>8 months) by 12% of patients. Compared with the results of previous research (Lienfooghe et al., 1995; Meulemans, 2000) the compliance rate in Bethania Hospital is gradually evolving towards the WHO target to cure 85% of the sputum smear positive tuberculosis cases detected (Raviglione, 2001).

Comparison of the scores of compliant and non-compliant patients on the stigmatization statements, yields significant results: 72% of patients who agreed with the statement ‘It is a disgrace for the family to have a family member with TB’, were compliant. Those who did not agree had a compliance rate of 82%. Other statements produced similar findings, for example, ‘Even your best friends sometimes desert you when you have an infectious disease, like TB’. Those who agreed had a compliance rate of 83%. Those who did not had a compliance rate of 89%.

The social workers who conducted the interviews, did their utmost to keep the non-response rate as low as possible. Out of a total group of 621 patients selected for the study on the basis of the positive result of their sputum test, everyone participated in the first interview, i.e. the interview that took place when the treatment started. Their number dropped to 568 patients after 1 month (second interview) and to 528 after 2 months (third interview). Consequently, the chances of sample bias as a result of refusals has been kept to a minimum and can be attributed to the phenomenon of defaulting or the gradual outflow of patients initially included in the population. The amount of missing data for the variables used in the model is also limited.
Causal model

The proposed structural model in Figure 2 was tested by using conventional maximum likelihood estimation techniques. The model was fitted to the covariance matrix. In order to avoid the scale indeterminacy problem, each latent construct has one observed reference variable (which factor loading has been fixed at 1). It is recommended to use the observed variable that represents the latent construct the best (Jöreskog and Sörbom, 1993: 173). In our case this meant: Famlaw1 for the construct ‘Support from family-in-law’, Fam1 for the construct ‘Support family’, Stigma2 for the ‘Stigmatization’ construct and Belief1 for the ‘Belief in curability of TB’ construct. The model showed an acceptable fit. Again the $\chi^2$ test of exact fit is significant but the $\chi^2$ ratio is lower than two (0.7). All of the path coefficients are significant. Anderson and Gerbing (1988) recommend a $\chi^2$ difference test (CDT) in order to enhance the confidence in the structural part of the model. The CDT compares the structural model (which is a restricted theoretical model $M_T$) with an unconstrained alternative model ($M_U$). Since the relevant test statistics lead to a non-significant CDT, the restricted theoretical model $M_T$ (Figure 3) is preferred to the theoretical uncorrelated model $M_U$.

Since most of the test-statistics show an acceptable model, we can look at the results of the two-step model presented earlier. First, we tried to model the influences on the degree of stigmatization of a patient. These influences come from very different sources. The most important factors determining stigmatization are sex and age. Women feel more stigmatized than men. This also holds for older people. From the latent factors, support from the family is the most important. The more one receives support from one’s family, the less one is stigmatized. Another influence on stigmatization comes from belief in the curability of the TB construct. The more one believes that TB is curable, the less one is stigmatized. These results suggest that a robust position within society prevents a person from being stigmatized.

We then tried to link the stigmatization of the TB patients and their compliance with the directly observed therapy. The restricted theoretical model reveals that the influence of stigmatization on compliance only becomes clearly visible after

![Figure 3. Structural model of compliance and TB](image)

Significance (p-value): * = 0.05 ** = 0.01 *** = 0.001. Fit statistics for structural model: $\chi^2(122) = 175.26, p = 0.00; \text{GFI} = 0.96; \text{RMR} = 0.041; \text{CFI} = 0.97; \text{PNFI} = 0.72; \text{NNFI} = 0.96; \text{RMSEA} = 0.039$. 

introducing the regularity and the duration of the therapy as intervening variables. On closer examination, compliance would appear to be a rather hybrid concept, which can take various forms and has many depths. Compliance comes clearer to the fore when regularity and duration are separated. In the model, stigmatization with an effect of $-0.16$, affects regularity. Subsequently, regularity has a direct effect of 0.10 on compliance, but there is a stronger effect on duration and from there on compliance. The regularity and the duration of the therapy, therefore, form a tandem, which can be brought out of balance by stigmatization and no longer provides any guarantees for compliant behaviour.

DISCUSSION

The structural model (Figure 3) hinges on the latent construct of stigmatization. Stigmatization affects compliance through the tandem of regularity and duration of therapy. Persons who have been strongly stigmatized display more irregular illness behaviour and find it more problematic to see the difficult and troublesome treatment through to the end. In this respect it could be said that ending or interrupting the regimen is not due to a lack of organization. On the contrary, non-compliance is a mechanism which helps to relieve the pain of stigmatization, ensuring that for a while, the TB patient does not have to be ashamed and can take a break when the pressure of the medical regimen becomes too much to handle. According to Goffman’s terminology, deviating from the standards of the regimen can be regarded as a technique for controlling information. Deciding whether to confide in someone or keep quiet, to lie or be truthful, and to whom, how, when, and where, are tricks for stopping the exhausting process of blame by society. They are, in summary, strategies for managing a spoiled identity. In the model, three social conditions affect the degree of stigmatization of TB patients. These conditions have to be taken into account to reduce the limits to patient compliance with DOT.

The first condition is related to the demographical situation of the patient and comprises two variables from the exogenous set, i.e. gender and age. Female patients feel more stigmatized than male patients, and older patients feel more stigmatized than young persons. Both links are highly significant. As housewives or elderly members of the extended family, many have a low socio-economic status. For them, health is above all a question of physical strength. The loss of physical strength through tuberculosis, the fact that those who have been stricken with the disease can no longer perform hard labour, do the housekeeping, are no longer reproductive, etc., are important contributors to stigmatization. This is all the more so in the countryside, where external signs of vulnerability often do not suffice to relieve people from their normal social tasks in the family, the village and the community.

The second condition closely concerns the belief of TB patients in the curability of their disease. We already said earlier that this latent construct in our research displayed features of serendipity. It is distinct from strict measurements of rational medical knowledge because it emphasises praxis, i.e. implementing knowledge and acting on insights. The higher the socio-economic status, the greater the belief in the curability of TB. It is impossible to ignore the phenomenon of social stratification.
when analysing illness behaviour of TB patients. Patients with a higher professional rank, have great faith in the curability of their disease. The opposite also applies in equal measure: unemployment and illiteracy are conducive for non-compliant behaviour. There is a negative correlation between belief in the curability of TB and the degree of stigmatization. Persons who are convinced they will soon be cured and are capable of strictly following the medical regimen, will be less stigmatized.

The third condition is situated at the level of the social networks in which TB patients function. As a general rule it can be said that persons who receive more help from others are less likely to be stigmatized. Roughly six out of ten patients are married, and for married women, the family-in-law occupies the central position in their social network. The model established a negative relationship between support from blood relatives and support from the family-in-law. Solidarity with the family-in-law reduces solidarity with blood relatives. This applies both in general, but also in the specific framework of help and support in times of illness. The fear married female TB patients have of being abandoned by their husbands and of being unable to perform their domestic tasks, should not be underestimated. The model revealed that the TB patients who received the least support from their family were stigmatized the most. This recalls the relational nature of all types of stigmatization.

In Pakistani society, and particularly in many villages and settlements in the Punjab, social networks and stigmatization are inextricably linked and have an enormous influence on community life (Khan et al., 2000). The biraderi, the patriarchal network of kinship, forms the framework for social and community networks. Special events and rites of passage such as birth, the circumcision of a son, marriage and the death of an old person, strengthen this solidarity within the biraderi. The biraderi uses many other occasions to promote social and community networks, and illness is perhaps one of the most important (Eglar, 1960). When a daughter-in-law becomes seriously ill or is hospitalized, her children are either looked after by the other daughters of the house or are temporarily housed with other members of the biraderi. If the sole breadwinner of a household cannot work because he is seriously ill, his nearest relatives and other members of his biraderi provide moral, material and financial support. A TB patient who is admitted to hospital, will initially be visited by members of his biraderi. He will usually receive a few hundred rupees and the traditional fruit. However, as news about the nature of the illness spreads within the biraderi, contacts become less frequent. The negative correlation between family support and stigmatization in case of TB is deeply rooted in Pakistani society. Stigmatization erodes solidarity within social networks and seriously impairs the civic status of TB patients. ‘The sociological model of the treatment of infectious diseases’ (Douglas, 1994: 85) which is required to make the TB treatment accepted as a standard of care for all TB patients, can only be developed if we recognize these subtle social mechanisms.

The distinction made in social policy between universal and selective award of benefits, is also applied at the level of TB control. Weis (1997), for example, distinguished two treatment policies—universal DOT and selective DOT. Universal DOT is a policy in which it is intended that observed therapy be used for all patients, whereas in selective DOT patients are observed taking medications only if certain selection criteria are satisfied. The criteria may relate to predictive factors such as
social, housing or economic status; compliance parameters, or drug susceptibility patterns. Patients not meeting the selection criteria are placed on traditional self-administered regimens. When studying the determinants of non-adherence to anti-tuberculosis treatment, Dick (1999) wonders whether we use the appropriate research methodology. She believes it is particularly important to develop ‘a unified conceptual approach’ to adherence in treatment behaviour. In turn, Farmer (1997) argues that often, social scientists mar contributions to an understanding of TB by making ‘immodest claims of causality’, regarding its distribution and course. In our model, we focused on stigmatization because it can seriously damage public health in Pakistan, where taboos concerning tuberculosis are considerable. Other variables have not been included in the model because it would genuinely pose a risk of immodest claims of causality. Nevertheless, the model explicitly confirms the importance of the patient’s socio-economic status. Although much research will still be needed to develop a unified conceptual approach, one thing is already quite clear: economic and cultural determinants are sure to figure most prominently.

CONCLUSION

Patient compliance with the DOT regimen is an essential condition for combating the tuberculosis epidemic both in countries with high and low levels of welfare. For TB patients, compliance means regularly taking different medicines for a long period of time under medical supervision. Many methods are used to make illness behaviour as compliant as possible: mass media campaigns, health education and counselling, mobilization of family members, local liaison persons, volunteers or field workers as supervisors, ‘chaperones’ for women patients, mailed or telephone reminders of appointments and follow-up to missed appointments, selection of cues (meals, other daily rhythms, etc.) to mentally programme the intake of medicines, serving-up medicines in well-organized containers, financial incentives, etc.

In our research we established that compliance is thwarted by many conditions. Economic, demographical, geographical, psychological and socio-cultural factors have an impact on illness behaviour. It is almost impossible to identify which of these factors is decisive. Moreover, these factors differ according to the context of tuberculosis. Our empirical material illustrated that the study of compliance is impossible without the social stratification perspective. Someone who is economically vulnerable, unskilled and unemployed, poor and socially threatened, will also be the first to abandon the TB regimen. A low socio-economic status is an important predictor of non-compliance and is therefore often used as a criterion for the selective application of DOT.

Furthermore, not only the social stratification perspective, but also the stigmatization perspective increase insight into the mechanisms of rejection of norms and non-compliance of TB patients. TB patients are stigmatized because their illness disrupts their lives and causes insecurities. It threatens their social relations and social structure because their illness bears the hallmark of a sub-culture of poverty, weakness and lack of hygiene. TB gradually and surreptitiously erodes the support afforded by social networks. The social network cannot hold out against so much social censure.
Furthermore, friends fail to muster support and are afraid of becoming ostracized as well. Completely distraught, patients who are already in a precarious situation from the very beginning, are stigmatized even further.

The only way to break this vicious circle, is to develop DOT as the standard of care and a service to all TB patients, rather than being seen as a procedure of last resorts for non-compliant patients. Although there are usually practical objections against implementing a universal DOT regimen, universalism is a powerful driving force, constantly encouraging us to consider the target groups which have been reached, and those which have not. This research has demonstrated that it is essential to permanently evaluate DOT and expose possible stigmatization effects. As soon as they have been detected, they have to be suppressed by, for example, integrating the programme into the primary health care system, available within the most decentralized delivery units in Pakistan (tehsils, rural health centres and basic health units), and obviating the need for hospitalization. Health professionals need to take responsibility for their TB patients’ compliance with DOT, provide purposeful information, education and take communication measures. Different forums such as health committees, women’s clubs, schools and colleges for health promotion and education, and TB associations, are ideally suited for playing an active role. The TB care delivery system needs to be located as close to the home of the patient as possible, needs to be patient friendly and reliable for the patient, incorporating a complete DOTS strategy.

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